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Which Entitlements and for Whom?

The Convention on the Rights of Persons with Disabilities and its Ideological Antecedents

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For Aidan, Klara and Tadgh

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List of Abbreviations

AFDO	Australian Federation of Disability Organisations
ARCC	African Regional Consultative Conference
CRPD	Convention on the Rights of Persons with Disabilities
CEDAW	Convention on the Elimination on All Forms of Discrimination against Women
CRC	Convention on the Rights of the Child
CSIE	Centre for Studies on Inclusive Education
DIG	Disability Income Group
DPI	Disabled People's International
DPO's	Disability Non-governmental Organisations
EDF	European Disability Forum
EU	European Union
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health – Children and Youth Version
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
IDC	International Disability Caucus
II	Inclusion International
ILO	International Labour Organization
JDF	Japan Disability Forum
LSN	Landmine Survivors Network
MDRI	Mental Disability Rights International
NACLC	(Australian) National Association of Community Legal Centres

NGO's	Non-Governmental Organisations
OHCHR	Office of the High Commissioner for Human Rights
PDCA	Physical Disability Council of Australia Ltd
PWDA	People with Disability Australia
RI	Rehabilitation International
StR	Standard Rules on the Equalization of Opportunities for Persons with Disabilities
UDHR	Universal Declaration of Human Rights
UN	United Nations
UPIAS	Union of the Physically Impaired Against Segregation
VCLT	Vienna Convention on the Law of Treaties
WBU	World Blind Union
WFD	World Federation of the Deaf
WFDB	World Federation of the Deafblind
WHO	World Health Organization
WNUSP	World Network of Users and Survivors of Psychiatry
WPA	World Programme of Action concerning Disabled Persons

Introduction

The term 'disability' is used in diametrically opposite senses. However, this term none the less constitutes an ideological, academic, political and legal platform which brings together different accounts of what 'disability' means and whom it implicates. Irrespective of the differences between such accounts or approaches to 'disability', these are all united in that they somehow address what a person with levels or modes of functioning of the body and mind diverging from some norm can do or be and should be able to do or be. Furthermore, such different approaches almost exhaustively use the term 'disability' to depict problems; problems the addressing of which is the purpose of the approach. These problems range from restricted social participation or uneven relationships of power to the level or mode of functioning of the body and mind of a person.

As different approaches to disability depict *different* problems, it follows that these have different implications for how society is to respond to these problems, for what is sought from society in the name of disability. The different meanings attributed to the term disability thus translate into very different versions of what the problem is and whom it affects and consequently *what is to be done about it, why, how, for whom and by whom?* Each approach to disability invites a different group of persons to be a part of the ideological, academic, political and legal platform that the concept of disability constitutes and serves to justify particular claims to entitlements for those persons. From the perspective of the individual, each approach to disability also offers up a portrayal of its constituency, with implication for those it is intended to cover as well as those it is not intended to cover.

Apart from 'health', 'disability' constitutes the main meta-term in the discourse about claims to entitlements concomitant with how our bodies and minds function: '*disability* rights', '*disability* perspective', '*disability* issues', '*disability* studies', '*disability* law', *disability* policy'.[1] Approaches to disability use further terms to illustrate additional aspects of the problems on which they have chosen to focus, such as 'handicap', 'impairment', 'activity limitations' or 'participation restrictions'. The term disability has however developed over time to become the shorthand term for speaking about salient issues related to levels and modes of functioning of the body and mind diverging from some norm.

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[1] As will be discussed at length throughout this book, the relationship between the concept of 'disability' and that of 'health' is the subject of considerable disagreement.

As a consequence of the term disability being the ticket for 'air time', the struggle for ownership of the term itself becomes a battlefield for deciding *what we should be talking about*. The answer to the question 'what is disability?' becomes the answer to a much larger question: what is relevant to rights, movements, issues, studies, laws, policies as well as to grouping people together under this label? This equation between the question 'what is disability?' and the question 'what is relevant and what should we be talking about' is visible from the common dismissive comeback that what another approach or person adherent to such an approach is talking about 'is not really *disability*'.[2]

Frameworks referred to as 'models of', 'accounts of', 'approaches to' or 'understandings of' disability are many, providing different visions of what disability is and who persons with disabilities are. These all represent efforts to establish the 'correct' meaning of disability as well as to direct meaningful change. The Convention on the Rights of Persons with Disabilities (CRPD) is a human rights convention developed under the auspices of the United Nations (UN) between 2001 and 2006.[3] As such, it embodies the formal as well as substantial heritage of that particular legal tradition. However, crafting this instrument necessitated taking a position on *what disability is and who persons with disabilities are*, with all that this entails. These are questions which the human rights tradition to that date had not answered in any principled or comprehensive manner. Before the CRPD, those advocating a 'human rights approach to disability' as a lodestar for international as well as national politics and policy toiled at connecting disability with the human rights framework, both formally and ideologically. Formally, such efforts consisted in suggestions for the development of a convention and illuminating instances where the human rights framework had indeed paid attention to disability. Ideologically, such efforts consisted in illustrating that the features and principles of human rights law such as individual entitlements, the areas of life protected and principles such as dignity, freedom and equality had much to say about the lives of persons with disabilities as well as much work to do.[4]

The CRPD was adopted on 13 December 2006 after five years of negotiations and entered into force 3 May 2008. Proceedings were initiated in 2001 when the United

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[2] See e.g. Pfeiffer, David, The ICIDH and the Need for its Revision [hereinafter Pfeiffer, 1998], Disability and Society, Vol. 13, No. 4, 1998, p. 509 or Union of the Physically Impaired Against Segregation (UPIAS), The Union of the Physically Impaired Against Segregation and the Disability Alliance Discuss Fundamental Principles of Disability [hereinafter UPIAS, 1975], 22 November 1975, p. 14.

[3] Convention on the Rights of Persons with Disabilities (CRPD). Adopted 13 December 2006. Entered into force 3 May 2008. 2515 UNTS 3.

[4] See e.g. Despouy, Leandro, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, Human Rights and Disabled Persons, United Nations Publications, Geneva, 1993. See also Degener, Theresia and Koster-Dreese, Yolan (Eds.), Human Rights and Disabled Persons - Essays and Relevant Human Rights Instruments, Martinus Nijhoff Publishers, Dordrecht, 1995 and Quinn, Gerard and Degener, Theresia with Bruce, Anna et al., Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability [Hereinafter Quinn and Degener with Bruce et al., 2002], United Nations Publications, New York, 2002.

Nations General Assembly adopted a resolution calling for the establishment of an "Ad Hoc Committee [...] to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities" (the Ad Hoc Committee) in order to explore the need and wisdom of adopting a convention addressing persons with disabilities.[5] In addition to State representatives and representatives from UN bodies, the Ad Hoc Committee was open to participation from civil society, a call heeded by Disability Non-governmental Organisations (DPO's) who had long called for a convention.[6] Much due to DPO's, there was no turning back once the Ad Hoc Committee was formed in 2002; a convention was to be developed. During the entire procedure, DPO's were present and usually spoke with one voice under an umbrella structure created for the purpose of the negotiations: the International Disability Caucus (IDC). As will be apparent in this book, the CRPD is to a considerable extent shaped by the positions taken and forwarded by IDC.

Through the adoption of the CRPD the question *what a human rights approach to disability is* has potentially been answered; it is what the CRPD says it is. If the speed of ratification of the CRPD is anything to go by then the understanding of disability in the CRPD can be expected to play a role in the development of disability law and policy worldwide.[7]

The aims of this book

The central aim of this book is to situate the CRPD and the process through which it was developed in the multifaceted and diverging practice of understanding and portraying 'disability' and 'persons with disabilities'. The book draws upon this practice in order to better understand the CRPD as a continuation of this practice as well as to better understand the challenges that the CRPD was created to meet.

The fulfilment of this aim requires two main building blocks. Firstly, it requires a comparison of approaches to disability constituting the practice of understanding and portraying 'disability' and 'persons with disabilities' preceding the CRPD. Through this comparison, principled positions, strategic considerations as well as points of contention within this practice are identified. A particular focus here, called for by the nature of the CRPD as a legal instrument, is which particular entitlements each approach to disability can serve to support as relevant and legitimate. Secondly, the fulfilment of the aim of this book requires a legal interpretation of which entitlements for whom the CRPD covers, particularly regarding aspects which

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[5] UN General Assembly Resolution on a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, 19 December 2001, UN doc: A/RES/56/168, para. 1.

[6] See e.g. Beijing Declaration on the Rights of People with Disabilities in the New Century. Adopted 12 March 2000 at the World NGO Summit on Disability.

[7] As of 30 November 2013, the CRPD had 138 States Parties and had been signed by another 20 States.

emerge as controversial within the preceding practice of understanding and portraying ‘disability’ and ‘persons with disabilities’. This is flanked by an account of how the principled positions, strategic considerations and points of contention identified within this practice were approached in the negotiations of the CRPD. This serves to better understand how these played out and shaped the inclusion as well as phrasing of particular entitlements in the CRPD.

To provide the first building block I have chosen to explore four approaches to disability: the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), the Social Model of Disability, the International Classification of Functioning, Disability and Health (ICF) and the Minority Group Model of Disability. This is done in Part I of this book. The rationale for my choice of approaches is that these are, arguably, the approaches to disability which have (or have had) the largest influence on the understanding of disability and the shaping of entitlements connected to disability on the international level. They have so in the sense that they have either been developed on the international level or have spread to countries outside their country of origin and have influenced instances of international cooperation where normative accounts of entitlements in relation to disability have been shaped, such as the UN.[8] To provide the second building block I interpret the CRPD and analyse the preparatory works (over and above the role these play in legal interpretation) and situate my conclusions against the approaches to disability explored in Part I. This is done in Part II of this book. Particular attention is paid to how the CRPD handles the two main points of contention between the approaches to disability explored in Part I of this book. The first one concerns the balance between approaching and forwarding impairment as a valuable form of diversity to be embraced *and* providing entitlements connected to prevention, minimisation and elimination of impairment. The second one concerns the balance between attributing the causes of and directing the solutions to restricted involvement in different life contexts to the environment[9] alternatively to the impairment.

While the centre of gravity of this study is the CRPD, considerable effort is put into presenting and analysing the four chosen approaches to disability in Part I. This serves the independent aim of making accessible to interested parties the positions on key questions of these arguably complicated frameworks, particularly the consequences of such positions for what entitlements these frameworks serve to protect

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[8] Numerous other such approaches exist, not to mention the plethora of approaches coined as terms of abuse such as the individual model of disability, the medical model of disability, the administrative model of disability, the charity model of disability, the pity model of disability and the tragedy model of disability. The latter approaches are not labels of anything anyone officially ascribes to; rather they are ways of describing attitudes, tendencies, policies or measures which are disapproved of. For an overview and comparison of different approaches to disability see e.g. Altman, Barbara M., Disability Definitions, Models, Classification Schemes, and Applications [hereinafter Altman, 2001], in Albrecht, Gary L. et al. (Eds.), Handbook of Disability Studies, Sage Publications, London, 2001, pp. 97-122 and Shakespeare, Tom, Disability Rights and Wrongs [hereinafter Shakespeare, 2006], Routledge, London, 2006, pp. 10-28.

[9] If not otherwise specified, I hereinafter use the concept “environment” to depict all factors external to the individual.

and for whom. With the CRPD, such background knowledge has become increasingly useful for human rights lawyers, as has the legal interpretation of the CRPD become for disability scholars and advocates.

The central aim of this book is thus to relate the CRPD and the process through which it was created to its ideological antecedents in disability theory. An additional aim, which builds on the fulfilment of the former aim, is to explore the implications of these findings for the implementation of the CRPD, particularly for the role of the treaty body overseeing such implementation, the Committee on the Rights of Persons with Disabilities (the CRPD Committee). This exploration has two dimensions. Firstly, how the CRPD Committee relates to the two points of contention mentioned just above (within the limits of the discretion left by the provision of the CRPD) will have different consequences for different segments of its constituency. This actualises questions of representation; how can the CRPD Committee do justice to its entire constituency? Secondly, the CRPD and the CRPD Committee are not isolated organisms, instead they are part of the larger UN human rights framework and their mandates overlap with the mandates of other conventions and other treaty monitoring bodies. Here, the aim is to explore how differing positions and practices by these bodies in relation to the two points of contention mentioned just above can and should be reconciled within the limits of the law.

How to get there

In order to illustrate different strategic considerations, ideological positions and points of contention as they play out among my four chosen approaches to disability, as well as in the CRPD and its preceding negotiations, I employ an analytical framework comprised of four questions. I have distilled these questions as delineating the formative aspects of how these approaches as well as the CRPD express what ‘disability’ is and who ‘persons with disabilities’ are:

1) What do the *problems* identified (as disability or parallel phenomena[10]) include – levels and modes of functioning of the body and mind, composite life opportunities[11] or both?
2) Where are the operative and relevant *causes* of identified problems (disability or parallel phenomena) to be found – in the person, in the environment or in a combination of these?
3) Where are the operative and relevant *solutions* to identified problems (disability or parallel phenomena) to be found – in the person, in the environment or in a combination of these?

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[10] See definition just below.

[11] See definition just below.

4) *Who* is included in the implicated constituency and by virtue of what characteristics or experiences?

Before I elaborate further on these questions, I want to briefly address the terminology I employ in this book in order to be able to compare the entitlements protected by these approaches and the CRPD. While I refer collectively to the approaches to disability explored in this book as approaches to just that, 'approaches to *disability*', they attribute radically different meanings to this term and they also use additional terms to make up the 'universe' of what they address. Consequently, while I refer on a general level to all of these as contributions to the larger ideological and political platform of '*disability*' (where points and claims are made in the name of disability as an overarching, all subsuming term), I require meta terminology to be able to compare the answers these approaches give to the questions above. Firstly, I will refer to forms of doing and being as *life opportunities*: the things we can do or be.[12] Secondly, I divide such life opportunities into *levels and modes of functioning of the body and mind* and *composite life opportunities.* A *level or mode of functioning of the body and mind* covers doings and beings of the body and mind of the person, including the system and organs by which these are made up. For example, it covers walking as well as moving a toe and breathing as well as moving muscles in the diaphragm. I will refer to restrictions of such levels and modes of functioning of the body and mind as *impairments*. I loosely define these as levels and modes of functioning of the body and mind departing from a norm, a description which is wide enough to be compatible with the use of the term by the Social Model of Disability, the Minority Group Model of Disability and the CRPD. In order to handle the terminological challenge that two of the approaches to disability explored in this book (ICIDH and ICF) use the term 'impairment' in a more specific sense than I do (to depict restriction of levels and modes of functioning of the body and mind on the level of organs and systems of the body and mind only and not on the level of the person, i.e. as depicting moving a muscle in a toe but not walking), I will endeavour to ensure that it emerges when I use impairment in the more specific sense ascribed to it by ICIDH and ICF. When referring to components of my chosen approaches to disability, I capitalise the terminology used, including "Disability" and "Impairment". When using these terms in the general sense described above (i.e. not as technical terms of these approaches) they are not capitalised.

A *composite life opportunity* is a form of doing or being which is not reducible to a particular level or mode of functioning of the body and mind. It is *composite* in the sense that it may be realised in many different ways, rather than simply through the facilitation of a particular level or mode of functioning of the body and mind such as walking, hearing or seeing. Examples are keeping a diary, being educated, playing, taking children to the playground, enjoying a cultural performance, cooking a meal or driving a car. Both levels and modes of functioning of the body and mind and

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[12] This generic term covers forms of doing and being which actually or potentially are considered to be of value for human beings.

composite life opportunities actualise the role of the environment as nothing is ever done in a physical or social vacuum; they are all dependent on the environment and alter with the environment. Breathing depends on air quality and walking depends on the ground surface. The role of the environment is thus not the rationale for the division above. Instead, what defines a composite life opportunity is that it can potentially be realised in a way which does not entail increasing the level or mode of functioning of the body and mind traditionally employed towards its realisation. Instead, it actualises the possibility of *alternative* roads towards the same, composite, end. For example, reading black and white flat print can only be done through eyesight, but enjoying a book can be done through a number of senses, as can receiving an education, which is increasingly composite yet.[13]

All approaches to disability use terminology and its definitions to emphasise what is important, to steer the focus in a certain direction and I am no different. My rationale for drawing the line as I do is fundamentally solution oriented. I wish to illustrate that valuable life opportunities can and shall be enjoyed irrespective of levels and modes of functioning of the body and mind and that the lack of imagination regarding alternative ways of enjoyment has been the core of denial of the majority of the human rights that the CRPD now protects. This does not imply that levels and modes of functioning of the body and mind cannot be valuable in and of themselves or as roads to composite life opportunities (i.e. that pain cannot require solutions both for its own sake and for the sake of its effects on composite life opportunities such as family life, employment or leisure activities). However, hitherto, what I refer to as impairment has been equated with lacking competence or ability to benefit from what I refer to as composite life opportunities, with the consequence of the latter's widespread denial. This is common knowledge; indeed it is what the CRPD aims to change.

Further on the subject of terminology, I use the term *universe* to connote the entire framework of the approaches to disability explored. I use the term *parallel phenomena* to refer to categories of restrictions of life opportunities which an approach to disability forwards as problematic, but under a label other than 'disability'.[14] Finally, I use the term *constituency* to depict the persons intended by each approach.

Returning back to the four questions which comprise my analytical framework, question 1 solicits the positions of approaches to disability on one of their central functions, namely to portray and highlight *problems* which should be addressed in the social community. The mirror images of these problems illustrate what opportunities to do or be things an approach to disability forwards as valuable and relevant to the constituency it implicates, as a restriction is only problematic in as much as it affects

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[13] There is of course no watertight dividing line between these two categories of life opportunities.

[14] As this book focuses on these approaches to disability as wholes rather than the meaning they each attribute to the term 'disability', such parallel phenomena are included in the analysis. Barbara Altman expresses this state of affairs and its implications as that "[f]requently, models use the same terminology but ascribe a different meaning to the terms. To understand the different shades of meaning that various models develop, one must start at the concept level to see how the ideas are similar or different across conceptualizations regardless of terminology". Altman, 2001, p. 101.

something valuable. Each approach to disability assumes a particular constituency and makes value judgements on what 'a good life' for such persons is, as well as what particular restrictions affecting life opportunities are relevant to them. An approach to disability thus, like any other theory on what human beings en masse should be able to do or be, will always be a generalisation, an assumption by proxy, which may or may not resonate with the experience or otherwise position of particular individuals.

Question 2 solicits the positions of approaches to disability regarding another central function, namely where they identify the *causes* of the problems which should be addressed in the social community. The question of causality is central to all approaches to disability. Without fail, a definition of 'disability' or a parallel phenomena depicting composite life opportunities contains its causal lineage, pointing either to the environment (features extrinsic to the person), to the individual (features intrinsic to the person) or to both. The answer to the question 'what is disability?' infallibly contains an answer to the question 'what is the cause of disability?'. Sometimes this causal lineage is expressed by explicitly noting that some factors are *not* recognised either as causes of 'disability' or parallel phenomena depicting composite life opportunities or as causes of problems full stop.

Question 3 solicits the positions of approaches to disability regarding another central function, namely what they identify as the *solutions* to the problems forwarded as 'disability' or parallel phenomena. The choice of solutions presented by an approach to disability is closely connected to what restrictions of which life opportunities it identifies as problematic and where it finds the causes of those problems. If an approach to disability does not recognise restriction of a particular form of doing or being as a problem it follows that it cannot, at least not without contradicting itself, call for a solution to such restriction. Similarly, while the solution to a problem can in principle be completely independent of causes identified, this is typically not the case in approaches to disability. Instead these are solution driven; the formulation of approaches to disability has clear strategic purposes and causes and problems are arguably formulated to fit desired solutions rather than the other way around.

Question 4 highlights the strong connection between the 'what' and the 'who' in approaches to disability. Even though the components of approaches to disability are expressed as phenomena, fundamentally, the person remains the engine room of every approach to disability. It is for the sake of the person that approaches to disability purport to explain something, condone something, condemn something or demand something. Similarly, the 'outcome' of the application of an approach to disability is generated in terms of the person; it is *the person* who comes out 'disabled'/'with a disability' or likewise 'dressed' in parallel phenomena. In addition, as all 'whats' do not carry the same relevance for all 'whos', each approach to disability caters differently for different parts of its implicated constituency. The constituency of an approach to disability can be explicit or implicit and its criteria for inclusion can concern only the presence of a certain situation or have an overlay of ideology, requiring its constituency to take a certain position on relevant problems, causes and solutions.

As disability is, de facto, an existing ideological, political and legal platform for demanding change, the question is not just about adequately representing the needs of the intended constituency, but also about who is explicitly or effectively excluded from that constituency and on what grounds.

The answers these questions solicit amount to principled points, strategic considerations and fundamental points of divergence from which it can be inferred, inter alia, what claims to entitlements for whom an approach to disability forwards or is able to support without contradicting itself. Question 1 does this as the mirror image of a particular problem is a life opportunity, which through the social, political and legal discourse translates into a claim to an entitlement to a valuable form of doing or being. Question 2 solicits answers which are indirectly connected to the question what solutions are implicated by an identified problem. Indeed, causality is habitually used to justify particular solutions. Question 3 solicits answers to the question how a claim for a particular life opportunity is to be realised; what actual measures are envisaged as securing such valuable life opportunities. Question 4 connects entitlements to the persons implicated; what the implications are of *what* entitlements an approach to disability recognises for *whom* it ends up covering and how well it represents those covered in terms of attention paid to central concerns.

These questions are theory driven in the sense that the answers they solicit map principled points, strategic considerations and fundamental points of divergence between the approaches to disability explored in this book. They bring to the fore central aspects of what claims to entitlements for whom an approach to disability forwards or is able to support without contradicting itself. The method applied in Part I of this book consists in systematically seeking answers to these questions through a content analysis of key texts conveying these approaches.

These questions are similarly the framework for the comparison of the CRPD with these approaches in Part II of this book. Part II, in addition, necessitates an account of what entitlements are covered by the CRPD, which in turn requires legal interpretation. The interpretation of the entitlements and obligations created by the CRPD is based on the Vienna Convention on the Law of Treaties (VCLT),[15] and thus, in accordance with Article 31 (1), takes its point of departure in "the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose". In addition, in order to confirm such meaning or ascertain the meaning of a provision which is inconclusive based on the exercise just described and the remaining means for interpretation provided for in Article 31, I resort to "the preparatory work of the treaty and the circumstances of its conclusion", as provided for by Article 32. Taken that the CRPD is relatively new, the additional sources provided for in Article 31, such as "any subsequent practice in the application of the treaty which establishes the agreement of the parties regarding its interpretation" are as of yet of limited use. Article 32 means thus potentially take on

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[15] Vienna Convention on the Law of Treaties (VCLT). Adopted 23 May 1969. Entered into force 27 January 1980. 1155 UNTS 331.

a comparatively large role in the initial phase after the adoption of a treaty. I access these means through the negotiation archives published on the website of the UN. These contain the official reports submitted to the General Assembly after each session of the Ad Hoc Committee, containing draft versions of the CRPD as well as written communications by the Chair of the Ad Hoc Committee. In addition, they contain written proposals submitted by States and other actors, including sometimes both explicit phrasing for provisions and the rationale for proposals, sometimes one or the other. Finally, I rely on the daily summaries of the negotiations compiled by Non-Governmental Organisations (NGO's) and accessible through the website of the UN. I corroborate these with my own recollections and notes gathered through participating in 4 of the 8 negotiation sessions of the CRPD (the 4th session to the 7th session).

Over and above legal interpretation the preparatory works of the CRPD are employed for an additional purpose, namely to explore how the principled positions of, strategic considerations of and points of contention between the approaches to disability explored in Part I played out and influenced the negotiations preceding the CRPD. Here, in addition to the sources used to establish the legal obligations and entitlements created by the CRPD, statements and proposals from NGO's and other non-state actors are used.

In the interest of limiting this vast bulk of material and as the main purpose for which the material is used is legal interpretation, I have focused on sources from the sessions subsequent to the first draft of the CRPD (the 3rd session) and the session of the Working Group compiling this draft.

Situating the contribution of this book in scholarship on disability

The exploration and comparison of approaches to disability, including the four explored and compared in this book, is a central feature of earlier scholarship on disability. Notwithstanding this, the systematic and detailed comparison of these approaches with a particular focus on the potential of these as the basis for claims to entitlements, and the added comparison with the CRPD, sets out to make a new contribution. Particularly, the entitlements perspective brings to the fore the potential conflict between strategic concerns about steering public opinion and policy in a certain direction and covering all entitlements to life opportunities seen as required and valuable to all persons implicated by an approach to disability. This conflict materialises in the formulation of entitlements as you cannot make a demand without forwarding that which is demanded as somehow important and valuable.

Throughout the book I interact with earlier scholarship on disability. The four approaches to disability included in Part I constitute in themselves earlier scholarship on disability. In addition, the account of each approach is closed by an introduction to the different analyses of it amounting to its critique. In Part II, my account of and interpretation of the CRPD will be situated against scholarship on the CRPD. References will be limited to instances when a question is subjected to different interpretations, i.e. to the extent that an interpretation, or the result of it, may be controversial. To the extent that existing scholarship engages with the specific question at the core of this book (the correspondence between the approaches to disability explored in Part I and the CRPD and associated consequences for what entitlements are protected and for whom) this is engaged with as a backdrop to my conclusions in Part II. Finally, in the Epilogue following Part II of this book, the scholarship constituted by the approaches to disability and the critique launched against these are used to chart out pitfalls pertaining to the task of the CRPD Committee to oversee and direct the implementation of the CRPD. Again, particular attention is paid to how the CRPD Committee handles the two main points of contention between the approaches to disability explored in Part I of this book. The first one concerns the balance between approaching and forwarding impairment as a form of valuable diversity to be embraced *and* providing entitlements connected to prevention, minimisation and elimination of impairment. The second one concerns the balance between attributing the causes of and directing the solutions to restricted involvement in different life contexts to the environment alternatively to the impairment. An additional aspect to which I devote particular attention is how the Committee handles the potential conflict between forwarding a depiction of the constituency of the CRPD which is seen as generally conducive to nurturing a social context which is receptive to the entitlements of its constituency *and* directing adequate attention to the situation and requirement of those not qualifying as 'showcase' constituents in this regard. In terms of articles of the CRPD, the above actualises the interpretation and implementation of in particular Preamble (e, i, j, m), Article 1 on Purpose, Article 3 on General principles, Article 8 on Awareness-raising, Article 25 on Health and Article 26 on Habilitation and rehabilitation.

The structure of this book

Following this introduction, this book is divided into two parts which are followed by an Epilogue. Part I focuses on my four chosen approaches to disability. In Part II the CRPD is compared to these approaches. Finally, the Epilogue brings the main findings of Parts I and II to bear on the future interpretation and implementation of the CRPD.

In Part I each approach to disability is devoted a chapter, the organisational principle for which is my four questions outlined above. In each chapter, an introductory section is followed by a section for each question, which in turn is followed by a concluding section summarising the answers solicited and drawing out their implications for which entitlement for whom follow from the approach. Finally, to end each chapter an account is given of the main strands of the critique launched at the approach.

Part II also applies the four questions as its organisational principle; however here these are devoted a chapter each. After an introductory chapter presenting the CRPD and the procedure through which it was negotiated, these questions are put to the CRPD. The answers thusly solicited are compared to the approaches explored in Part I, through the answers solicited by the same questions there. In addition, the critique of these approaches presented in Part I is brought to bear on the CRPD. Each chapter contains both legal interpretation of the entitlements and obligations created by the CRPD as well as a larger account of how the principled positions of, strategic considerations of and points of contention between the approaches explored in Part I were approached in the negotiations. Part II is closed by a chapter providing a summarising comparison between these approaches to disability and the CRPD: which features of the CRPD resonate the most with each approach and which features of the CRPD are most alien to each approach? In addition, the understanding of the two approaches most visible in the negotiations (the Social Model of Disability and ICF) is sought after; what meaning was attributed to these approaches?

Finally, the Epilogue addresses the future of the two articles of the CRPD situating the above mentioned main points of divergence between the approaches to disability explored in Part I: Article 25 on Health and Article 26 on Habilitation and rehabilitation. These articles create entitlements to the prevention, minimisation and elimination of impairment for its own sake as well as (in the case of Article 26) based on impairment being a cause of restricted composite life opportunities. They do so in an instrument which otherwise directs its focus towards the enjoyment of composite life opportunities and the role of the environment in the realisation of these. Consequently, these articles actualise the question if the life opportunities addressed from the ideological, political and legal platform of disability should include levels and modes of functioning of the body and mind, as well as the question of where the operative causes of restricted composite life opportunities are to be placed: with the environment, with the individual or with a combination of these. The focus of the Epilogue is on the role of the CRPD Committee in relation to Articles 25 and 26, taking into account in particular the fact that its mandate in terms of monitoring the implementation of the subject matter of these articles is shared with other UN human rights conventions as well as their monitoring bodies.

An additional provision the future of which is focused upon in the Epilogue is Preamble (j), calling as it does for attention to "those who require more intensive support". As mentioned above, the focus here is the potential conflict between forwarding a depiction of the constituency of the CRPD which is generally conducive to nurturing a social context receptive to entitlements while paying adequate attention to the situation and requirement of those not qualifying as 'showcase' constituents in this regard.

PART I

2. International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

ICIDH was developed under the auspices of the World Health Organization (WHO) as one of their classification schemes organising information about "dimensions of health-related experience".[16] The following account of ICIDH draws on the book in which it was published: "International Classification of Impairment, Disabilities, and Handicaps – A Manual of Classification Relating to the Consequences of Disease".[17]

The novelty of ICIDH consisted in that while earlier WHO schemes covered "dimension of health-related experience […] embraced by the concept of *disease*"[18], ICIDH covered "*consequences of disease*"[19]. In the introduction to ICIDH, great pain is taken to emphasise this expansion. According to the authors, the concept of Disease reflects the "medical model of illness" and while this model is adequate for understanding "disorders that can be prevented or cured" it is lacking in that it does not cover the Consequences of disease:[20] conditions which "can be controlled even though their underlying causes cannot be eliminated" and the consequences of these conditions in turn.[21] The need for such a framework was emphasised against the background of actual life experience:

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[16] World Health Organization, International Classification of Impairments, Disabilities, and Handicaps – A Manual of Classification relating to the Consequences of Disease [hereinafter WHO, 1980], World Health Organization, Geneva, 1980, p. 7. The work started in the early 1970's and culminated in the approval by the World Health Assembly for publication of the scheme for trial purposes in 1976 and its subsequent wide dissemination in 1980. For an account of the development process see Ibid., pp. 11-13.

[17] If not otherwise indicated, references are to the 1980 edition.

[18] Ibid., p. 7. Emphasis added.

[19] Ibid., p. 10. Emphasis added.

[20] Ibid.

[21] Ibid., p. 9.

> It is the latter [consequences of disease], particularly, that intrude upon everyday life, and some framework is needed against which understanding of these experiences can be developed; this is especially true for chronic and progressive or irreversible disorders.[22]

Consequently, the authors of ICIDH wanted to complement the concept of *Disease* with the concept of *Consequences of disease* (represented symbolically as Disease → Impairment → Disability → Handicap).[23] Such Consequences of disease include "the effects of trauma, impairments of special sense organs, mental retardation and mental illness, and the chronic diseases of middle and later life, particularly heart disease, stroke, bronchitis, and arthritis"[24] and are referred to generally in the manual presenting ICIDH as e.g. "a residue of conditions"[25] or "chronic and disabling conditions"[26].

ICIDH, with its focus on Consequences of disease, was an effort to get the clinical context to realise that chronic conditions necessitate taking the entire context of the individual's life into account:[27]

> Demands [regarding chronic as opposed to acute illness] differ in [...] important aspects. Thus, the impact of the condition on the individual, though important, does not dominate the scene to the exclusion of all else. Clinical status has to be set against the background of life, moving, as it does, between home and work.[28]

ICIDH was thus a call for breaking with a tradition where clinical intervention was separated from the context of the person's life. This call was bolstered by reference to the upsurge of "*chronic* and disabling conditions"[29], i.e. *living life* with such conditions:

> [T]he concept of disease [has led to] consider[ing] pathological phenomena as though they were unrelated to the individual in whom they occur. […] However, certain limitations in this approach are evident. By isolating thoughts of disease from consideration of the sufferer, the consequences tend to be neglected. These consequences - responses by the individual himself and by those to whom he relates or upon whom he depends – assume greater importance as the burden of chronic illness alters. The problems may be illustrated by contrast between acute and chronic processes.[30]

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[22] Ibid., pp. 10-11.

[23] Ibid.

[24] Ibid., pp. 9-10.

[25] Ibid., p. 9.

[26] Ibid., p. 18.

[27] Ibid., p. 9-11. One of the Authors of ICIDH, Mike Bury, later expresses this aim in 1995: "Our aim, it will be remembered, was to challenge the medical model and assumptions about disablement. Most importantly, our aim was to bring handicap onto the healthcare agenda. That is, we were pressing for greater recognition of (what came to be called) social exclusion in responses to disablement.". Bury, Mike, A Comment to the ICIDH2 [hereinafter Bury, 2000], Disability & Society, Vol. 15, No. 7, 2000, p. 1074.

[28] WHO, 1980, p. 25.

[29] Ibid., p. 18. Emphasis added.

[30] Ibid., p. 23.

According to the introduction of the manual to ICIDH, a changing "morbidity experience" is asserted as calling for attention to these conditions: "[d]isorders like these are coming to dominate current morbidity experience in some countries and they are especially noteworthy as causes of disability".[31] Such changes in "the burden of morbidity" are partly put down to the development of medical expertise entailing that diseases that were once fatal now can be if not eliminated then controlled.[32]

ICIDH has been put to much use as a system for classification of information.[33] In addition, and more interesting for the purpose of this book, as an approach to disability it has had considerable influence worldwide on how levels and modes of functioning of the body and mind and their interaction with a life context are *understood*. The creators of ICIDH explicitly stated its purpose against the backdrop of "the lack of a coherent scheme or conceptual framework against which to set such experiences [Consequences of disease]"[34], recognising that "some framework is needed against which the understanding of these experiences [chronic and progressive or irreversible disorders] can be developed".[35] This conceptual lack was seen as responsible for the lack of adequate information, which in turn hindered adequate policy development. The manual notes that "limitations in understanding are an obstacle to improving relevant information, and this in turn inhibits progress towards more helpful responses."[36]

The creators of ICIDH thus asserted that by collecting and organising relevant information on these conditions separated into the dimensions Impairment, Disability and Handicap "policy development in response to the problem, clarifying the potential contributions of medical services, rehabilitation facilities, and social welfare respectively" would be facilitated.[37] In addition to the impact of this call on the collection of information, it can safely be said that ICIDH has exercised a major influence on the answer to the questions which problems are relevant to address from the ideological, political and legal platform of disability, what the relevant causes and solutions to those problems are and who persons with disabilities are.[38]

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[31] Ibid., p. 10.

[32] Ibid., p. 9.

[33] See e.g. Pfeiffer, 1998, p. 505 and Bury, 2000, p. 1073.

[34] WHO, 1980, p. 25.

[35] Ibid., p. 10.

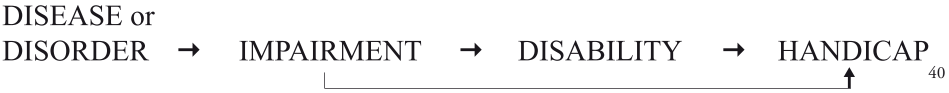
[36] Ibid., p. 25.

[37] Ibid., p. 11.

[38] For a positive view on this influence see Bury, 2000, p. 1073. For a negative view on this influence see Hurst, Rachel, To Revise or Not to Revise? [hereinafter Hurst, 2000], Disability & Society, Vol. 15, No. 7, 2000, pp. 1083-1084.

2.1. The universe of ICIDH

That which ICIDH portrays, its universe, is referred to as the Consequences of disease.[39] The components of this universe are Impairment, Disability and Handicap. The manual graphically represents their relationship like this:



[40]

The first component, Disease (sometimes, as here, flanked by Disorder), is not part of the ICIDH classification scheme but is rather presented as the chronological ancestry of that which is portrayed in ICIDH. The three remaining components, Impairment, Disability and Handicap, are described as "each relating to a different plane of experience consequent upon disease".[41] These planes are described as the organ, the person and society, respectively.[42]

The manual gives the following definition of Impairment:

> In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function [. . .]. Impairment represents deviation from some norm in the individual's biomedical status [...]. Impairment is characterized by losses or abnormalities that may be temporary or permanent, and it includes the existence or occurrence of an anomaly, defect, or loss in a limb, organ, tissue, or other structure of the body, or a defect in a functional system or mechanism of the body, including the system of mental functioning.[43]

Such "loss or abnormality" is further categorised as: "Intellectual", "Other psychological", "Language", "Aural", "Ocular", "Visceral", "Skeletal", "Disfiguring" and "Generalized, sensory, and other".[44]

The manual gives the following definition of Disability:

> In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being [. . .]. Disability [. . .] is concerned with compound or integrated activities expected of the persons or of the body as a whole, such as are represented by tasks, skills, and behaviours. [...] The concept is characterized by excesses or deficiencies of customarily expected behaviour or activity, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive.[45]

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[39] WHO, 1980, p. 10.
[40] Ibid., p. 30.
[41] Ibid., p. 13.
[42] Ibid., p. 26.
[43] Ibid., p. 27.
[44] Ibid., p. 45.
[45] Ibid., p. 28.

Disability is thus understood as "disturbances at the level of the person […] reflecting the consequences of impairment in terms of functional performance and activity by the individual".[46] Such "disturbances" concerns "the more important behaviours and activities associated with everyday life"[47] and are further categorised as: "Behaviour", "Communication", "Personal care", "Locomotor", "Body disposition", "Dexterity", "Situational", "Particular skill", and "Other activity".[48]

Finally, the manual gives the following definition of Handicap:

> In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual [.] Handicap is characterized by a discordance between the individual's performance or status and the expectations of the particular group of which he is a member. […] Handicap is thus a social phenomenon, representing the social and environmental consequences for the individual stemming from the presence of impairments and disabilities.[49]

Three features of the concept Handicap are underscored in connection with this definition: a value is attached to such departure from a norm (by the person him- or herself or by others), this value is dependent on cultural norms and the valuation is likely to be to the disadvantage of the person.[50] Aspects of such "disadvantage" are further categorised as: "Orientation", "Physical independence", "Mobility", "Occupation", "Social integration", "Economic self-sufficiency" and "Other".[51]

To conclude, these three concepts all aim to portray Consequences of disease, but on different "planes" of manifestation, expressed as the body (Impairment), the person (Disability) and society (Handicap).[52] The manual give a number of examples to illustrate what belongs in each category, such as these:

Impairment	*Disability*	*Handicap*
skeletal	dressing, feeding, walking	physical independence, mobility
psychological	behaving	social integration

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[46] Ibid., p. 14.

[47] Ibid., p. 37.

[48] Ibid., p. 141.

[49] Ibid., p. 29.

[50] Ibid.

[51] Ibid., p. 181.

[52] As ICIDH is a tool for classification the categories subsumed under Impairment, Disability and Handicap in turn give rise to nested sub-categories which can be further specified by using numerical qualifiers. As the focus here is on the function of ICIDH as a way to understand disability rather than as a system for classification, this will not be explored further.

[53] Ibid., p. 33. For more examples see Ibid., p. 31.

2.2. What problems does ICIDH recognise?

The assumption underlying ICIDH is that certain levels and modes of functioning of the body and mind represent problems in and of themselves. The problems understood as Impairments and Disabilities are clearly envisaged as residing within the individual person, Impairment being “disturbances at the organ level”[54] and Disability being “disturbances at the level of the person”[55]. These envisaged problems include restrictions of forms of doing and being such as “paralysis”[56], “visual impairments”[57], “disfigurement”[58], “[d]epression”[59], “[b]ack pain”[60], “[w]alking disability”[61] and “listening disability”[62]. That the forms of doing and being of which these depict restrictions are inherently valuable (i.e. that “disturbances” are not ‘neutral variations’) is taken for granted; nowhere in the manual is this assumption discussed or problematised.

As will be explored in the next section, Impairment and Disability are viewed as problematic by virtue of being instrumental to the emergence of Handicap. However, they are also presented as requiring intervention for their own sake, illustrating that they are seen as problematic in and of themselves. The manual forwards that “[s]ymptoms reflecting impairments and disabilities call for attempts at amelioration in their own right”.[63] The inherent undesirability of Impairment or Disability is also indirectly communicated by referring to those concerned as “sufferers”.[64] The following account of expected reactions to these is illustrative:

> Confidence and hopes are undermined; the experience is usually difficult to account for, no end is in sight, and self-perception – the sense of identity – is assaulted by changes in the body and its functional performance.[65]

Through the concept of Handicap, the problems identified through ICIDH also include disadvantage in relation to what I refer to in this book as composite life opportunities. This is so as the forms of doing and being included under this concept, at least in theory, actualises alternative ways of performance and enjoyment.[66] Handicap refers to “disadvantage” on a plane described as “socialization of an impair-

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[54] Ibid., p. 14.
[55] Ibid.
[56] Ibid., p. 97.
[57] Ibid., p. 79.
[58] Ibid., p. 106.
[59] Ibid., p. 63.
[60] Ibid., p. 115.
[61] Ibid., p. 161.
[62] Ibid., p. 154.
[63] Ibid., p. 25.
[64] Ibid.
[65] Ibid., p. 24.
[66] Some of the activities under Disability, such as e.g. “shopping in immediate neighbourhood” also fall into this category. Ibid., p. 163.

ment or disability"[67] and covers forms of doing and being which "reflect interaction with and adaptation to the individual's surroundings"[68]. Such forms of doing and being are referred to as valuable "roles":

> In terms of disadvantage, the consequences are that an individual is unable to sustain the roles to which he is accustomed or to attain those to which he might otherwise aspire.[69]

Areas for such disadvantage include "employment"[70], "domestic role"[71], "educational opportunities"[72] , "[s]ocial integration"[73] and "[e]conomic self sufficiency"[74]. Consequently, composite life opportunities are included as relevant to the intended constituency of ICIDH. As noted above, while all Consequences of disease (Impairment, Disability and Handicap) are seen as important in their own right, the framers of ICIDH put major emphasis on the need to assess *Handicap*, to note the needs of persons to continue their lives in society when Disease or Disorder leaves "a residue of conditions".[75] The manual recognises that the particular categories subsumed under Handicap ("Orientation", "Physical independence", "Mobility", "Occupation", "Social integration" and "Economic self-sufficiency")[76] are not exhaustive but are restricted to "key social roles"[77]. The rationale presented for the choice of these particular categories is that they represent "survival roles"[78] and that they have cross-cultural relevance.[79] To cater for the non-exhaustiveness of this list, ICIDH provides the category "other" to complement these categories of Handicaps.[80]

2.3. What causes does ICIDH recognise as relevant to the problems it identifies?

At the outset, it should be recognised that causality is central in the description of the problems recognised by ICIDH. This is evident from its graphic depiction reproduced above under 2.1., starting with Disease or Disorder and following the arrows

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[67] Ibid., p. 183.
[68] Ibid., p. 14.
[69] Ibid., p. 41.
[70] Ibid., p. 195.
[71] Ibid.
[72] Ibid.
[73] Ibid., p. 199.
[74] Ibid., p. 202.
[75] Ibid., p. 9.
[76] Ibid., p. 181.
[77] Ibid., p. 14.
[78] Ibid., p. 39.
[79] Ibid., p. 38.
[80] Ibid., p. 206.

through Impairment and Disability to Handicap. Illustratively, the umbrella term for Impairment, Disability and Handicap deployed in the manual is C*onsequences* of disease.[81] The first two concepts portraying such consequences, *Impairment and Disability*, represent what this book refers to as levels and modes of functioning of the body and the mind.[82] Impairment is described as problems on the "organ" level.[83] Disability is described as problems on the "person" level[84] and as "resulting from an impairment".[85] The problem of an "organ" thus translates into a problem of the "person".[86] The cause of Impairment (and thus the indirect cause of Disability) remains the Disease or Disorder and the origin of the latter is in turn noted as irrelevant. Examples given of categories of causes of Disease and Disorder are "genetic abnormality or the consequences of a road traffic accident".[87]

The third concept included in the depiction of the problems covered by ICIDH, *Handicap*, covers disadvantage in relation to composite life opportunities, including "employment"[88], "domestic role"[89], "educational opportunities"[90], [s]ocial integration"[91] and "[e]conomic self-sufficiency"[92]. Mirroring the direction of the arrows in the graphic depiction of ICIDH reproduced above under 2.1., Handicap is defined as "*resulting from* an impairment or a disability".[93] Consequently, by defining Impairment and Disability as aspects of the individual and conceptualising Handicap as resulting from these aspects, disadvantage in relation to composite life opportunities are portrayed as the result of individual factors, i.e. of "deviation from some norm in the individual's bio-medical status"[94] (Impairment) and/or "departure from the norm in terms of performance of the individual"[95] (Disability).

Simultaneously however, parts of the manual indicate that Handicap is not envisaged by ICIDH as simply an automatic consequence of Impairment and/or Disability on the areas of life covered by the "key social roles"[96] in relation to which Handicap is measured. Variation in "disadvantage" is also dependant on something else, on factors outside the person embodying the Impairment or Disability. Compare the

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[81] See e.g. Ibid., p. 10.
[82] With some exceptions regarding disability, see note 66, Part I, above.
[83] Ibid., p. 47.
[84] Ibid., p. 143.
[85] Ibid., p. 28.
[86] The manual notes that not all Impairments result in Disabilities, however all Disabilities remain the result of Impairments. Ibid., pp. 30-31.
[87] Ibid., p. 27.
[88] Ibid., p. 195.
[89] Ibid.
[90] Ibid.
[91] Ibid., p. 199.
[92] Ibid., p. 202.
[93] Ibid., p. 29. Emphasis added. The manual notes that not all Impairments or Disabilities result in Handicap, however all Handicap remains the result of Impairments and Disabilities. Ibid., pp. 30-31.
[94] Ibid., p. 27.
[95] Ibid., p. 28.
[96] Ibid., p. 14.

following statement in the manual which explicitly recognises the effect of "family or social network" on the degree of Handicap experienced:

> [T]here can be striking disparities in the degree to which the various elements of the sequence [Impairment → Disability → Handicap] depart from their respective norms, and, as a result, *one cannot assume consonance in degrees of disability and handicap*. For instance, one individual with rheumatoid arthritis may be only mildly disabled and yet at a severe disadvantage, whereas another person with the same disease who is much more severely disabled may, perhaps because of greater support from the family or social network, experience considerably less disadvantage.[97]

Furthermore, Handicap is recognised as reflecting the effects of "attitudes" and "behaviour", the latter category including "legislation":

> This plane [Handicap] reflects the response of society to the individual's experience, be this expressed in attitudes, such as the engendering of stigma, or in behaviour, which may include specific instruments such as legislation.[98]

A concrete example of the influence of behaviour is noted in relation to "Mobility handicap":

> The behaviour of bus drivers in one area might preclude use of public transport by disabled persons in that area, whereas more sympathetic behaviour by bus drivers in another area might allow someone with the same disability to use public transport.[99]

In addition, while the features of the environment are not part of the factors classified in ICIDH, the categories available for registration of what the individual can do or be in relation to Handicap are constructed in a way which sometimes explicitly recognises the role of the environment in the creation of composite life opportunities. For example, in relation to "Physical independence handicap", assignment to the category "Adapted independence" is called for when "physical obstacles to independence, e.g., structural or architectural barriers such as ladders or stairs" are present in an individual's environment and "the potential to create or provide an alternative environment is available in that culture".[100]

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[97] Ibid., p. 30. Emphasis added. Additionally, according to the manual, the adjective "mental" or "physical" is to be reserved for Impairment and is discouraged as "unsuitable" in connection with Handicap, as "the disadvantage experienced by individuals with psychological impairments can vary, so that it is inappropriate to refer to a handicap as "mental"". Ibid., p. 32.

[98] Ibid., p. 26. Adding to the confusing, the subsequent sentence reads: "These experiences represent *handicap*, the disadvantage resulting from impairment or disability.". Emphasis in original.

[99] Ibid., p. 194.

[100] Ibid., pp. 188-189. The manual also sometimes indicates the role of the environment in mediating Disability. For example, "adjustment or adaptation of the environment (for instance, by use of raised marks on control gear, such as knobs, to allow tactile reinforcement of precision in adjustment)" is recognised as relevant to registering "level" of Disability. Ibid., p. 174.

To sum up, the gist of the Handicap concept in ICIDH is repeatedly presented as consequences that Disease and Disorder (and in turn, Impairment and Disability) have for the enjoyment of certain composite life opportunities:

> Handicap is thus a social phenomenon, representing the social and environmental consequences for the individual *stemming from* the presence of impairment and disabilities.[101]

However, irrespective of the repetition of this categorically expressed individual vantage point from which ICIDH gazes at composite life opportunities throughout the ICIDH manual, the fact remains that the elaboration and operationalisation of the concept of Handicap in the manual sometimes explicitly recognises that the degree of disadvantage experienced is a result of the interplay between the person and the environment. In other words, the connection between Impairment/Disability and Handicap is both categorical presented as exhaustive of the causality of Handicap, while the causality of Handicap elsewhere simultaneously is effectively as well as explicitly recognised as intermediated by the environment. It is as if two parallel incompatible postulates are presented alongside each other on the pages of the manual, but never allowed to confront each other.

2.4. What solutions does ICIDH recognise as relevant to the problems it identifies?

The primary solution envisaged in ICIDH is the collection of relevant information to improve the planning, execution and evaluation of services, notably those provided within the health care system. The usefulness of the data collected on the Consequences of disease (Impairment, Disability and Handicap) is however seen as extending beyond "medical services, rehabilitation facilities and social welfare"[102] to "broader areas of social policy, such as those concerned with education, employment, and housing"[103]. In addition to the planning of services, "research enquiries into the epidemiology and sociology of disability and handicap" is also identified as an area of use for the data.[104] The actors implicated by these solutions are both policy planners as well as individual clinicians. The assertion is that the data on Consequences of disease (as opposed to data on just Disease) will advance the potential of information to improve services and in addition, that the inclusion of and delimitation between the three planes of experience (Impairment, Disability, Handicap) will influence "everyday clinical contexts [...] to promote more sensitive and comprehensive

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[101] Ibid., p. 29. Emphasis added.

[102] Ibid., p. 11.

[103] Ibid., p. 18.

[104] Ibid.

assessments of individual problems and to facilitate more critical evaluation".[105] In addition, the conceptual framework created by these terms is aimed at improving communication among professionals, including both between professions and regarding "transcultural application".[106] Notwithstanding this widely envisaged area of application, the main actors envisaged as key contributors to solving the three categories of problems recognised in ICIDH are, respectively, "medical" (Impairment), "rehabilitation" (Disability) and "welfare services" (Handicap).[107]

In addition to the emphasis put on the potential of information to improve policy (through improving e.g. planning, evaluation, research and cross-cultural and cross-professional communication), ICIDH collects particular pieces of information about the problems conceptualised as Impairment, Disability and Handicap in ways which implicate *particular solutions* to these. If we begin with Impairment and Disability, these are problems which are part and parcel of the individual body and mind and so it is necessarily so that the information collected in order to measure these and identify ways of improvement target the individual body and mind.[108] The category of Handicap is different. It concerns what this book refers to as composite life opportunities, the calling card of which are that they could potentially be realised through alternatives to augmenting the level and mode of functioning of the body and mind traditionally employed towards their performance or enjoyment. Against this background, it can be noted that the manual does emphasise the need for solutions to target Handicap directly; not only to direct attention towards Handicap so as not to infer Handicap as an automatic consequence of Disability, but also because *Handicap calls for different solutions:*

> However, disability will only indirectly influence disadvantage, and it is therefore important to be quite clear about one's goals. If handicap is the prime area of social concern, not all those with activity restrictions are necessarily at a disadvantage – because activity restriction cannot be viewed as a sociological phenomenon *per se*. There is a distinct cleavage between disability and handicap, both conceptually and *in the means for intervention*".[109]

A rationale for the Handicap category is thus that it calls for "means of intervention" different from those called for by the problems in the Disability category. However, that which ICIDH measures to determine Handicap remains the ability of the in-

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[105] Ibid.

[106] For the transferability of data between different professional groups, see Ibid. See Ibid., p. 207 for a note on the desirability of and challenges inherent in the "transcultural application" of the assessment of Handicap.

[107] Ibid., p. 18. See also Ibid., p. 11: "[T]he distinctions [between Impairment, Disability and Handicap] facilitate policy development in response to the problems, clarifying the potential contributions of medical services, rehabilitation facilities, and social welfare respectively.".

[108] Again, it should be noted here that some of the activities under Disability, such as e.g. "shopping in immediate neighbourhood" also fall into the category of composite life opportunities. Ibid., p. 163.

[109] Ibid., p. 41. First emphasis in original, second emphasis added.

dividual and not the ability of the environment. For example, under "Occupational handicap", "disabilities that preclude a child from attending a normal school" and "disabilities that require a child to be resident in an institution for purposes of education" are measured and registered and no measurement of the "normal school" is made and registered.[110] The sequence Impairment → Disability → Handicap in the graphic illustration of ICIDH portrayed above under 2.1., as well as the definition of Handicap as "*resulting* from an impairment or a disability"[111] is mirrored in the solutions envisaged to the problems of Handicap:

> The great value of presenting the concepts in this way [Impairment → Disability → Handicap] is that a problem-solving sequence is portrayed, intervention at the level of one element having the potential to modify succeeding elements.[112]

The lack of a call for any change in the organisation of society remains odd against the background that the elaboration of the concept of Handicap explicitly recognises that the degree of disadvantage is a result of the interplay between the person and the environment (see under 2.3. above). The following statement provides an illustrative example of how the recognition of the importance of composite life opportunities (employment) and the recognition of the important role of the environment to this end stops short of any call for adaptation of the environment, as if were it immutable:

> The key influence in designing this classification [Disability] has been the feasibility of recording the interface between the individual and his environment in such a way as to display his potential; this may be supplemented by the handicap classification as a means of indicating the extent to which potential is realized. Perhaps the ideal aim for the D code would be to present a profile of the individual's functional abilities, as determined from what disabilities were present, in such a way that reciprocal specification of the environment allowed matching with the individual's capabilities. For instance, in the context of job placement, a factory extending over two floors but with toilet facilities located on only one of these would require separate specification of each floor for purposes of matching with the (residual) functional abilities of potential employees.[113]

While the role of the environment as a determinant of Handicap is clearly recognised and the recording of it called for, the vision is thus to match the optimised individual and the environment *as the latter is;* nowhere is the adaptation of the environment implicated as a solution. Another example of this is one of the definitions of Handicap given in the manual, reading that "handicaps thus reflect interaction with and adaptation *to* the individual's surroundings".[114] The reference to adaptation "to" the environment is not matched with a reference to any adaptation 'of' the environment.

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[110] Ibid., p. 197.

[111] Ibid., p. 29. Emphasis added.

[112] Ibid., p. 30.

[113] Ibid., p. 37.

[114] Ibid., p. 14. Emphasis added.

2.5. Who is the intended constituency of ICIDH and by virtue of what characteristics or experiences?

The manual of ICIDH refers to its intended constituency by various terms: "disabled individuals"[115], "the disabled in society"[116], "the disabled"[117], "the disabled and handicapped"[118] and "people with chronic illness"[119]. Indirectly, it points out persons by describing the phenomena to which ICIDH applies: "chronic and progressive or irreversible disorders"[120] and "chronic and disabling conditions"[121]. These include "the effects of trauma, impairments of special sense organs, mental retardation and mental illness, and the chronic diseases of middle and later life, particularly heart disease, stroke, bronchitis, and arthritis"[122] as well as "diabetes and pernicious anaemia"[123]. Neither the manual nor the classification function of ICIDH differentiates between "the disabled" and "people with chronic illness". Both are seen as entailing a "residue of condition"[124], stemming from Disease or Disorder. From the perspective of ICIDH it is the *chronicity,* the *living with* conditions, which is the common denominator meriting the merger between all such envisaged "chronic and disabling conditions". While chronicity, as opposed to acute conditions, is the focus of ICIDH this limitation is qualified by the manual explicitly stating that Impairment as well as Disability may be "temporary and permanent".[125]

The constituency of ICIDH are persons who are diagnosed as currently having an Impairment *and* persons experiencing Handicap because of a previous Impairment. The example of the latter situation given in the manual is "the individual who has recovered from an acute psychotic episode but who bears the stigma of being a "mental patient"".[126] While the graphic depiction of ICIDH illustrates that Disease or Disorder are the original entry points into ICIDH, it is the *Consequences* of disease or disorder (present or former) which trigger the application of ICIDH. While Handicap is recognised as a valid entry point to ICIDH, it is made contingent upon a *previous Impairment*. Similarly, persons with a predisposition for an Impairment are not covered by ICIDH:

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[115] Ibid., p. 11.
[116] Ibid., p. 31.
[117] Ibid., p. 16.
[118] Ibid., p. 34.
[119] Ibid., p. 25.
[120] Ibid., p. 11.
[121] Ibid., p. 18.
[122] Ibid., pp. 9-10.
[123] Ibid., p. 9.
[124] Ibid.
[125] Ibid., pp. 27-28. Elsewhere in the manual such delimitation is stated as a choice available to the user of ICIDH: "[O]ne might well wish to restrict consideration to relatively persistent impairments, eliminating transitory states and other trivia by adopting duration and severity criteria.". Ibid., p. 37.
[126] Ibid., p. 31.

> [T]he individual exposed to or harbouring an extraneous etiological agent of disease is not impaired; impairment ensues only when the agent has initiated a reaction by the body so that pathological processes develop.[127]

The inclusion of "third-party handicap – i.e., handicap in an individual who is not himself impaired but who suffers disadvantage because of the demands made upon him by chronic illness or disability in the family" is discussed in the manual, but is discarded as impossible to include if the definition of Handicap is to be followed "with rigour", as "disadvantage is not consequent upon [his or her] own impairment or disability".[128] Along these lines, disadvantage for persons not having an Impairment according to ICIDH, but who are thought to have such an Impairment, would not be covered by ICIDH. This is so as any disadvantage experienced would not be, as quoted just above, "consequent upon their own impairment or disability".

It is thus the individual diversity of the person in question in terms of level and mode of functioning of the body and mind rather than disadvantage in relation to composite life opportunities which remains the central common denominator of the constituency of ICIDH, the only sine qua non for inclusion.

2.6. ICIDH as a basis for entitlements

The previous five sections have addressed key features of how ICIDH constructs disability. In this section, a summary is provided of these features and their implications as to for what claims to entitlements ICIDH can be used as a basis.

The *problems* recognised in ICIDH cover a broad range of life opportunities: levels and modes of functioning of the body and mind as well as composite life opportunities. As each of the three main categories (Impairment, Disability and Handicap) has sub-sections labelled 'others', the potential coverage is infinite.

The *causes* of problems in relation to levels and modes of functioning of the body and mind (Impairment and Disability) are referred to as Disease or Disorder and the range of causes of these is in turn open ended. The *solutions* identified are medical services including rehabilitation, which are to be improved through the use of ICIDH.

The *causes* of problems in the enjoyment of composite life opportunities (Handicap) are similarly identified as levels and modes of functioning of the body and mind and the *solutions* identified correspondingly amount to medical services, the collection of information about the individual and the provision of social welfare. This statement must be somewhat qualified against the background that the instrumental character of the environment in relation to Handicap is recognised in ICIDH. However, this remains overshadowed by general statements on and symbolic depictions of the causality of Handicap as implicating only Impairment and Disability. In addition,

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[127] Ibid., p. 27.

[128] Ibid., p. 43.

the solutions called for effectively blank the environment and focus solely on the individual (these include medical measures targeting the individual, the collection of information about the individual and the provision of social welfare).

The *constituency of ICIDH* are persons who have an Impairment or experience disadvantage in relation to composite life opportunities due to previous Impairment. Its coverage in terms of constituency ('who' would have these entitlements) turns on the 'chronic' as opposed to 'acute' character of levels and modes of functioning of the body and mind (albeit it does explicitly include conditions which may be "temporary or permanent").[129] ICIDH covers a broad range of persons, explicitly including both "the disabled"[130] and "people with chronic illness"[131]. The only explicit caveat of protection is people somehow predisposed to Impairment and a person disadvantaged in relation to the Impairment of someone else.

If ICIDH be used as the ideological basis for claims to entitlements, such entitlements would potentially cover all areas of life, including levels and modes of functioning of the body and mind as well as composite life opportunities. The instrumental measures envisaged to realise these life opportunities are however limited to the solutions mentioned above. In the universe created by the connections made in ICIDH, the need for e.g. education, employment and social integration is thus recognised as a legitimate rationale for measures, but only for measures to change the individual and for the collection of information about the individual, not for measures to change the environment and for the collection of information about the environment. This does not mean that ICIDH expressly advices against such measures; indeed it can be inferred from ICIDH both implicitly and explicitly noting the import of factors extrinsic to the person on the existence of Handicap that such measures would be welcomed. However, the factors singled out as targets for action in ICIDH are limited to the abilities of the individual and it is consequently too farfetched to say that ICIDH functions as an ideological basis for entitlements to a changed environment. To conclude, ICIDH as a basis for claims supports entitlements to medical intervention including rehabilitation aimed at improving levels and modes of functioning of the body and mind as an inherent good and as an instrumental good towards the enjoyment of composite life opportunities, as well as entitlements to the provision of social welfare.

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[129] Ibid., pp. 27-28.

[130] Ibid., p. 16.

[131] Ibid., p. 25.

2.7. Critique of ICIDH

The critique launched at ICIDH targets both its function as a classification and an approach to disability. The aim of this section is limited to introducing in general terms the main strands of the critique of ICIDH as a way of understanding disability.

The lion's share of the criticism launched as ICIDH concerns, predictably enough, the failure to unequivocally and systematically implicate the environment in the creation of disadvantage relating to the enjoyment of composite life opportunities (Handicap in ICIDH terms) and the corresponding failure to point to the environment for solutions to such disadvantage. This omission of environmental factors meant that "handicap was still considered or understood in a medical perspective as an individual characteristic".[132] Much for this reason, the international disability organisation Disabled People's International (DPI) explicitly rejected ICIDH.[133] The criticism of the missing environment in the creation of disadvantage dates back to the time of the publication of ICIDH and has continued since.[134] In a foreword added to the reprinted ICIDH manual from 1993 this criticism is recognised through WHO noting that "concern has been expressed that the ICIDH does not state clearly enough the role of social and physical environment in the process of handicap, and that it might be construed as encouraging "the medicalization of disablement"".[135]

Closely connected to this criticism are assertions that there is no relevant connection between the framework of 'health' and that of 'disability'. As noted in a reflection on this critique, this health connection flows from ICIDH being created by "an organisation whose middle name was "Health"".[136] More importantly, ICIDH clearly portrays health concerns and care as central to its constituency. Critics, such

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[132] Fougeyrollas, Patrick, Documenting Environmental Factors for Preventing the Handicap Creation Process: Quebec Contributions Relating to ICIDH and Social Participation of People with Functional Differences [hereinafter Fougeyrollas, 1995], Disability & Rehabilitation, Vol. 17, No. 3, 1995, p. 147. See also e.g. Oliver, Michael, The Politics of Disablement (1st Ed.), [hereinafter Oliver, 1990], Macmillan Press Ltd, Basingstoke , 1990, p. 24.

[133] See e.g. Hurst 2000, pp. 1083-1084.

[134] For an account of such criticism and efforts to rectify this aspect of ICIDH see Fougeyrollas, Patrick and Beauregard, Line, Disability: An Interactive Person-Environment Social Creation [hereinafter Fougeyrollas et al., 2001], in Handbook of Disability Studies, in Albrecht, Gary L. et al. (Eds.), Sage Publications, London, 2001, pp. 177-184. See also Bickenbach, Jerome E. et al., Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps [hereinafter Bickenbach et al., 1999], Social Science & Medicine, 1999, Vol. 48, p. 174-176.

[135] World Health Organization (WHO), International Classification of Impairments, Disabilities, and Handicaps – A Manual of Classification Relating to the Consequences of Disease, World Health Organization, Geneva, 1993, Reprint with added foreword, p. 1. This is recognised in the manual for International Classification of Functioning, Disability and Health (ICF), the revised version of ICIDH, as a reason for revision of the latter. World Health Organization (WHO), International Classification of Functioning, Disability and Health (ICF) [hereinafter WHO, 2001], World Health Organization, Geneva, 2001, Annex 7 Summary of the Revision Process, p. 247.

[136] Miles, M, ICIDH Meets Postmodernism, or 'Incredulity toward Meta-terminology', Disability World, Issue No. 7, March-April 2001.

as David Pfeiffer, maintain that there is no reason to single out neither health concerns nor health care as particularly relevant to persons with disabilities. This is asserted against the background that being "disabled" is different from being "sick":

> However, disability is not sickness. The author of this article became disabled from a disease, polio. He no longer has that disease and is not sick. Some persons with disabilities have chronic conditions, but for half to three-quarters of the disability community there is no present sickness which disables them.[137]

The health focus of ICIDH is held by Pfeiffer as not only irrelevant but harmful, as it diverts attention away from the need to change the context of the person:

> Disability is not a health question. It is a political one. By making disability a health question or by associating it with health problems, the WHO contributes to the oppression of persons with disabilities. It contributes to the oppression when people with disabilities are actually the victims of class-based standards and barriers.[138]

In addition to directing attention away from an oppressive environment, "the medicalization of disability" through "equating poor health with disability" places persons with disabilities as the rightful objects of the medical field and as an extension of this, of the medical profession.[139] Pfeiffer holds that "[t]he medicalization of disability is grossly inappropriate. It gives control of the lives of people with disabilities to medical professionals (not just physicians)".[140] He deplores that this habitually gives the same profession power to make decisions which far extend the area of medical care but instead reaches into other areas of life, such as employment.[141] Pfeiffer furthermore makes a connection between medical professionals being tasked with judging the quality of life of persons with disabilities and the use of such judgements in the elimination of persons with disabilities:

> The worst problem with the medicalization of disability is that it leads to medical personnel producing judgements on the quality of life of persons with a disability. Once a person with a disability is saddled with the judgement of having a poor quality of life, the person is a prime candidate of oppression and even euthanasia [.][142]

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[137] Pfeiffer, 1998, p. 508.

[138] Ibid., p. 519.

[139] Ibid., p. 509.

[140] Ibid.

[141] Ibid., pp. 509-510. See also record of statement by Rachel Hurst, in The Use and Usefulness of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), Proceedings from an International Workshop under the Council of Europe, Strasbourg (France) 25-26 March 1996, p. 71: "[T]he medical profession has not remained in the medical field and has moved into a new field where expertise from social, psychological and environmental disciplines is needed.".

[142] Pfeiffer, 1998, p. 510.

As ICIDH is a tool not only for individual application but for *general classification*, these threats are perceived by Pfeiffer on a broader scale, implicating its entire constituency:

> However, one of the first things that an oppressive government does before it begins to eliminate a group of people is to classify them. Once classified it is easy to select subgroups for elimination as did Nazi Germany in the 1930s and 1940s (Gallagher, 1995). The ICIDH is one step in this direction and the ICIDH-2 is little better. They are dangerous and must be dealt with by the community of people with disabilities.[143]

Another strand of criticism launched by Pfeiffer is that the problems identified in ICIDH reflect a suspect understanding of what and who is "normal":

> The ICIDH is a document tied to Western, middle class concepts of what is and what is not normal in terms of human behavior. Behavior which is not normal is considered to be bad and to stigmatize the individual as a person with a disability. [144]

In his critique of what is presented as "normal" in ICIDH, Pfeiffer notes a particularly suspect group of problems subsumed in ICIDH as Disability and labelled as "'Conduct out of context' include[ing]cultural shock (such as immigrants), moving in different identities (e.g., transvestism and passing, such as black passing for white), pseudo-feeble-mindedness, and breaking taboos".[145] He also brings up the example of walking versus using a wheelchair or another mode of transportation: what decides when (at what distance) it becomes "normal" not to walk?[146] On a more general note, Rachel Hurst objects to that according to ICIDH "non-disabled 'normality' was the yardstick against which disabled people were to be measured, suggesting that disability is outside the range of human experience and that disabled people are not really human".[147] Pfeiffer also notes that the designation of the constituency of ICIDH as deviant from the norm in a negative way, which in turn is seen as the operative reason for restricted composite life opportunities "is a clear form of blaming the victim and must be changed".[148] He further notes the effect of such blaming on the self-regard of the individual:

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[143] Ibid., p. 520. ICIDH –2 was the working name for the International Classification of Functioning, Disability and Health (ICF), explored below in Chapter 4. See also Hahn, Harlan, The ICF and the ICIDH: Privacy, Paradigms, and Definitions [hereinafter Hahn, 2002a], 8th North American Collaborating Centre Conference on ICF, June 2–4, 2002.

[144] Pfeiffer, 1998, p. 513. Calls for recognition of the complexities tied to what is seen as 'normal' around the world is further recognised by e.g. Barnes, Colin, Rehabilitation for Disabled People: a 'Sick' Joke?, Scandinavian Journal of Disability Research, Vol. 5, No. 1, 2003, p. 9 and Oliver, 1990, p. 24.

[145] Pfeiffer, 1998, p. 513 quoting WHO, 1980, p. 149.

[146] Pfeiffer, 1998, p. 513.

[147] Hurst, 2000, p. 1084.

[148] Pfeiffer, 1998, p. 518.

> The final effect of the ICIDH is to oppress people with disabilities. Having been blamed and told of inadequacies, the person with a disability internalizes the shame and the blame.[149]

A connected strand of criticism of ICIDH is that much of the language it uses is offensive, in the words of Pfeiffer, "handicapist".[150] Besides objecting to the term Handicap as "devaluing and paternalistic"[151], Pfeiffer notes the repeated use of negative expressions such as "failures in accomplishment"[152] to describe Disabilities and references to the constituency of ICIDH as "sufferers"[153]. Pfeiffer also objects to the use of the term "chronic illness" in the context of disability as "[m]any persons with disabilities have chronic conditions, but are not ill".[154]

As visible through the statement by Pfeiffer above on the dangers of classification, part of the reservations expressed towards ICIDH stems from suspicion against classifying the levels and modes of functioning of the body and mind of persons per se. The framers of ICIDH anticipated reservations about classification leading to stigmatisation and the following statement in the manual shows an attempt to pre-empt such arguments by asserting the utility of "categorization" and "counting":

> [A]ny attempt to clarify thinking in this area [disability] can be vulnerable to the protest of those who are concerned that categorization and labelling engenders stigma. However, this attitude surely denies the possibility of any coherent attempt to alter the present situation; until categories can be identified, one is unable to begin to count, and until counting is possible one cannot know how big the problems are or deploy the resources intelligently in an endeavour to control the problems.[155]

Referring to this statement, Pfeiffer protests that "[t]he clear implication is that until people with disabilities are willing to admit to so-called lack of ability, nothing can be done to combat discrimination".[156] Rachel Hurst similarly questions the need to categorise and count "individual characteristics":

> There is no other group of individuals who have been subjected to this analysis of individual characteristic. Women and indigenous people as discreet groups have been analysed, but only in relation to their social, cultural and economic status. An in-depth classification of their individual characteristics has never been seen as necessary as an analysis of their status or for the provision of services or the implementation of policies to implement rights.[157]

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[149] Ibid.

[150] Ibid., p. 515.

[151] Ibid.

[152] Ibid., quoting WHO, 1980, p. 14.

[153] Pfeiffer, 1998, p. 516, quoting WHO, 1980, p. 25.

[154] Pfeiffer, 1998, p. 516, quoting WHO, 1980, pp. 24-25.

[155] WHO, 1980, p. 35.

[156] Pfeiffer, 1998, p. 515.

[157] Hurst, 2000, p. 1084.

Finally, ICIDH has been criticised for the process through which it was developed, namely that it did not involve its intended constituency in its elaboration.[158]

To sum up, the main strands of criticism launched at ICIDH concern its failure to implicate the environment, the fact that it addresses disability from the platform of ‘health’, its conceptualisations of ‘normality’ and the fact that it is a system for classification.

This account of the critique of ICIDH concludes this chapter. In the following chapter I will turn to the Social Model of Disability, which, on all accounts, differs the most from ICIDH among the approaches to disability explored in this book.

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[158] See e.g. Hurst, 2000, p. 1083.

3. The Social Model of Disability

The concept 'social', used in opposition to 'individual' or 'medical', is key to discourses about disability. Terms such as 'a social approach/model/perspective/understanding/theory of disability' are used in varying contexts and with varying meanings.[159] Similar to other emancipatory struggles for justice, the key role of the concept 'social' is to illustrate where the operative reason for disadvantage lies. It is not aspects of human diversity such as sex, ethnicity or level and mode of functioning of the body and mind which 'naturally' and inevitably cause this disadvantage, instead it is the responses by surrounding society to persons thusly designated (women, persons with e.g. dark skin colour or persons with disabilities) which represent the problem and consequently the solution. Additionally, in relation to disability, the concept 'social' plays a role in illustrating the nature of the life opportunities hitherto denied as *social* participation.

Against the background of the pivotal role and the broad usage of the concept of 'the social' in relation to emancipatory movements in general and in the disability discourse in particular, it is perhaps not surprising that a particular effort to establish the 'right' meaning of disability as an ideological and political platform has actively claimed the name 'the social model of disability'. This particular approach to disability originated in the Disabled People's Movement in the United Kingdom (UK) and remains their "big idea".[160] It is this particular approach to disability which is the focus of this section. As will be discussed below under 3.7., within the UK Disabled People's Movement and the academic discipline which sprung from its front figures, disability studies, there are many competing accounts of what 'the social model of disability' entails. My interest here is not to pursue the 'rightful' owner of the term 'the social model of disability', nor to explore these different accounts (which would be a book in itself). However, in pursuing the aim to analyse the main approaches to disability being drawn upon in the global disability discourse (of which 'the social

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[159] See e.g. Shakespeare, 2006, pp. 10-28 and Traustadóttir, Rannveig, Disability Studies, the Social Model and Legal Developments [hereinafter Traustadóttir, 2009], in Arnardóttir, Oddný Mjöll and Quinn, Gerard (Eds.), The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, Martinus Nijhoff Publishers, Leiden, 2009, pp. 3-16.

[160] Hasler, Frances, Developments in the Disabled People's Movement, in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (1st Ed.), Sage Publications Ltd, London, 1993, p. 280.

model of disability' is the reigning one) I must choose between, as one author puts it "competing positions" in "social model theory".[161]

For this purpose, I have chosen an account which is regularly forwarded as "the original, and now 'classic' formulation"[162] of what became the social model of disability: two documents produced by the Union of the Physically Impaired Against Segregation (hereinafter UPIAS) named "Aims and Policy Statement"[163] and "The Union of the Physically Impaired Against Segregation and the Disability Alliance discuss Fundamental Principles of Disability".[164] UPIAS was formed as an outcome of the failure of a civil society campaign in the UK for 'disability income', meaning a monetary allowance to disabled people who did not have employment: Disability Income Group (DIG). UPIAS opposed the continuation along the political path of this campaign which they criticised as characterised by experts speaking on behalf of disabled people and treating each aspect of the life situation of disabled people in isolation, thus missing the bigger picture of the systematic oppression of disabled people in society. Instead the aim of UPIAS was for disabled people to organise themselves and to speak for themselves rather than having 'experts' speaking for them. In addition, the focus should be directed towards the way society oppressed disabled people, by relating every issue, including the poverty of disabled people, to the exclusionary organisation of society:

> We as a Union have drawn the necessary lesson from this experience in DIG, and therefore our Union's Aims and Policy Statement place incomes firmly in the context of the wider struggle for us to participate fully in society, and so achieve our emancipation from all aspects of our oppression, including poverty.[165]

In the two documents referred to just above, UPIAS do not themselves refer to their position as 'the social model of disability'. Instead it is those claiming to reiterate the UPIAS position, in particular Michael Oliver, who have termed this position "the social model of disability".[166] In light of this I have chosen to base my analysis of 'the social model of disability' on the position expressed by UPIAS in the two named

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[161] Tregaskis, Claire, Social Model Theory: The Story So Far… [hereinafter Tregaskis, 2002], Disability & Society, Vol. 17, No. 4, 2002, p. 457.

[162] Thomas, Carol, Female Forms: Experiencing and Understanding Disability [hereinafter Thomas, 1999], Open University Press, Buckingham, 1999, p. 14.

[163] Union of the Physically Impaired Against Segregation (UPIAS), Aims and Policy Statement [hereinafter UPIAS, 1974], 3 December 1974.

[164] UPIAS, 1975. 22 November 1975, UPIAS held a meeting with another organisation, the Disability Alliance, and distributed the minutes of this discussion, commented on by both organisations, under the heading "The Union of the Physically Impaired Against Segregation and the Disability Alliance Discuss Fundamental Principles of Disability".

[165] Ibid., p. 4.

[166] "It was Mike Oliver, however, who was most successful in promoting a clearly expressed version of the UPIAS interpretation in the public arena. […] This interpretation he identified as a *social model of disability*." Finkelstein, Victor, The Social Model of Disability Repossessed [hereinafter Finkelstein, 2001], originally published in Manchester Coalition of Disabled People, December 2001, p. 2. Emphasis in original.

documents, supplemented by selected later writings elaborating upon the position of UPIAS by one of its authors, Victor Finkelstein, as well as on selected writings by Michael Oliver.[167] I refer to the approach to disability thusly collectively constructed as 'the Social Model of Disability', however I will endeavour to clearly indicate to which of the sources above a particular position is attributed.

3.1. The universe of the Social Model of Disability

That which the Social Model of Disability portrays, its universe, is referred to by UPIAS as "the social definition of disability",[168] "[t]he Union's firmly principled approach to disability"[169], "a new approach to disability"[170] and "[t]he Union's social theory of disability"[171]. As mentioned above, Michael Oliver later christened it the "social model of disability".[172]

The components of this universe are *Impairment and Disability*. Impairment is defined by UPIAS as "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body".[173] Impairments thus represent certain levels and modes of functioning of the body. In the words of Michael Oliver, "impairment is, in fact, nothing less than a description of the physical body".[174] Disability is defined by UPIAS as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical

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[167] Michael Oliver first applied the label "a/the social model of disability" to the texts of UPIAS in Oliver, Michael, A New Model of the Social Work Role in Relation to Disability, in Campling, Jo (Ed.), The Handicapped Person: A New Perspective for Social Workers? [hereinafter Oliver, 1981], Radar, London, 1981, see e.g. pp. 19, 28. This connection has been repeated and elaborated on in Michael Oliver's subsequent work, see e.g. Oliver, Michael, Understanding Disability [hereinafter Oliver, 1996], Macmillan Press Ltd, London, 1996, pp. 28-29: "[T]he social model of disability […], in my formulation at least, emerged out of the Fundamental Principles document (Oliver 1983) and owes a debt to it.", pp. 30-31: "The idea of the individual and the social model was taken quite simply and explicitly from the distinction originally made between impairment and disability by the Union of the Physically Impaired Against Segregation in the Fundamental Principles document (1976)." and p. 33: "The social model itself can be located within the original UPIAS definition". Oliver has written widely on disability, particularly elaborating and applying the Social Model of Disability and providing a materialist understanding of the creation of Disability. I have strived to include sources that primarily elaborate on the former; however these two aspects of Oliver's scholarship are more or less present in all his works. While I have strived to include some recent sources, I have chosen the original version of books which have subsequently been updated through the inclusion of additional authors.

[168] UPIAS, 1975, p. 8.

[169] Ibid., p. 11.

[170] Ibid., p. 13.

[171] Ibid., pp. 15, 20.

[172] Oliver, 1981, see e.g. pp. 19, 28.

[173] UPIAS, 1975, p. 14.

[174] Oliver, Michael, Defining Impairment and Disability: Issues at Stake, [hereinafter Oliver, 1996a], in Barnes, Colin and Mercer, Geof (Eds.), Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996, p. 42.

impairments and thus excludes them from participation in the mainstream of social activities".[175] Disability is defined by UPIAS as *"social oppression"*.[176] Disability is thus oppressive social responses (or lack of responses) to Impairment. Oliver subsequently quotes the passages above in branding them "the social model of disability".[177]

3.2. What problems does the Social Model of Disability recognise?

The central problem according to UPIAS is Disability, which is understood as oppressive restrictions of "participation in the mainstream of social activities".[178] Such mainstream social activities are further exemplified by UPIAS as including economic sustenance (including retirement benefits), mobility (including transport), employment, education, housing (particularly the element of choice) and independence.[179] Among these, employment is repeatedly accorded a particularly important position:

> Only when all physically impaired people of working age are as a matter of course helped to make whatever contribution they can in ordinary work situations, will secure foundations for full integration into society as a whole be laid. All the other situations from which physically impaired people are excluded are linked, in the final analysis, with the basic exclusion from employment.[180]

The problems in focus for UPIAS, Disability, are composite life opportunities, expressed as being "unnecessarily isolated and excluded from full participation in society".[181] A related question, which has been subject to much debate, is whether the Social Model of Disability, in addition, includes levels and modes of functioning of the body and mind among the problems it recognises as relevant to its constituency. UPIAS conceptualise such levels and modes of functioning as Impairments. As mentioned above, the concept of Impairment is explicitly separated from the concept of Disability. Impairment is defined to illustrate what Disability *is not about*, i.e. not about the body. Making a clear distinction between Impairment and Disability, not "confusing disability with physical impairment"[182] is central to the position of UPIAS. Levels and modes of functioning of the body are thus not included in the problems intended by the Disability concept, but rather actively excluded from these.

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[175] UPIAS, 1975, p. 14.
[176] Ibid. Emphasis added.
[177] Oliver, 1981, pp. 28-29.
[178] UPIAS, 1975, p. 14.
[179] See e.g. Ibid., p. 19 and UPIAS, 1974, initial paragraph on Aims.
[180] UPIAS, 1975, pp. 15-16.
[181] Ibid., p. 14.
[182] Ibid.

However, while the focus of UPIAS is unequivocally on the problem of Disability (composite life opportunities), there is no explicit rejection of Impairment, in its own right rather than as part of the Disability concept, potentially representing a relevant problem to the intended constituency of UPIAS. Indeed, rather the opposite is indicated since Impairment is referred to as something which must be "*accepted*" by the person, with Disability being described, with reference to Impairment, as "*additional* and totally unnecessary *problems*":[183]

> In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted.[184]

According to a more recent account of the UPIAS position on this issue by one of its founding members, Victor Finkelstein, the UPIAS agreement was that "although it may be a *tragedy* to have an impairment, it is *oppression* that characterises the way our society is organised so that we are prevented from functioning".[185] According to the same author such recognition of Impairment as potentially problematic in and of itself, however, does not mean that Impairment should be included on the political platform for which the UPIAS statements were intended:

> In other words, at the personal level we may talk about acquiring an impairment being a personal tragedy, but at the social level we should talk about that the restrictions we face are, and should be interpreted as, a crime.[186]

Furthermore, the terminology in the definition of Impairment, "lacking" and "defective", conveys negative connotations and the texts by UPIAS do not at any point indicate a positive viewpoint on impairment.[187] The exclusion of Impairment from the ideological and political platform named Disability consequently appears as a strategic move, rather than a refutation of its significance. Michael Oliver similarly recognises the strategic dimension of not paying attention to Impairment:

> The denial of the pain of impairment has not, in reality been a denial at all. Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than by medical or other professional treatment.[188]

Oliver refutes the critique that "the social model ignores or is unable to deal adequately with the realities of impairment" and that "it is only fit, white men in wheel-

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[183] Emphasis added.
[184] UPIAS, 1974, para. 15.
[185] Finkelstein, 2001, p. 2. Emphasis added.
[186] Ibid.
[187] UPIAS, 1975, p. 14.
[188] Oliver, 1996a, p. 48.

chairs who are able to ignore their impairments".[189] He does so both by emphasising that he, as the author of the Social Model of Disability, is himself "a severely disabled tetraplegic, who every day of my life needs to make the necessary arrangements to be able to get up in the morning and go to bed at night and indeed use the toilet" and that "the limitations that our functional impairments impose upon us are an inadequate basis for building a political movement".[190]

Consequently, it is *the suitability and relevance* of any problematic character of Impairment to public discourse which is denied, not the possibility, likelihood or rationality of individual experience of Impairment (levels and modes of functioning of the body), as distinct from Disability (oppressive restrictions of social participation), as negative. Having said that, both Oliver and Finkelstein actively question the correctness of the habitual presumption of Impairment as a problem. Oliver's instruction to social workers is informative:

> [The social model] does not deny that some people may grieve or mourn for their lost able body but suggests that such a view should not dominate the social worker's assessment of what the problem may be.[191]

While such grieving and mourning thus happens to some people, Oliver emphasises that this is only one possible response and should not be expected, or reinforced or enforced, as "it is surely a value-judgement to assume that disability is a tragedy rather than that it is a phenomenon which may be explained in a number of ways".[192] Furthermore, Oliver has repeatedly identified the assumption that Impairment necessarily equates tragedy, "'the personal tragedy theory of disability'", as underpinning "the individual model of disability", which in turn is cast as the opposite and the target of the Social Model of Disability.[193] This individual model "locates the 'problem' of disability within the individual and [...] sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability".[194] In addition to noticing these problematic ideological and political implications of the perception of Impairment as a problem, Oliver furthermore steers away from this perception by welcoming the emerging "politics of personal identity", demanding "through a growing collective identity,

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[189] Oliver, Michael, The Social Model in Action: If I Had a Hammer [hereinafter Oliver, 2004], in Barnes, Colin and Mercer, Geof (Eds.), Implementing the Social Model of Disability: Theory and Research, The Disability Press, Leeds, 2004, p. 22.

[190] Ibid., p. 23.

[191] Oliver, Michael, Social Work with Disabled People (1st Ed.) [hereinafter Oliver, 1983], The Macmillan Press Ltd, London, 1983, p. 28. See also Oliver, 2004, p. 22: "It is similarly recognised that for many people coming to terms with the consequences of impairment in a society that devalues disabled people and disabled lifestyles is often a personal tragedy. But the real misfortune is that our society continues to discriminate, exclude and oppress people with impairments viewed and labelled as disabled.".

[192] Oliver, 1983, pp. 18-19. From the context is appears that Oliver is here using "disability" in the sense he categorically attributes to "impairment".

[193] Oliver, 1996, p. 32.

[194] Ibid.

that difference not be merely tolerated and accepted but that it is positively valued and celebrated".[195] Finkelstein similarly questions the standard which produces the person as having ""suffered" a personal loss":

> The deviation from one modality of existence (e.g. seeing) to another (e.g. blindness) can only be called a loss, and therefore the person has problems, if the first modality is used as the standard for judgements about the second. Purely in terms of physical existence, which can be of infinite variation, any modality may be used as the standard. Hearing, for example, could be construed as the loss of peaceful silence. The attitude that a disabled person has "suffered" a personal loss is a value judgement based on an unspoken acceptance of the standard being able-bodied normalcy.[196]

Turning back to UPIAS, the strategy of denying the relevance of Impairment to politics is not consistent in its account, as medical measures targeting Impairment are part of the demands put to the state:

> It is of course a fact that we sometimes require skilled medical help to treat our physical impairments – operations, drugs and nursing care. We may also need therapists to help restore or maintain physical function, and to advise us on aids to independence and mobility.[197]

From these references to "medical help" as a desired solution and to "restore or maintain physical function" as a desired result, Impairments logically emerge as problems, and problems of political relevance at that.

3.3. What causes does the Social Model of Disability recognise as relevant to the problems it identifies?

In the previous section I concluded that the Social Model of Disability recognises (implicitly in the case of UPIAS) that certain levels and modes of functioning of the body (Impairments) may represent problems in themselves. However, such problems are in general terms denied as relevant to the political platform which should instead focus on restrictions of composite life opportunities (Disability). Indeed, mentioning the former is implicated as counterproductive to the eradication of the latter. In this section the question is posed differently: are certain levels and modes of functioning of the body (Impairments) forwarded as *causes of Disability*?

A note is in place here on the connection between the Social Model of Disability as I delineate it and the materialist tradition of thought. Both Oliver and Finkelstein

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[195] Ibid., p. 89.

[196] Finkelstein, Victor, Attitudes and Disabled People: Issues for Discussion [hereinafter Finkelstein, 1980], World Rehabilitation Fund Inc., New York, 1980, p. 17.

[197] UPIAS, 1974, para. 14.

adhere to this tradition and their scholarship includes both accounts of the Social Model of Disability and a materialist analysis of the creation of Disability i.e. how production forces determine the social exclusion of disabled persons.[198] When UPIAS and Oliver depict the Social Model of Disability they however do not present it as inextricably dependent on a materialist analysis and so for the purposes of this book I will not bring out the latter dimension of their scholarship.[199]

In the Social Model of Disability, the cause of Disability is included in its very definition, Disability beeing "disadvantage or restriction of activity *caused by* a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities".[200] The cause of lacking "participation in the mainstream of society" is thus unequivocally found in the organisation of society and this relationship is referred to by UPIAS as "the objective fact that society causes our disablement by the way it is organised".[201] By 'ring fencing'[202] the concept of Disability in this way, it does not encompass any restrictions of composite life opportunities caused by levels and modes of functioning of the body. One of the founders of UPIAS, Victor Finkelstein, later referred to this approach as a clear cut case of either/or and as a necessary choice which had to be made:

> At an early stage in re-thinking the meaning of disability, when members of UPIAS began debating our socially inferior situation and asking why we found ourselves in this situation we confronted a crude, but fundamental choice:
>
> - either our tragedy is that the impairments we possess make us incapable of social functioning, or
> - our society is constructed *by* people with capabilities *for* people with capabilities and it is **this** that makes people with impairments incapable of functioning.[203]

This "crude but fundamental choice" is explained as having clear strategic dimensions, to redirect the focus at a time "(early 1970's) [when] there were no dissent-

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[198] See e.g. Finkelstein, 1980, Oliver, 1990 and Oliver, Michael, Capitalism, Disability and Ideology: A Materialist Critique of the Normalization Principle [hereinafter Oliver, 1999], in Flynn, Robert J. and Lemay, Raymond A., (Eds.) A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact, University of Ottawa Press, Ottawa, 1999. Mark Priestley notes that the tenets of the social model are (and thus can be) applied without contradiction by "Idealism" as well as "Materialism". See Priestley, Mark, Constructions and Creations: Idealism, Materialism and Disability theory [hereinafter Priestley, 1998], Disability & Society, Vol. 13, No. 1, 1998.

[199] For accounts of how subscribers to the "social model of disability" divide themselves along such lines see e.g. Priestley, 1998 and Thomas, Carol, Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology [hereinafter Thomas, 2007], Palgrave Macmillan Ltd, Basingstoke, 2007, pp. 49-82.

[200] UPIAS, 1975, p. 14. Emphasis added.

[201] Ibid., p. 19.

[202] Expressed thusly by Carol Thomas. See Thomas, Carol, Defining a Theoretical Agenda for Disability Studies, Paper for Disability Studies Conference: Theory, Policy and Practice, Lancaster, September 2003, p. 5.

[203] Finkelstein, 2001, p. 2. Emphasis in original.

ing opinions that the *'problems'* disabled people faced were caused by our impaired individual bodies".[204] Finkelstein stresses the importance of that the UPIAS "interpretation of 'disability' led us to focus on the nature and workings of society, **not** (I emphasise) our personal and individual attributes (which we saw as related to impairments)".[205]

Stating that certain levels and modes of functioning of the body (Impairments) do not cause Disability, is however not equivalent to saying that such levels and modes do not cause any restriction in social participation (potential parallel phenomena conceptualised as something other than Disability). However, as no concept encompassing restrictions of composite life opportunities caused by Impairment is forwarded by UPIAS, it can be concluded that even if the existence of such restrictions may be recognised, they are not considered politically relevant and/or suitable. This interpretation is consistent with the way UPIAS generally approach the causality of problems in particular domains covered by the Disability concept, here in relation to the generation of an income through employment:

> Since it is the social organisation that prevents us from gaining an adequate income from employment and meeting our other needs it follows that it is this social organisation that need to be assessed by physically impaired people and our supporters.[206] […] Instead of approaching physically impaired people as though our physical status decides whether or not we can work […] the conditions of work, and those other environmental situations leading to a working life and enabling one to get to work, etc., would be assessed.[207]

While UPIAS do not explicitly deny any causal connection between levels and modes of functioning of the body and restricted composite life opportunities, politically relevant restrictions of composite life opportunities are however effectively 'colonised' by the Disability concept, which is explicitly causally severed from the Impairment concept. According a causal role to Impairment is, in turn, approached as irrelevant (and potentially harmful) to the political agenda. Consequently, any possible role of levels and modes of functioning of the body (Impairment) as a cause of relevant restriction of composite life opportunities is, by a series of conceptual delimitations, 'defined' out of the conceptual, ideological and political map of UPIAS. This approach was followed by Michael Oliver, as he explicitly holds that "the social model" deals with Disability only, not Impairment or any restrictions connected to Impairment:

> The point I am making is that the social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability as defined earlier

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[204] Ibid.

[205] Ibid., p. 1. Emphasis in original.

[206] UPIAS, 1975, p. 18.

[207] Ibid., p. 19.

> by DPI and UPIAS. [T]he social model has insisted that there is no causal relationship between impairment and disability.[208]

Furthermore, "disability according to the social model" excludes anything which is the consequence of "individual limitations":

> It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation. Hence disability, according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on.[209]

Hence, when a disabled person cannot do or be something thought to be of value, the locus where the cause for this can be found appears limited to the environment:

> The importance of this social model of disability is that it no longer sees disabled people as having something wrong with them – it rejects the individual pathology model. Hence when disabled people are no longer able to perform certain tasks, the reasons are seen as poor design of buildings, unrealistic expectations of others, the organisation of production or an unsuitable housing environment. This inability does not stem therefore from deficiencies in the disabled individual.[210]

This general position, expressed by UPIAS as well as by Michael Oliver, appears to be somewhat contradictory to a simultaneous recognition of UPIAS of "medical [...] help" as a solution to restricted participation:

> The union aims to have all segregated facilities for physically impaired people replaced by *arrangements for us to participate fully in society. These arrangements must include* the necessary financial, *medical,* technical, educational and other *help* required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.[211]

From the above it can be concluded that medical measures are included on the political agenda as one area of solutions demanded by UPIAS to the key problems of their constituency, "to participate fully in society". This logically means that the problem that medical care targets, presumably implicating Impairment, is causally related to lacking participation in society. Furthermore, as medical care is asserted as politically relevant, the target of such care, Impairment, emerges as politically rel-

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[208] Oliver, 1996a, p. 48.

[209] Oliver, 1996, pp. 32-33.

[210] Oliver, 1983, p. 27.

[211] UPIAS, 1974, initial paragraph on Aims. Emphasis added.

evant. It would seem that by presenting medical care (which targets levels and modes of functioning of the body) as relevant to achieve full participation in society (the restriction of which is the core of the Disability concept), *Impairment is casually connected to Disability.* The only alternative is to assume an additional concept depicting a parallel phenomena encompassing restriction of social participation caused by Impairment.[212] As medical care is on the political agenda for social participation such a category would, according to UPIAS, have political relevance. Another possibility is to argue that medical care *is* social organisation and thus the lack of medical care as a cause of Disability amounts to a social rather than an individual, Impairment related cause. However, enlarging the category of recognised causes of Disability ("social organisation") to include a lack of measures targeting the individual Impairment rather than the environment effectively collapses Disability into any restriction of participation which can and should be remedied by social intervention targeting either the environment *or the individual.* Such an approach seems purely cosmetic, as the causal connection between Impairment and Disability is only hidden behind an intermediary concept, "social organisation", rather than in any real way severed. In addition, it implicates that Disability, as understood by UPIAS, can potentially be remedied by medical intervention targeting the individual in addition to by changing the environment. Either way, the categorical assertion that Impairment is politically irrelevant to restrictions of social participation (called Disability or otherwise) arguably effectively falls through the political recognition of medical help as a means to such social participation.

To conclude, the presentation of the Social Model of Disability as the categorical denial of any causal relationship between Impairment and Disability arguably connects to the main task of that approach. This task of the Social Model of Disability is expressed by Michael Oliver as "an attempt to switch the focus away from the functional limitations of individuals with an impairment on to the problems caused by disabling environments, barriers and cultures".[213] Consequently, the causality of restricted composite life opportunities expressed by the Social Model of Disability reads as primarily strategically motivated.

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[212] See further below under 3.7.1.2.

[213] Oliver, 2004, p. 4. This has been recently affirmed in Oliver, Michael and Barnes, Colin, Back to the Future: the World Report on Disability, Disability & Society, Vol. 27, No. 4, 2012, p. 576: "This [the conceptual distinction between the biological (impairment) and the social (disability)] was necessary to direct attention away from the general tendency to view disability as an individual problem rather than a socio/political issue – a tendency that allows policy-makers to focus on 'people fixing' rather than disabling barriers.".

3.4. What solutions does the Social Model of Disability recognise as relevant to the problems it identifies?

From the above it can be concluded that the problems recognised by the Social Model of Disability as relevant to the venture for change are generally asserted as those covered by the concept of Disability. The Social Model of Disability defines this concept as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities".[214] UPIAS was created as a tool for social change, to eliminate problems that "contemporary social organisation" posed for disabled people. The link between the chosen approach to disability and its potential as the basis for demands for social change was explicit, as what was sought after by UPIAS was "a social theory of disability which could guide our struggle against oppression":[215]

> For us as disabled people it is absolutely vital that we get this question of the cause of disability quite straight, because on the answer depends the crucial matter of where we direct our main energies in the struggle for change.[216]

UPIAS thus underscore the importance of establishing the causality of a problem in order to identify its correct solutions:

> Any scientist, seeking to deal effectively with a problem, knows that the cause must first be identified. Therefore, if disability is a social condition then an analysis of the ways in which society actually disables physically impaired people is obviously required before the condition can be eliminated.[217]

A central theme for the solutions to Disability envisaged by UPIAS is the development of *the political organisation of its constituency*. They emphasise the necessity to "draw the mass of disabled people (of whatever age or type of physical impairment) into the great movement to raise our consciousness of our social identity".[218] This collective focus follows from the relational characterisation of the disadvantage of disabled people, oppression, which naturally implicates two groups; "disabled people" and "able-bodied people". This was also closely linked to creating opportunities for disabled people to speak (and to be heard) for themselves. Thus, while help from others is welcomed, *control* must stay with the constituency:

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[214] UPIAS, 1975, p. 14.

[215] Finkelstein, 2001, p. 1.

[216] UPIAS, 1975, p. 4.

[217] Ibid., p. 13.

[218] Ibid., p. 16. See also Ibid., p. 7: "[T]he prime task is to raise the involvement of disabled people, to help disabled people to recognise their particular position." and p. 16: "A general mass movement of disabled people, and our increasing integration into normal work and other social situations, will radically improve our status as a group.".

> We know that as a small, weak, minority group, disabled people cannot achieve a fully human life by their own efforts alone. We need and welcome the help of sympathetic able-bodied people. But the basic problem we face is our exclusion from full social participation. It follows that this oppressive situation can be put right only by disabled people actually taking a more active part in society. The efforts of professionals and other able-bodied people are therefore really constructive only when they build on and encourage the self-help and activity of disabled people themselves.[219]

Michael Oliver similarly recognises that "[i]t is from this growing consciousness and political power of disabled people that ultimately solutions to the problems of disability may emerge".[220]

The unifying factors of the problems defined by UPIAS as Disability, spanning over different areas of life, was *lack of control over one's own life and segregation and exclusion from mainstream society*. Thus, according to UPIAS, efforts for change in any area of life must be connected to "the wider struggle for us to participate fully in society".[221] UPIAS expresses its aims as "to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives".[222] As noted above under 3.2., such composite life opportunities are exemplified further as including economic sustenance (including retirement benefits), mobility (including transport), employment, education and housing (particularly the element of choice). Solutions to the problem of Disability called for by UPIAS ("arrangements for us to participate fully in society [including] the necessary financial, medical, technical, educational and other help derived from the State")[223] must have *inclusion* as their rationale. Consequently, UPIAS underscores that "the financial and other special help required to meet the extra costs and problems of living with impairments must increasingly be replaced by arrangements which include us as an integral part of society for example, fully accessible and reliable public transport".[224] The inadequacy of this "special help" emerge through segregated living arrangements:

> The union of the Physically Impaired believes that the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrap-heaps of this society. Thousands of people, whose only crime is being physically impaired, are sentenced to these prisons for life – which may these days be a long one. For the vast majority there is still no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself.[225]

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[219] UPIAS, 1974, para. 16.
[220] Oliver, 1983, p. 116.
[221] UPIAS, 1975, p. 4.
[222] UPIAS, 1974, initial paragraph on Aims.
[223] Ibid.
[224] UPIAS, 1975, p. 15.
[225] UPIAS, 1974, para. 6.

In addition to inclusion, control over one's own life was central. A key target of UPIAS was to loosen "the stranglehold the professions have over disabled people"[226], to take back the power of professionals acting as "social controllers"[227] of disabled people:

> [T]he imposition of medical authority, and of a medical definition of our problems of living in society, have to be resisted strongly. First and foremost we are people, not 'patients ', 'cases', 'spastics', 'the deaf', 'the blind', 'wheelchairs' or 'the sick'. Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withholding information from us, or take decisions behind our backs.[228]

However, as elaborated above under 3.2.-3.3., the rejection by UPIAS of *the authority and power of the medical and related professions* in relation to "living in society" above does not appear to amount to a rejection of the relevance of medical intervention to its intended constituency, either per se or as a means to social participation. This is so as UPIAS calls for "medical" solutions addressing both Impairment ("to help restore or maintain physical function")[229] and Disability ("arrangements [...] to participate fully in society")[230]. Michael Oliver agrees with this recognition of the importance of medicine to disabled people:

> The social model of disability does not ignore questions and concerns relating to impairment and/or the importance of medical and therapeutic treatments. It acknowledges that in many cases, the suffering associated with disabled lifestyles is due primarily to the lack of medical and other services.[231]

Like UPIAS, recognition of the role of medicine is flanked by recognition of the harm done by medical interventions 'out of bounds', stemming from trying to solve problems in the individual which should be solved through targeting the environment:

> [D]octors can have a role to play in the lives of disabled people: stabilising their initial condition, treating any illnesses which may arise and which may or may not be disability related. The problem arises when doctors try and use their knowledge and skills to treat disability rather than illness. Disability as a long-term social state is not treatable medically and is certainly not curable. Hence many disabled people experience much medical intervention as, at best, inappropriate, and, at worst, oppressive.[232]

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[226] UPIAS, 1975, p. 8.

[227] Ibid., p. 18.

[228] UPIAS, 1974, para. 14.

[229] Ibid.

[230] Ibid., initial paragraph on Aims.

[231] Oliver, 2004, p. 22. See also Ibid., p. 20: "[E]ndorsement of the social model does not mean that individually based intervention in the lives of persons with disabilities, whether they be medically, rehabilitative, educational or employment based, are of no use or always counter-productive (Oliver 1996 b).".

[232] Oliver, 1996, p. 36.

In addition, Oliver highlights that the medical and other therapeutic professions are driven by a misguided as well as dangerous "ideology of normality" which prioritises the pursuit of eliminating impairment above all else and at any cost to the individual.[233]

> [T]he medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image; physiotherapy, occupational therapy, speech therapy, clinical psychology; each one geared to the same aim – the restoration of normality.[234]

Oliver emphasises the role of this ideology in preserving the legitimacy of and the need for these professions:

> In terms set by the rehabilitation enterprise, walking is rule-following behaviour; not walking is rule-ignoring, rule-flouting or even rule-threatening behaviour. Not-walking can be tolerated when individuals are prepared to undergo rehabilitation in order to nearly walk or to come to terms with their non-walking. Not walking or rejecting nearly-walking as a personal choice is something different however; it threatens the power of professionals, it exposes the ideology of normality and it challenges the whole rehabilitation enterprise.[235]

In a lecture targeting medical professionals, Oliver poses the rhetorical questions "whether medicine has a role to play in dealing with disability" and "whether there is an appropriate role for doctors within the social model of disability".[236] He proceeds to answer these questions "in the affirmative" but stresses that doctors and disabled people must address problems together:[237]

> [D]octors must attempt to understand why and how disabled people experience disability in the way that they do and disabled people must attempt to understand how doctors are socialized into thinking about disability in particular ways.[238]

He concludes that the power which is now wielded by doctors must be shared with disabled people, that "doctors must learn to give up some of their power and disabled people must learn how to empower themselves and what to do when they have".[239]

Besides having issues with medicine connected to normalising ideologies, power imbalances and abuses, Oliver challenges the medical professions to show that "they

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[233] Oliver, Michael, The Individual and Social Models of Disability [hereinafter Oliver, 1990a], Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospital, 23 July 1990, p. 4.

[234] Oliver, 1996, p. 37.

[235] Ibid., p. 104.

[236] Oliver, 1990a, p. 4.

[237] Ibid.

[238] Ibid., p. 5.

[239] Ibid.

have provided cures rather than promises".[240] Victor Finkelstein similarly recognises the often illusory goal of eliminating Impairment, while at the same time recognising the power that this idea holds:

> First, very many disabled people would welcome physical interventions which *guarantee* elimination of an impairment. This is surely demonstrated by the continuing attraction of rehabilitation programmes to return function; support for research into modifying multiple sclerosis, epilepsy or spinal injury, etc.; the frequency of corrective surgery (such as removal of cataracts) and use of equipment to approximate normal behaviour (such as hearing and walking aids). Even disability organisations sceptical about experiments to make disabled people 'normal' do not campaign against the prospect of eliminating impairment.[241]

To conclude, it is clear that the focus of UPIAS, expressed above as to "clarify the correct interpretation of the cause of disability and hence the correct way of struggling to improve our lives" envisages intervention in the environment as the "correct" struggle, as do Michael Oliver and Victor Finkelstein. There is no question about that it is Disability, (categorically asserted as neither covering Impairment nor being caused by Impairment), which is the envisaged problem to be solved. The general focus for solutions is thus *problems in relation to composite life opportunities which are caused by social organisation* (and not Impairment or problems in relation to composite life opportunities which are caused by Impairment). In addition, the recognition of the harm done by medical solutions 'out of bounds' expresses clear reservation to the execution of the medical profession. However, it remains that the particular responses envisaged by UPIAS, in the name of Disability or otherwise, seem to target the individual as well as the environment as it expressly includes medical assistance and rehabilitation. Victor Finkelstein and Michael Oliver similarly recognise the relevance of and importance attached to medical intervention by the constituency of the Social Model of Disability. The relationship between the Social Model of Disability and medical intervention thus remains a double-bind: the importance of the latter to disabled people is emphasised, but equally emphasised are the dangers of medicine. These dangers are convened through juxtaposing interventions targeting the individual with interventions in the environment, as well as through highlighting abuse. In relation to the former concern Oliver notes that "[f]rom a social model perspective, too much is invested in individually based interventions with ever diminishing returns. As a consequence, modifications to environments tend to be neglected or under resourced despite the greater potential benefits of such investments".[242] In ad-

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[240] Oliver, 1996, p. 109. See also Ibid., p. 101: "The problem is, of course, that throughout the history of humankind, the number of cures that have been found to these 'chronic and crippling diseases' could be counted on the fingers of one hand and still leave some over to eat your dinner with.".

[241] Finkelstein, Victor, The Commonality of Disability [hereinafter Finkelstein, 1993] in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (1st Ed.), Sage Publications Ltd, London, 1993, p. 10. Emphasis in original.

[242] Oliver, 2004, p. 20.

dition to diverting resources from environmental change, medical interventions are presented as *ideologically* juxtaposed with the social model:

> We are increasingly demanding acceptance from society as we are, not as society thinks we should be. It is society that has to change not individuals and this change will come about as part of a process of political empowerment of disabled people as a group and not through social policies and programmes delivered by establishment politicians and policy makers nor through individualised treatments and interventions provided by the medical and para-medical professions. This is the core of the social model.[243]

The Social Model of Disability thus takes the position that calls for medical intervention have no place on the Social Model of Disability as an ideological, political and legal platform and are potentially counterproductive.

3.5. Who is the intended constituency of the Social Model of Disability and by virtue of what characteristics or experiences?

UPIAS defines the persons implicated by their definition of Disability interchangeably as "disabled people"[244], "physically impaired people"[245] and "the physically impaired"[246]. While physical Impairment remains a prerequisite for belonging, the point of connection in focus is *being disabled*. This constitutes a "social identity"[247] stemming from being "an oppressed group in society"[248]. The common denominator for the constituency is that "it is the same society which disables whatever their type, or degree of physical impairment".[249] This commonality is asserted as transcending diversity of physical Impairments and "degrees of exclusion (degrees of disability)".[250]

UPIAS expressly limits its coverage to *physically* impaired people. While acknowledging common ground with "mentally handicapped" and "mentally ill" as "oppressed groups", this limitation was justified through reference to differences in "situations" and "problems":

> The particular form which oppression takes in this society differs somewhat for each distinct oppressed group. Some, such as people who are called 'mentally handicapped', or those 'mentally ill', clearly have a great deal in common with us. Full membership of

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[243] Oliver, 1996, p. 37.
[244] UPIAS, 1974, para. 3.
[245] Ibid., initial paragraph on Aims.
[246] Ibid., para. 4.
[247] UPIAS, 1975, p. 16.
[248] Ibid., p. 14.
[249] Ibid., p. 15.
[250] Ibid.

> our Union is however based simply on the fact of physical impairment. This is because we believe the important thing at the moment is to clarify the facts of our situation and the problems associated with physical impairment.[251]

On the topic of exclusion, UPIAS mentions further groupings, such as "people who are blind, or deaf, or cannot speak, or who have brain damage".[252] When Michael Oliver presented his interpretation of the position of UPIAS as the "social model of disability", he broadened its constituency by asserting its relevance to other categories of Impairments:

> According to Finkelstein (1980), this social model of disability may be most appropriately applied to physical impairments but it can also take in sensory impairments. For example, deaf people may be disabled by the way we communicate in that increasing use of the telephone may restricts people who can communicate perfectly adequate at a face to face level or meetings may not be organised in well lit rooms where the hearing impaired can adequately see other participants and follow their lips. Similarly mental handicap can be seen as less the problem of the intellectual impairment of certain individuals but more related to general expectations about levels of social competence.[253]

Finally, it would seem that Oliver makes a distinction between "disabled people" and "people with impairment" in his scholarship on the Social Model of Disability, with the consequence of the Social Model of Disability only 'being about' those who agree with its position (disabled people):

> Throughout [the book "Understanding Disability"] I shall attempt to remain within the distinction between impairment and disability developed by UPIAS [.] Following on from this, my definition of disabled people contains three elements; (i) the presence of impairment; (ii) the experience of externally imposed restrictions; and (iii) self-identification as a disabled person. This book therefore is about disabled people, not people with impairments and should be read as such.[254]

To conclude, while Impairment is a prerequisite for the constituency of the Social Model of Disability, it is being on the receiving end of exclusion and disadvantage, understood as oppression, which is forwarded as the core commonality, as amounting to *being* disabled. While UPIAS extended this commonality only to people with physical Impairments, Victor Finkelstein and Michael Oliver enlarged the constituency of the Social Model of Disability to encompass additional categories of Impairments.

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[251] UPIAS, 1974, para. 22.
[252] UPIAS, 1975, p. 15.
[253] Oliver, 1981, p. 30.
[254] Oliver, 1996, p. 5.

3.6. The Social Model of Disability as a basis for entitlements

The previous five sections have addressed key features of how the Social Model of Disability constructs disability. In this section, a summary is provided of these features and their implications as to for what claims to entitlements the Social Model of Disability can be used as a basis.

The Social Model of Disability, as I have delineated it, defines the problem to be addressed as *Disability,* as oppressive restrictions of "participation in the mainstream of social activities".[255] Such mainstream social activities are exemplified further by UPIAS as including economic sustenance (including retirement benefits), mobility (including transport), employment, education, housing (particularly the element of choice) and independence. Among these, employment is repeatedly accorded a particularly important position. UPIAS insist categorically that Impairment and any effects of such Impairment on composite life opportunities are not the business of disability as an ideological and political platform, albeit the recognition by UPIAS of medical measures targeting Impairment contradicts this categorical stance. While Michael Oliver has gradually recognised that it is "inevitable" that Impairment will be theorised,[256] there has been no change in his position that only the Social Model of Disability should be the basis for politics and that neither Impairment nor its effects have a place in this model.[257] To conclude, it would seem that while certain areas of priority are explicitly or implicitly identified in the UPIAS position (employment, independence, participation) the list of composite life opportunities the Social Model of Disability holds is potentially open-ended. Impairment is, however, categorically excluded from the problems focused on by the Social Model of Disability.

The *cause* of Disability according to the Social Model of Disability is "contemporary social organisation".[258] As repeatedly noted, Impairment is categorically asserted as *not* being a cause of Disability (even though it remains implicitly implicated as such by UPIAS).

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[255] UPIAS, 1975, p. 14.

[256] See Oliver, 1996a, p. 52: "Despite my reservations about the project, the development of a social model of impairment to stand alongside a social model of disability appears inevitable.".

[257] See e.g. Oliver, Michael, Disability Issues in the Postmodern World [hereinafter Oliver, 2001], in Barton, Len (Ed.) Disability, Politics and the Struggle for Change, David Fulton Publishers Ltd, London, 2001, p. 152: "She [Carol Thomas] rejects the position of some disability theorists, notably Finkelstein and myself, who argue that attempting to incorporate personal experiences of impairment into the social model of disability risks diluting our political struggles to overcome the barriers in society we face.". See also Oliver, Michael, The Social Model of Disability: Thirty Years On [hereinafter Oliver, 2013], Disability & Society, 2013, p. 2: "[…] I, and others, have often pointed out that focusing on impairment and difference will only de-politicise the social model and will not lead to the development of any approaches or alternative models that are likely to be useful in developing campaigns to improve or defend the lifestyles of disabled people.".

[258] UPIAS, 1975, p. 14.

The *solutions* envisaged by the Social Model of Disability consequently focus on eradicating environmental barriers. A key mechanism in the change of social organisation is the political organisation of its constituency. While categorically denying measures targeting Impairment as relevant solutions, the call in the UPIAS account for medical measures to improve functioning in relation to social participation remains in contradiction with this.

The *constituency* of the Social Model of Disability was, as mentioned above, broadened by Michael Oliver from covering only persons with physical Impairments to a seemingly open-ended coverage. However, it would also seem that Oliver only envisages those intended by the Social Model of Disability as those agreeing with it, as he includes an element of self-identification.

To conclude, the *entitlements* flowing from the Social Model of Disability are to a changed environment and the primary road to this is the political organisation of disabled people. Choice, participation and independence constitute a red thread through entitlements in all areas of life. Despite the reference to medical measures in the UPIAS account and the recognition by Oliver and Finkelstein of the importance accorded medical solution by the constituency of the Social Model of Disability, the categorical denial of, as well as warning against, asserting the political and otherwise relevance of measures targeting the individual is a central feature of the Social Model of Disability. Against this background, demands highlighting the need for such measures cannot be characterised as flowing from the Social Model of Disability. In any event, this seems to be the understanding of the Social Model of Disability in campaigns for measures by the UK Disabled People's Movement; as a "litmus test"[259] for the acceptability of law and policy amounting to an either/or approach to "medical cure and rehabilitation" versus "social transformation":

> The social model played a crucial role in enhancing the collective consciousness of disabled people, and the emergence of the Disability Movement (Campbell and Oliver 1996). It gave disabled people a framework to distinguish between organisations, policies, laws and ideas which were emancipatory, and those which were oppressive or inadequate. Most importantly, the social model enabled the identification of a political strategy, namely **barrier removal**. If people with impairments were disabled by society, then the priority was to dismantle these disabling barriers in order to promote the inclusion of people with impairments. Rather than pursuing a strategy of medical cure or rehabilitation, it was better to pursue a strategy of social transformation.[260]

Indeed, it is the categorical stance on Impairment which has earned the Social Model of Disability the bulk of its criticism. Such criticism is the focus of the following section.

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[259] Shakespeare, Tom and Watson, Nicholas, The Social Model of Disability: An Outdated Ideology? [hereinafter Shakespeare and Watson, 2002], Research in Social Science and Disability, Vol. 2, 2002, p. 10.

[260] Campbell, Jane, Fighting for a Slice, or for a Bigger Cake?, The 6th Annual Disability Lecture, University of Cambridge, St John's College, 29 April 2008, p. 3. Emphasis in original.

3.7. Critique of the Social Model of Disability

Ever since the position of UPIAS was named the 'social model of disability' by Michael Oliver it has been the hub of the debate in the UK about what disability is, what is relevant to the ideological, political and legal platform of disability and what entitlements should be pursued from this platform. It is the background against which everything else gains it shape and is so well established as the dominant version of disability that all contributions to the disability discourse are "almost invariably in dialogue with it".[261] The academic debate about the social model takes place mainly within the academic discipline called disability studies and, to some extent, in medical sociology.[262]

Most of those who have quarrels with what they see as the 'current' version of the social model of disability tend to name their efforts as "reclaiming"[263], "updat[ing]"[264] or "renewing"[265] it, rather than as replacing it. Only few voices extend their critique to arguing that the social model of disability should be done away with in order for alternative versions of disability to gain ground.[266] The indignation with which such proposals are met illustrates the position of the social model of disability as the only acceptable framework for understanding disability.[267] As a consequence of this hegemony many different analyses are put forward in its name and quarrels with its perceived contents are habitually presented as either a 'better' way to interpret the existing contents or as new features that should be included in the same jar, under the same label. Part of the power of the idea of 'the social model of disability' in the UK is attributed to its genesis being the Disabled People's Movement rather than academia and the fact that it remains the ideological epicentre of this Movement.[268]

Since the term 'the social model of disability' is used very loosely in the debate, it is difficult to know exactly what understanding of 'the social model of disability' a

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[261] Thomas, Carol, How is Disability Understood? An Examination of Sociological Approaches [hereinafter Thomas, 2004], Disability & Society, Vol. 19, No. 6, October 2004, p. 573.

[262] For accounts of the relationship between these two areas see Barnes, Colin and Mercer, Geof (Eds.), Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996, Thomas, 2007 or Williams, Simon J., Is Anybody There? Critical Realism, Chronic Illness and the Disability Debate, Sociology of Health and Illness, Vol. 21, No. 6, 1999.

[263] Greater London Action on Disability (GLAD), Reclaiming the Social Model of Disability Conference Report [hereinafter GLAD, 2000], February 2000.

[264] Ibid., p.1.

[265] Crow, Liz, Including All of Our Lives: Renewing the Social Model of Disability [hereinafter Crow, 1996], in Barnes, Colin and Mercer , Geof (Eds.) Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996, p. 55.

[266] See e.g. Shakespeare and Watson, 2002 and Shakespeare, 2006, p. 2.

[267] See under 3.7.1.5. below.

[268] The academic discipline disability studies is closely linked to the Disabled People's Movement. Compare Campbell, Jane, Valuing Diversity: The Disability Agenda – We've Only Just Begun, Disability & Society [hereinafter Campbell, 2002] Vol. 17, No. 4, 2002, p. 473: "Over the past 30 years, disabled people have used the 'Social Model Principles' in our campaigns for comprehensive civil rights, anti-discrimination legislation and independent living. […] The social model gave disabled people the confidence to campaign for rights in a way that was uncompromisingly based on social oppression.".

particular critical account is targeting.[269] In addition, it is not always clear if critique is launched at 'the social model of disability' per se or at the role and function it has been given in the Disabled People's Movement. While this debate is multifaceted, the account below focuses on two particular aspects of it. The first aspect is the role of impairment, which remains the key controversy between the approaches to disability explored in this book as well as resonates with the recognition in the negotiations of the CRPD of potential limitations of 'the social model of disability'.[270] The second aspect is the role of diversity other than impairment, such as age, sex, ethnicity or sexual orientation.[271] The following account only aims to catch the formative features of these debates and is painted with a broad brush. It does not attempt to cover all important contributions supporting a particular position, nor is emphasis put on academic discipline or broader theoretical or ideological affiliation.[272]

3.7.1. The role of impairment

The centre of the "critiques and qualifications"[273] of the social model of disability thus touches the role that impairment (defined by the Social Model of Disability as "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body"[274]) 1) should be presumed to play for the individual and 2) should have in theorising and politics. Critics target the 'silence' around as well as the 'silencing of' impairment and call for increased attention to such levels and modes of functioning of the body and mind from the ideological, political and legal platform of disability.

3.7.1.1. Impairment as personally and politically relevant and as creating problems immune to social restructuring

The most direct critic of the social model of disability writing within the tradition of disability studies, Tom Shakespeare, largely bases his conclusion that the social model of disability has outlived its usefulness on its neglect of impairment:

> By looking back at the origins of the British social model, it is possible to trace how an important and unarguable insight – that many problems which disabled people face

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[269] The accounts of critique of the 'social model of disability' explored below can be assumed to target a version of it corresponding fairly closely to the way I have delineated the Social Model of Disability for the purpose of this work. However, in order not to indicate absolute and certain correspondence, I will in the following not capitalise 'the social model' or its components as in 'impairment' and 'disability'.

[270] See below under 11.1.

[271] These two aspects have recently been recognised by Michael Oliver as the "two main areas of concern" within the critique of the social model of disability. See Oliver, 2013, p. 2.

[272] For accounts mapping such positions see e.g. Thomas, 2007, Tregaskis, 2002, Priestley, 1998 or Watson, Nick et al. (Eds.), Routledge Handbook of Disability Studies, Routledge, London, 2012.

[273] de Wolfe, Patricia, Private Tragedy in Social Context? Reflections on Disability, Illness and Suffering [hereinafter de Wolfe, 2002] Disability & Society, Vol. 17, No. 3, 2002, p. 258.

[274] UPIAS, 1975, p. 14.

> are generated by social arrangements, rather than by their own physical limitations – evolved into a rigid ideology claiming that disability was everything to do with social barriers, and nothing to do with individual impairments.[275]

Claims for increased attention to impairment draw upon what is seen as the experiences of the implicated constituency of the social model of disability, namely that impairment is a fundamental aspect of life. One of the forerunners in this debate, Liz Crow, asserts the widespread influence of impairment on life in noting that "[a]s individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence so much of our lives".[276] The basic argument is that attention to impairment is required to represent the experiences of the constituency of the ideological, political and legal platform of disability and to offer up an account which 'fits' this constituency. In the words of Crow, an account including "all of our lives".[277]

An underlying theme of many of the calls for attention to impairment is the potentially *problematic* character of impairment. As Crow puts it, that "[i]mpairment *in itself* can be a negative, painful experience".[278] The argument runs that since impairment can be experienced as negative by the individual, this must be reflected by the social model of disability if the latter is to represent the central problems of its constituency:

> It is this rejection of impairment as problematic [...] that is the social model's flaw. [B]y refusing to discuss impairment, we are failing to acknowledge the subjective reality of many disabled people's daily lives. Impairment *is* problematic for many people who experience pain, illness, shortened lifespan or other factors.[279]

Crow calls for acknowledgment of that impairment opens up for a whole repertoire of, sometimes changing, reactions. She notes that "[i]ndividuals might regard their impairment as positive, neutral or negative, and this might differ according to time and changing circumstances".[280] The assertion that impairment is relevant as a problem per se is mixed with the assertion that it is a cause of restricted composite life opportunities. Crow questions the equation between disability and *relevant* restricted composite life opportunities:

> Our current approach is based primarily on the idea that once the struggle against disability is complete, only the impairment will remain for the individual and there will be no disadvantage associated with this. […] Removal of disability does not necessarily mean the removal of restricted opportunities. For example, limitations to an

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[275] Shakespeare, 2006, p. 10.

[276] Crow, 1996, p. 59.

[277] Ibid., title.

[278] Ibid., p. 67. Emphasis in original.

[279] Ibid., pp. 65-66. Emphasis in original.

[280] Ibid., p. 61.

> individual's health and energy levels or their experience of pain may constrain their participation in activities.[281]

Assertions of the potential negativity of impairment are thus often flanked by the assertion that some problems are *immune to the removal of environmental barriers to participation* and will remain after such barriers are eradicated, i.e. after the vision of the social model of disability is completed. In apparent opposition to the UPIAS position reproduced above under 3.3., Ruth Pinder argues that "reducing the difficulties disabled people encounter in forging viable work lives for themselves almost entirely to a question of external environments is misleading".[282] Nasa Begum, in a conference with the explicit purpose of "reclaiming the social model of disability" recognises the immunity of certain problems to barrier removal as representative of the experiences connected to psychosocial impairment:

> Although mental health system survivors face numerous barriers I would not want for a minute to trivialise the fact that we have conditions which affect our lives. I believe the social model means we must understand disability as a form of social oppression like hetero-sexism, racism, sexism etc. However we also have to have a safe place to talk about the reality of our conditions, after all you could try to remove as many barriers as possible but pain, hearing voices and feeling the need to self harm may still exist.[283]

Exploring her own experiences, Sally French similarly notes the limits of barrier removal in relation to visual impairment and exemplifies this with problems such as those relating to restrictions in social interaction through not recognising people and not responding to non-verbal social cues, and not hearing on windy days.[284] She concludes that "[w]hile I agree with the basic tenets of this model [a social model of disability] and consider it to be the most important way forward for disabled people, I believe that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation".[285] Jenny Morris similarly questions focusing solely on environmental barriers and social attitudes:

> [T]here is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is

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[281] Ibid., p. 67.

[282] Pinder, Ruth, Sick-but-Fit or Fit-but-Sick? Ambiguity and Identity at the Workplace [hereinafter Pinder, 1996], in Barnes, Colin and Mercer, Geof (Eds.) Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996, p. 149.

[283] Begum, Nasa in GLAD, 2000, p. 7.

[284] French, Sally, The Wind Gets in my Way, in French, Sally and Corker, Mairian (Eds.), Disability Discourse, Open University Press, Buckingham, 1999, pp. 21-22.

[285] French, Sally, Disability, Impairment or Something in Between? [hereinafter French, 1993], in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (1st Ed.), Sage Publications Ltd, London, 1993, p. 17.

> to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying.[286]

To conclude the above, the argument runs that problematic consequences of impairment which are not amenable to changing the environment are phenomena of general relevance. In the words of Liz Crow, that "for many disabled people personal struggle related to impairment will remain even when disabling barriers no longer exist".[287]

It should be noted here that the silence on impairment attributed to the social model of disability is, in addition, criticised from a direction habitually referred to as its 'post modern' critique.[288] This critique problematises the conceptual separation of impairment and disability and the lack of attention to impairment resulting in the ignorance of its social character. As expressed here by Bill Hughes and Kevin Paterson, this leads to a lack of questioning the designation of certain levels and modes of functioning of the body and mind as impairments:

> The social model – in spite of its critique of the medical model – actually concedes the body to medicine and understands impairment in terms of medical discourse. To recapture this lost corporeal space without returning to the reactionary view that physicality determines social status, the social model requires to mount a critique of its own dualistic heritage and establish, as an epistemological necessity, that the impaired body is part of the domain of history, culture and meaning, and not – as medicine would have it – an ahistorical, pre-social, purely natural object.[289]

Hence the designation of a difference as an 'impairment' by medicine as well as current medical interventions remain below the radar of the social model of disability:

> Thus, for the social model of disability, the body – reduced to impairment – finds itself, inescapably, in the jurisdiction of medicine. The relationship of disabled people to their bodies is mediated by medicine and therapy, and has nothing to do with policy and politics.[290]

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[286] Morris, Jenny, Pride against Prejudice – Transforming Attitudes to Disability, Women's Press, London, 1991, p. 11 (source not paginated). See also Shakespeare and Watson, 2002, p. 6: "[O]ur contention is that many British activists in their public discourse use exactly this 'strong' version of the social model that we are critiquing. It may be that in private, their talk is at odds with the 'strong social model'. Most activists concede that behind closed doors they talk about aches and pains and urinary tract infections, even while they deny any relevance of the body while they are out campaigning.".

[287] Crow, 1996, p. 58.

[288] For such accounts see e.g. Corker, Mairian and Shakespeare, Tom (Eds.), Disability/Postmodernity: Embodying Disability Theory, Continuum, London, 2002 and Shildrick, Margrit, Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity, in Watson, Nick et al. (Eds.), Routledge Handbook of Disability Studies, Routledge, London, 2012.

[289] Hughes, Bill and Paterson, Kevin, The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment, Disability & Society, Vol. 12, No. 3, 1997, p. 326.

[290] Ibid., p. 331.

In opposition to the accounts above, the 'post-modern' critique, exemplified here by Hughes and Paterson, is not calling for attention to impairment *as problematic*, but rather for according attention to how impairment becomes seen as 'problematic' and how this 'problem' is addressed.

3.7.1.2. Attempting reconciliation: "Impairment effects" integrated into the Social Model of Disability

Carol Thomas has constructed a conceptual solution to the challenged silence on impairment in the social model of disability. Thomas has introduced the concept "[I]mpairment effects" as a parallel phenomenon to disability, aiming "to acknowledge that impairment do have direct and restricting impacts on peoples social lives".[291] Like most critics of the social model of disability within disability studies, Carol Thomas' aim is not to leave the social model of disability behind, but to improve it:

> [T]he impairment effects idea [...] has provided a means by which academics signed up to the social model of disability can acknowledge the *direct* and *immediate* impact that 'being impaired' can and does have on the daily lives of disabled people. That is, it allows impairment and its effects to be acknowledged without undermining the importance and centrality of disablism.[292]

Thomas defines Impairment effects as "those restrictions of bodily activity and behaviour that are *directly attributable* to bodily variations designated 'impairments' rather than those *imposed upon* people *because* they have designated impairments (disablism)".[293] Her position that the concept of Impairment effects 'fits' into the UPIAS version of disability is based on that UPIAS did not state that *all* restriction of activity are socially caused, only that *disability*, defined as oppressive social relations, is:

> It is important to understand that the UPIAS social relational approach, that disability is the social imposition of restrictions of activity on impaired people, does *not* assert that *all* disadvantages or restrictions of activity experienced by people with impairment constitute 'disability'. That some restrictions of activity may be directly associated with, or 'caused by', having a physical, sensory or intellectual impairment (not being able to do certain things because of the absence of a limb or the presence of chronic pain or fatigue, for example) is not ruled out – it is just the case that these are not 'disabilities'.[294]

Through adding the component of Impairment effects to the social model of disability, impairments are recognised as causing "disadvantages or restrictions of activity" and are accorded a place on the ideological, academic, political and legal

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[291] Thomas, Carol, Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda, in Barnes, Colin and Mercer, Geof (Eds.), Implementing the Social Model of Disability: Theory and Research, The Disability Press, Leeds, 2004, p. 42.

[292] Thomas, 2007, p. 135. Emphasis in original.

[293] Ibid., p. 136. Emphasis in original.

[294] Thomas, 1999, p. 42.

agenda. As discussed above under 3.2. -3.4., the position of UPIAS on Impairment is ambiguous. UPIAS does not explicitly reject that Impairment can be problematic in itself or cause restrictions in relations to composite life opportunities and certain contradictions exist (particularly the call by UPIAS for "medical" assistance as one of the roads to "participate fully in society").[295] However, the categorical position (at least in principle) of UPIAS (as expressed by Victor Finkelstein above under 3.2.) seems to be that Impairment and its effects are not politically relevant questions and that political attention should be directed to Disability only. Adding the component Impairment effects does allow the concept of Disability as defined by UPIAS to remain intact (Disability is not Impairment nor is it caused by Impairment). Still, the silence on Impairment effects by UPIAS reads as a highly intentional political strategy. With the addition of Impairment effects to the account of UPIAS, the *concept* of Disability stands unchanged but its strategic *function* is arguably fundamentally altered. This is even more so in the interpretation of the position of UPIAS by Michael Oliver, as he expressly denies and discourages the inclusion of the consequences of Impairments in the Social Model of Disability.[296] Similarly, Victor Finkelstein holds on to the UPIAS position on Impairment:

> At that time (early 1970s) there were no dissenting opinions that the *'problems'* disabled people faced were caused by our impaired individual bodies. Sympathetic professionals loved talking about, and encouraged us to talk about, our awful experiences (an approach the 'rectifiers' of the social model now promote as if it was something new!) The problem has *never* been a lack of concern or interest by disabled people in the effects of 'impairment', but our unwillingness to tenaciously focus on the way society disabled us – i.e. to concentrate on 'disability; as socially interpreted by UPIAS.[297]

To conclude, Carol Thomas interprets the UPIAS position as being open to 1) impairment being problematic in and of itself, 2) impairment causing restrictions in social participation and 3) that these are politically relevant issues. Through the concept Impairment effects she seeks a way to accommodate the critique of the social model of disability without abandoning it.

3.7.1.3. The implications of problematising impairment for which solutions are advocated for

As discussed above under 3.4. the ideological and political position of the Social Model of Disability on the role of measures which aim to minimise, stop the progression of or eliminate impairment is ambiguous. The call to bring problematic consequences of impairment back into the ideological, academic, political and legal disability discourse is closely connected to implicating impairment as the target for solutions, including general prevention and medical intervention to manage, mini-

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[295] UPIAS, 1974, initial paragraph on Aims.

[296] See above under 3.3.

[297] Finkelstein, 2001, p. 2. Emphasis in original.

mise, stop the progression of or eliminate impairment. The following statement by Liz Crow illustrates this link between problems and implicated solutions:

> Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realising our potential or railing fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments; we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments. [298]

In relation to prevention, Crow argues that the silence on impairment renders this issue taboo, which creates constraints on those motivated to work for prevention.[299] In relation to existing impairment, she argues that as impairment can be a negative experience to which intervention in the environment holds no solution, access to interventions targeting impairment remains a salient issue for the intended constituency of the social model of disability as well as for the Disabled People's Movement. This issue consequently merits political attention which it is not receiving:

> Our [the Disabled People's Movements'] message tends to come across as rejecting all forms of intervention when it is clear that some interventions, such as the alleviation of pain, in fact require more attention and resources.[300]

Susan Wendell similarly asserts in opposition to "social constructionist analyses of disability" that rejection of the elimination of impairment is not universal among their constituencies, as "some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amounts of social justice can eliminate".[301] Because of this and because of "their suffering, their deteriorating health, or the threat of death", she asserts that "some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it".[302] Patricia de Wolfe notes in relation to chronic illness, while emphasising the individuality of experience,[303] that some levels and modes of functioning of the body and mind are more likely than others to be experienced as problematic and thus "differing groups of people may respond with varying degrees of enthusiasm or indignation to the prospect of being reconstituted as curable clients of medical science".[304] de Wolfe furthermore notes, in line with the passage by Finkelstein quoted above

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[298] Crow, 1996, p. 59.

[299] Ibid.

[300] Ibid., p. 66.

[301] Wendell, Susan, Unhealthy Disabled: Treating Chronic Illnesses as Disabilities [hereinafter Wendell, 2001], Hypatia, Vol. 16, No. 4, 2001, p. 18.

[302] Ibid.

[303] de Wolfe, 2002, p. 265.

[304] Ibid., p. 260.

under 3.4., that "although reservations are frequently expressed about various aspects of the medical enterprise […] few people would advocate the wholesale abandonment of the (scientific) project of cure for everybody".[305]

Corresponding to this analysis of the relevance of cure, Liz Crow argues that a negative perception of impairment by a person should not be dismissed as internalising negative perceptions emanating from surrounding society and cannot be dismissed as "false consciousness":

> Impairment *is* problematic for many people who experience pain, illness, shortened lifespan or other factors. As a result, they may seek treatment to minimise these consequences and, in extreme circumstances, may no longer wish to live. It is vital not to assume that they are experiencing a kind of false consciousness - that if all the external disabling barriers were removed they would no longer feel like this. We need to ensure the availability of all the support and resources that an individual might need, whilst acknowledging that impairment *can* still be intolerable. This does not imply that *all* impairment is intolerable, or that impairment causes *all* related disadvantage; nor does it negate the urgency with which disability must be confronted and removed.[306]

The validity of the opinion of persons seeking the elimination of impairment is likewise asserted by Karen Beauchamp-Pryor, who asserts that "[i]t is important to recognise that the opinions of those who do not desire a cure and those who search for a cure are equally important".[307]

Liz Crow notes that as long as the problematic character of impairment is denied, solutions which target the creation of *impairments which are the result of disability* cannot be advocated:

> Discrimination in general can also cause major emotional stress and place mental health at risk. Our reluctance to discuss impairment obscures this aspect of disability. If we present impairment as irrelevant then, even where impairment is caused by disability, it is, by implication, not a problem. This limits our ability to tackle social causes of impairment and so diminishes our campaigns.[308]

The statements by Crow above touch on the most inflamed aspects of what choices and measures a problematic character of impairment justifies, namely where elimination of impairment amounts to eliminations of the person (and person to be, depending on how one sees it), including prenatal screening and euthanasia. Some authors, such as Tom Shakespeare argue that while these areas as well as genetic engineering are ripe for abuse, the wholesale rejection of these by the Disabled People's

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305 Ibid.

306 Crow, 1996, p. 66. Emphasis in original.

307 Beauchamp-Pryor, Karen, Impairment, Cure and Identity: 'Where Do I Fit in?' [hereinafter Beauchamp-Pryor, 2011], Disability & Society, Vol. 26, No. 1, 2011, p. 5. See further Ibid., pp. 9-11.

308 Crow, 1996, p. 69.

Movement (often in the name of the social model of disability) is not in the best interest of disabled people:[309]

> In particular, it is important to distinguish situations where the autonomy of disabled people is undermined (abuse of 'do not resuscitate' notices, non-voluntary euthanasia) from situations where disabled or terminally ill people themselves are exercising their autonomy by requesting assistance with death, or withdrawal of treatment (advance directives, assisted suicide).[310]

Shakespeare emphasises that the position on solutions targeting impairment need not be a case of either/or. Instead he calls for the engagement of disabled people with the potential of medicine as "critical supporters":

> It would be foolish to hope for quick results from stem cell or gene therapy research. It would be dangerous to rely on medical research as an alternative to barrier removal. However, if safe, effective treatments eventually materialise then disabled people will benefit and quality of life will improve. Resort to medicine is not contrary to other objectives of disability rights, and activist and scholars should be critical supporters of the endeavour to mitigate or prevent impairment."[311]

Further on the relationship between the social model of disability and medicine, Bill Hughes notes that disability activism in the UK "has bifurcated into two camps" in the sense that members of the Disabled People's Movement (comprising of what he refers to in the title of his article as "Social Model Stalwarts") remain as a rule "somatophobi[c]" while others, which he refs to as "biological citizens" embrace medical diagnosis as the starting point of a critical engagement with, inter alia, medicine:[312]

> They might be described as 'biological citizens', but they are also disability activists. They are not cut from the same cloth as those who mobilise around the social model of disability. They are, however, intent on influencing thinking and policy about the particular medical condition that inspires their interest and activity.[313]

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[309] Shakespeare, 2006, See Chapter 6 (Questioning Prenatal Diagnosis) and Chapter 8 (Autonomy at the End of Life) where Shakespeare reviews this debate.

[310] Ibid., p. 119.

[311] Ibid., p. 116. In relation to cure, it is also noted, here by Liz Crow, that without recognising the dual function of medicine for persons implicated by the disability platform as potential oppressor and potential ally, medicine will remain outside the political purview of the social model as a political platform. Where and how the line between benefit and abuse is to be drawn in each context will thus not be addressed: "[T]he movement's rejection of medical and rehabilitation professionals approaches to treatment and cure has not been accompanied by an exploration of what forms of intervention *would* be useful.". Crow, 1996, pp. 65-66. Emphasis in original.

[312] Hughes, Bill, Disability Activisms: Social Model Stalwarts and Biological Citizens, Disability & Society, Vol. 24, No. 6, 2009, p. 678.

[313] Ibid.

Consequently, Hughes notes a tendency towards what is called for by Shakespeare above, namely that activism and rights need not be divorced from medicine, but rather may actively engage with it.

3.7.1.4. Exclusionary aspects of the silence on and silencing of impairment

The silence on impairment is asserted as having exclusionary effects on certain groups, as it obscures the different needs amongst persons with disabilities. If impairment is not to be spoken of, then forms of disadvantage affecting impairments which are straightforward and visual will set the agenda. The following statement by a man on the situation in the group of disabled activists where he was a member (UNISON), quoted by Jill Humphrey, expresses this to the point:

> It's very *convenient* for people with *apparent* disabilities or impairments to operate a social model which says. 'We don't want to discuss things in terms of 'impairments'. Because these people have got priority anyway, and impairment-related provisions [in UNISON] … The trouble with it [the social model] is that it's very difficult… for people with learning difficulties or other conditions…which are not catered for…to raise their concerns as things which need dealing with on a service level, without feeling that they're *breaking the law* and *talking about impairments*.[314]

Similarly, a statement at a conference called "Reclaiming the Social Model of Disability" notes how the reluctance to mention impairment makes it hard to ask for what one needs as "people may find it hard to speak up for what they need for fear that it is seen as a weakness".[315] The same conference report asserts the necessity of mentioning impairment in order to include the needs of all on the agenda:

> There must be an understanding that the different requirements relating to our impairments have to be met on an individual basis.[316] […] The social model of disability should include every disabled person – in the past it was defined by a small group of articulate disabled people with particular impairments.[317]

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[314] Humphrey, Jill, Researching Disability Politics, Or, Some Problems with the Social Model in Practice [hereinafter Humphrey, 2000], Disability & Society, Vol. 15, No. 1, 2000, p. 67. Emphasis and brackets in original.

[315] GLAD, 2000, What People Said in the Workshops, p. 12. The following statement by Nasa Begum at the same conference expressing anticipation of being perceived as "pushing one's own agenda" when the needs of a more sidelined group (here "mental health survivors") is expressed in a cross impairment context indicates the vulnerability inherent in expressing needs: "I know many of you are probably thinking I'm just pushing my own agenda and to some extent I would agree, but more importantly I believe that the only way of properly addressing the rights of any group of people is to make ourselves inclusive and address all the diversity within our movement. This will be invaluable in terms of strengthening our campaign for full human and civil rights, and ensuring we have a representative and democratic movement.". GLAD, 2000, p. 7.

[316] Ibid., What People Said in the Workshops, p. 14.

[317] Ibid., Conclusion, p. 14. Liz Crow notes that attention to impairment is necessary to accommodate diversity in campaigns: "As a movement, we need to be informed about disability *and* impairment

The conference report exhibits frustration over this felt exclusion, expressed as being "fed up with the exclusiveness of the social model – that only certain disabled people have the right to define it".[318] Jill Humphrey notes how the silence on impairment hides issue of slanted representation, as "the reluctance or refusal to differentiate between impairments by identifying them bolsters up the claims by people with apparent impairments that they represent all disabled people".[319] Liz Crow calls upon the ethos of the Disabled People's Movement, inclusion, as an argument to allow room for impairment in the discourse on disability:

> What we risk is a world which includes an 'elite' of people with impairments, but which for many more of us contains no real promise of civil rights, equality or belonging. How can we expect anyone to take seriously a 'radical' movement which replicates some of the worst exclusionary aspects of the society it purports to challenge?[320]

In addition to the silence on impairment concealing and preserving a hierarchy of impairment, it is asserted that this silence serves to sideline those for whom part of everyday efforts is indeed related to impairment and not only, or even mainly, to oppressive social relationships. The silence on impairment, especially its potentially problematic character, is asserted as working in a way which devalues and excludes those with impairment-related problems and needs requiring medical attention. In other words, the shunning of impairment, particularly as problematic carries with it a shunning of health- or illness-related needs and, as a consequence, of persons with disabilities with such needs. Susan Wendell puts it that "[i]llness is equated with impairment, even by disability activists and scholars, in ways that disability is not; hence there is anxiety to assure non-disabled people that disability is not an illness".[321] She notes the vulnerability of all "[s]ocial constructionist analyses of disability" to this tendency:

> Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can reduce attention to those

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in all their diversity if our campaigns are to be open to all disabled people.". Crow, 1996, p. 59. Emphasis in original.

[318] GLAD, 2000, What People Said in the Workshops, p. 9. In addition to setting a slanted agenda for change, opposition is raised against "a hierarchy of impairment developing in the movement". Ibid., p. 12.

[319] Humphrey, 2000, p. 67.

[320] Crow, 1996, p. 60. In general terms, it has been noted that certain impairments are more represented than others on the academic as well as political scene: "The dominant group can be seen as those (predominantly white male) who have spinal cord injuries and whose voices are most often heard in academic debate. This leaves disabled women and those from other groups, like persons with learning disabilities and mental health difficulties, on the edge of the dominant discourse, getting their views often marginalised.". Corbett, Jenny, Independent, Proud and Special: Celebrating Our Differences, in Barton, Len and Oliver, Michael (Eds.), Disability Studies: Past. Present and Future, The Disability Press, Leeds, 1997, p. 96.

[321] Wendell, 2001, p. 22.

> disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. […] Thus, in promoting the libratory vision of social constructionism, it is safer and more comfortable for disability activism to focus on people who are healthy disabled.[322]

Wendell suggests that such application of social constructionism silences "important differences between healthy disabled and unhealthy disabled people" to the detriment and alienation of the latter.[323] If an approach to disability is built on a separation from impairment, then connections with ill-health and illness will not be welcomed, even though "[m]any people are disabled by chronic and/or life-threatening illness, and many people with disabilities not caused by illness have chronic health problems as consequences of their disabilities".[324]

Patricia de Wolfe has explored the position of persons with chronic illness in the UK, noting how interplay between the silence on impairments and the shunning of "suffering"[325] as well as urges to separate the disability platform from the health platform is detrimental to the inclusion of persons with chronic illness on the disability platform. She notes that "[d]isability felt like a category of which I did not have legitimate membership".[326] Critics such as de Wolfe mean that insisting on preserving the distance between disability and health/ill-health amounts to an acceptance of health as a prerequisite for social inclusion and consequently of ill-health as a marker of those 'others' who can be kept outside:

> [A]ttempts to specify a distinction between disability and illness simply shift the boundaries of social and conceptual exclusion. Chronically sick people remain stigmatised, with their strengths unrecognised and measures to improve their lives unformulated.[327]

de Wolfe questions the underlying assumption that the key need for persons with chronic illness is elimination of impairment (a presumption painfully familiar to the disability discourse) and means that this reproduces medical reductionism, but this time in relation to persons with chronic illness. The thrust of the argument is that the message of the Disabled People's Movement resonate a major concern for persons with chronic illness. However, by constructing disability as dependant on the rejection of as many negative connections to impairment (construed as 'ill-health' or 'illness') as possible, persons with chronic illness are both excluded from the disability platform *and* cast as the opposite of persons with disabilities. By consequence, they suffer from the dualist view perpetuated by the message about disability, amounting to that either you want measures targeting impairment only or you want accom-

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[322] Ibid., pp. 18-19.

[323] Ibid., p. 17.

[324] Ibid.

[325] de Wolfe, p. 255. "This reluctance [to acknowledge suffering as human] relegates to the realm of the private, both conceptually and materially, those whose suffering cannot be relieved by either medical intervention or social change." Ibid., pp. 255- 256.

[326] Ibid., p. 257.

[327] Ibid., p. 255.

modation only and either you can be accommodated completely by society or you do not need to/cannot be accommodated at all. Consequently, "a divide remains between disability and illness, with social responsibility for the latter construed mainly in terms of provision of individual health care and personal support".[328] de Wolfe asserts that disability understood in this way 'colonises' the relevance of social accommodation, leaving only the relevance of medical care for chronic illness:

> The idea of claiming a right of access to the library – or indeed any concession other than permission to go home to bed or to seek medical help – on grounds of *illness* seemed like an absurdity. But why?[329]

Like Liz Crow, de Wolfe argues that the venture of the disability platform to stay on the 'right'/'safe' side of the 'healthy'/'unhealthy' divide by separating itself out from chronic illness mirrors the exclusionary approach by society *en large* towards disability. First the levels and modes of functioning of the body and mind suitable for portraying the disability platform are chosen based on perceptions of their distance from notions of 'ill-health', 'illness' or 'sickness', then the focus of those included is firmly steered away from such notions, cementing the divide traditionally made 'on the wrong side of disability' now 'on the wrong side of chronic illness':

> The disability movement does not explicitly address the issue of the controllability of the body, but its message is targeted at those whose bodies can, in fact, be controlled, in the sense of being subsumed into the social. It may, hence, be seen as (unintentionally) complicit in the marginalization and stigmatization of the incurably long-term sick. The 'disappearing' of the body for which phenomenologists criticise disability theory (Hughes and Paterson, 1997); the (arguably impractical) project of separating out and privileging bodily impairment which can be rendered irrelevant by social change (Oliver, 1996, pp. 48-49) – all this contributes to the notion that integration into society is contingent on absence of suffering, on a particular kind of physical and mental vigour.[330]

By letting chronic illness represent 'that which disability is not', those qualifying as disabled are included among those potentially 'apt, willing and able' (with the right accommodations) to be a part of society, leaving others, i.e. people grouped as those with 'chronic illness', outside the gates. Similar conclusions are drawn by Ruth Pinder:

> For reasons grounded historically in its own struggles, the Movement is ill at ease with ambiguity. Chronic illness is still seen as `medical' and therefore falling outside its provenance. The voices of those who […] may weave in and out of disability, have so far been comparatively muted.[331]

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[328] Ibid.

[329] Ibid., p. 257. Emphasis in original.

[330] Ibid., p. 262.

[331] Pinder, 1996, p. 153.

Patricia de Wolfe also notes how a focus on particular abilities, such as for employment, reproduces the general connection between human value and economic productivity through assuming that all persons can, and must, work. Through this, some people are overlooked:

> However, even given some degree of transformation in the conditions of work, the possibilities of integrating *all* people with bodily disorder into the workforce are limited. [...] Human value would need to be divorced not only from economic productivity, but from other, less tangible social values: activity, measurable achievement, vigour, bodily control.[332]

Against these accounts of the need to acknowledge problematic aspects of impairment, particularly ill-health and its effects on what a person can do or be, stand many statements of the power of the social model of disability in revolutionising self-regard from shame to pride and thereby fuelling the energy to fight injustice on a personal as well as a collective level.[333] In the words of Jane Campbell, "[h]ow liberated I felt when I realised I was not the problem and no longer had to apologise for my existence!".[334]

Like Campbell, Liz Crow adds to this liberating freedom from blame the revolutionary realisation that there was a solution, namely changing society:

> This was the explanation I had sought for years. Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being disabled – my capabilities and opportunities were being restricted – by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary![335]

As made clear in the statements just above, the core and the attractiveness of the social model of disability is to not have ones disadvantage explained away and demands defused by reference to individual characteristics. There is a clear link between this

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[332] de Wolfe, 2002, p. 264. See also Ibid., p. 265: "Thus, some sick or disabled people may fight for the right to work, or to participate in other 'normal' social activities, perhaps claiming special arrangements to enable them to do so; while others will demand exemptions; the right to an income without working, and the right to rest.".

[333] See Tregaskis, 2002, p. 457: "The social model analysis has had many positive outcomes, not least in challenging disabled people's own internalised oppression by enabling them to make sense of their experience in a way which explains that it is not, after all, 'their own fault', that they face discrimination and social exclusion.". See also Shakespeare and Watson, 2002, p. 11: "Replacing a traditional 'medical model' view of disability – in which the problem arose from deficits in the body – with a social model view – in which the problems arose from social oppression – was and remains very liberating for disabled individuals. Suddenly, people were able to understand that they weren't at fault: society was. They didn't need to change: society needed to change. They didn't have to be sorry for themselves: they could be angry.".

[334] Campbell, 2002, p. 472.

[335] Crow, 1996, p. 56.

and the urge not to draw attention to impairment, at least not as a potential problem or as connected with notions of 'ill-health', 'illness' or 'sickness'. Taking on board the critique addressing the sidelining or excluding effect of silence on and silencing of impairment would need to somehow bridge the gap to this function of the social model of disability.

3.7.1.5. Silencing of problematic aspects of impairment?

The question is if the predisposition for *silence* on impairment asserted above under 3.7.1.4. amounts to *silencing*. The following comeback by Victor Finkelstein to a conference in 2000 called "Reclaiming the Social Model of Disability"[336] illustrates that efforts to introduce impairment on the agenda of the social model of disability have been refuted not only by arguments in case, but also with regard to who 'owns' this approach:

> I cannot accept that this conference was about *reclaiming* the social model of disability when a key point is to produce an *updated* version. This is not **reclaiming**. This is **revising** (or in Tom Shakespeare's wonderful phrase **rectifying** the social model of disability). Who is reclaiming? Have the conference speakers lost something that they created? Not one of the speakers at the conference helped create the social model so how can they reclaim it? Certainly Mike Oliver could make a case for reclaiming the social model of disability from those who are now trying to rectify it; but he was not a speaker. I have no objection to people devising and promoting new social models of disability in their own name; but I do object when they try to insinuate that they can legitimately reclaim the social model of disability rooted in the ideas of UPIAS.[337]

In the previous sections, numerous examples of people perceiving both silence on and silencing of impairment were presented. The following account by Sally French similarly concerns such experiences in relation to efforts to discuss a situation "not concerned solely with visual impairment, for it involves social interaction, but neither is it born of social oppression":

> When discussing these issues with disabled people who adhere strictly to the definition of disability as 'socially imposed restriction', I am either politely reminded that I am talking about 'impairment' not 'disability', or that the problems I describe have nothing to do with lack of sight but do indeed lie 'out there' in the physical and social environment; my lack of perception of this is put down to my prolonged socialisation as a disabled person. Being told that my definitions are wrong, that I have not quite grasped what disability is, tends to close the discussion prematurely; my experiences are compartmentalised, with someone else being the judge of which are and which are not worthy of consideration. This gives rise to feelings of estrangement and alienation.[338]

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[336] GLAD, 2000.

[337] Victor Finkelstein, 2001, p. 3. Emphasis in original.

[338] French, 1993, p. 19.

Jenny Morris, who has been at the forefront of the call to include experiences of impairment in the public discourse, tells a parallel account of lack of freedom to acknowledge experiences of the body:

> [T]here was a concern amongst some disabled women that the way our experience was being politicised didn't leave much room for acknowledging our experience of our bodies; that too often there wasn't room for talking about the experience of impairment, that a lot of us felt pressurised into just focusing on disability, just focusing on social barriers.[339]

In addition to such accounts of being on the receiving end of 'undocumented' silencing, the comeback to exploring individual experiences of impairment and emphasising the importance of such experiences has left a discernible paper trail. This dismissive review by Colin Barnes of Susan Wendell's book "The Rejected Body: Feminist Philosophical Reflections on Disability" speaks for itself:

> Now this essentially individualistic approach might be an appropriate remedy for those sections of the disabled community who do experience physical pain as a consequence of their impairment, but what of those who don't, examples include blind people, deaf people, people with epilepsy, people of short stature or people with learning difficulties. […] I have little doubt that it [The Rejected Body: Feminist Philosophical Reflections on Disability] will be welcomed by the true confessions brigade; those intent on writing about themselves rather than engaging in serious political analysis of a society that is inherently disabling [.][340]

Michael Oliver warns, apropos the prospects of "somehow integrat[ing] impairment into the social model of disability"[341], against "public criticism":

> [E]ngaging in public criticism may not broaden and refine the social model; it may instead breathe new life in the individual model with all that means in terms of increasing medical and therapeutic interventions into areas of our lives where they do not belong.[342]

This quote illustrates that critique of the social model of disability often is designated as representing or re-approaching that which the Social Model of Disability was aimed at replacing, "the individual model". Oliver makes clear that he has no interest in integrating Impairment into the Social Model of Disability and refers to the difficulty to find common ground, as experience of Impairment is diversifying rather than uniting:

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[339] Morris, Jenny, Introduction, [hereinafter Morris, 1996] in Morris, Jenny (Ed.), Encounters with Strangers, The Women's Press Ltd, London, 1996, p. 13.

[340] Barnes, Colin, Review of Wendell, Susan, The Rejected Body: Feminist Philosophical Reflections on Disability, Disability & Society, Vol. 13, No. 1, 1998, p. 146.

[341] Oliver, 1996a, p. 51.

[342] Ibid., p. 52.

> Personally, I have no interest in such attempts [to somehow integrate impairment into the social model of disability] because, as Vasey (1992) has already pointed out, the collectivising of experiences of impairments is a much more difficult task than collectivising the experience of disability.[343]

Furthermore, in one of his most recent contributions to the debate, Oliver blames those who have criticised the Social Model of Disability and sought to bring Impairment onto its agenda for current deficiencies in UK policy:

> I, and others, have often pointed out that focusing on impairment and difference will only de-politicise the social model and will not lead to the development of any approaches or alternative models that are likely to be useful in developing campaigns to improve or defend the lifestyles of disabled people. [...] Just as we had predicted, emphasising impairment and difference was a strategy that was impotent in protecting disabled people, our benefits and services, from the economic firestorm that was raging around us. In fact government policy has now begun to use these criticisms of the social model by bringing impairment and difference back into their economic and social policy while steadfastly ignoring the barriers we still face. […] Those who have talked down the social model while failing to replace it with something more meaningful or useful must bear a heavy burden of responsibility for this state of affairs. Remarkably they have been rather silent in speaking out or building alternative models to address what is happening to disabled people now. Surely it is time to either re-invigorate the social model or replace it with something else. One thing is for sure; the talking has to stop.[344]

Efforts to silence experiential accounts of impairment can similarly be found in publications from the Disabled People's Movement. Anne Rae, in Manchester Coalition of Disabled People, holds that writing about personal experience of impairment is a sign of women having "become overwhelmed by the "the personal is political" philosophy" which has made them "reluctant to enter into the stricter discipline of purer political analysis and debate".[345] She strongly discourages calling for or providing accounts of experiences of impairments:

> The Social Model of Disability […] is under attack. […] What is happening now is that a few people, disabled people, are saying that the Social Model of Disability does not take into account the specific needs relating to impairment. They are calling for a "Social Model of Impairment" within which we can chart our individual experiences of impairment, including from our experiences of rejection, pain, lack of self-esteem etc etc. Should fill a few hundred volumes, adding to those which already exist on library shelves, which are poured over by academics determined to establish the psychological state of impaired people. This, and the accounts of the negative effects on individuals of

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[343] Ibid., p. 51.

[344] Oliver, 2013, pp. 2-3.

[345] Rae, Anne, Social Model under Attack, p. 2, originally published in Manchester Coalition of Disabled People, August 1996.

> the fact of impairment, will lend weight to the arguments for aborting us and practising euthanasia upon us. The other effect of this sort of stuff is that it feeds into the voyeuristic needs of some non-disabled people who seem to need to know what it is like to be impaired - those who read the "triumph over tragedy" stories of disabled people in magazines, gulping "Isn't it a shame" at the end of each one. [...] Jenny Morris is quite wrong to state in her article in the May edition of "Disability Now" that the disability movement prohibits any discussion of our personal experiences - what is recognised by the movement is the need to keep that discussion out of the public domain for the reasons already given.[346]

Others in the movement, such as Richard Light, while being adamant that the criticism of the social model of disability is built on misunderstandings and does not stick, cautions that the close link between this model and the Disabled People's Movement creates responsibility to consider the effect of criticism:

> This article is not intended to condemn efforts to theorise disability and what it means, but it is a heartfelt plea for theorists to understand that damage is done by sweeping claims as to the social model's shortcomings, without proposing alternatives that are acceptable to the disability community.[347]

Ruth Pinder summarises the reluctance of the Disabled People's Movement towards personal accounts of experiences connected to impairment as the tension between "the search for clear-cut, univocal messages crucial for the success of any political movement, and the necessarily more complex and subtle reality of peoples' lived experience".[348] To conclude, it seems that silencing of accounts of impairment, some hostile and some merely dismissive, have indeed been a feature in the disability discourse, including by those delineated in this work as the origin of the Social Model of Disability. It can also be assumed, merely by these comebacks, that these accounts were the exception rather than the norm and were heard and responded to because, indeed, they broke a silence of some sort. However, presumably linked to the aim to 'speak with one voice', attempts to establish 'ownership' of the Social Model of Disability as a protest against the efforts of others to re-define its contents on the basis of 'we used it first' are rare.

3.7.1.6. Calls for according attention to impairment as a cause for celebration and to question ideas of normality

The relative silence and ensuing ambiguity on impairment flowing from the social model of disability is also criticised from the opposite position, namely that it does not *deny* any potential negativity of impairment:

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[346] Ibid., pp. 1-2.

[347] Light, Richard, Social Model or Unsociable Muddle?, Article for Disability Awareness in Action, undated, p. 1.

[348] Pinder, Ruth, A Reply to Tom Shakespeare and Nicholas Watson [hereinafter Pinder, 1997], Disability & Society, Vol. 12, No. 2, 1997, p. 304.

> Whilst the social model is certainly totally incompatible with the view that disability is a personal tragedy, it can be argued that the social model has not, in itself, underpinned a non-tragedy view. First, to be a member of an oppressed group within society does not necessarily engender a non-tragedy view. There is, for instance, nothing inherently non-tragic about being denied access to buildings. Secondly, the social model dissociates impairment from disability. It, thus, leaves the possibility that even in an ideal world of full civil rights and participative citizenship for disabled people, an impairment could be seen to be a personal tragedy. There is, for instance, nothing inherently non-tragic about having legs that cannot walk or feel.[349]

Instead, the authors of the statement above, Sally French and John Swain, propose an 'affirmative model of disability':

> It is essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled.[350]

According to John Swain and Sally French, the key enemy, the belief that non-disabled society will not give up, is the view that impairment and disability is a tragedy, something that is 'wished away' by implicated individuals:

> There is an assumption that disabled people want to be 'normal', although this is rarely voiced by disabled people themselves who know that disability is a major part of their identity (Mason 2000). Disabled people are subjected to many disabling expectations, for example to be 'independent', 'normal', to 'adjust' and 'accept' their situation. It is these expectations that can cause unhappiness: rarely the impairment itself (French 1994).[351]

They refute the arguments that "a negative side to impairment" should be acknowledged by the social model of disability, both because this would be counterproductive to disabled people and with reference to that the examples focused on by those advocating recognition of such a negative side, "pain and chronic illness", have "distorted the debate":

> Pain and chronic illness are neither impairments nor restricted to the experiences of disabled people. Non-disabled people experience both pain and chronic illness.[352]

To Swain and French, the crucial issue is to recognise and strengthen "disabled identity", which they see developing in the Disabled People's Movement:

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[349] Swain, John and French, Sally, Towards an Affirmative Model of Disability [hereinafter Swain and French, 2000], Disability & Society, Vol. 15, No. 4, 2000, p. 571.

[350] Ibid., p. 569.

[351] Swain, John and French, Sally, Whose Tragedy? Towards a Personal Non-tragedy View of Disability [hereinafter Swain and French, 2004], p. 3. Originally published in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (2nd Ed.), Sage Publications Ltd, London, 2004.

[352] Swain and French, 2000, pp. 571-572.

> The affirmation of positive identity is collective as well as individual. The growth of organisations of disabled people has been an expression not only of the strength of united struggle against oppression and discrimination, but also of group identity. Disabled identity, as non-disabled identity, has meaning in relation to and constructs the identity of others. To be disabled is to be 'not one of those'. The affirmation of positive identity challenges the tyranny of the personal tragedy theory of disability and impairment.[353]

Swain and French addresses "medical intervention" as something which must be under the control of the individual and which must (quoting Disability Action North East) "see our differences not as Geneticists do (as 'defective traits') but as a *positive* sign of our human diversity"[354]:

> The development of an affirmative model takes this fight [for empowerment] squarely into the arena of medical intervention. Some impairments, such as diabetes, epilepsy and those involving pain, can respond to intervention. [...] The control of intervention is paramount. This is an affirmation by disabled people of the right to control what is done to their bodies.[355]

Such medical intervention is not conceptualised as including "cure", which is addressed elsewhere by Swain and French under the heading "Who needs cure and normality?".[356] The questioning of the desirability of "normality" is key to the affirmative model of disability and Swain and French emphasises that "[i]n affirming a positive identity of being impaired, disabled people are actively repudiating the dominant value of normality".[357] They also note the abuse coupled with interventions based on a negative view of impairment. In the words of Swain and French "[p]erhaps the most intrusive, violating and invalidating experiences, for disabled people, emanate from the policies, practices and interventions, which are justified and rationalised by the personal tragedy model".[358]

In addition to affirming the value of *impairment*, Swain and French challenge the portrayal of *disability*, as in the restriction of composite life opportunities, as negative:

> Furthermore, from the documented viewpoint of disabled people, far from being tragic, being disabled can have benefits. Disabled people sometimes find that they can escape class oppression, abuse or neglect by virtue of being disabled.[359]

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[353] Swain and French, 2004, p. 3.

[354] Disability Action North East, Fighting Back Against Eugenics and the New Oppressors, Newcastle-upon-Tyne, 1998, p. 3, quoted in Swain and French, 2000, p. 579. Emphasis in original.

[355] Swain and French, 2000, p. 579.

[356] Swain and French, 2004, p. 6.

[357] Swain and French, 2000, p. 578.

[358] Ibid., p. 573.

[359] Swain and French, 2004, p. 7. See also Swain and French, 2000, p. 570: "[B]eing disabled need not be a tragedy for disabled people, but may, on the contrary, enhance life or provide a lifestyle of equal satisfaction and worth.".

They question the value usually accredited life opportunities such as “paid employment” or “to marry and have children”.[360] Swain and French thus assert that restrictions of such life opportunities can just as well be seen as a blessing rather than a tragedy, by creating a way to escape “society’s expectations and requirements”.[361] The quote by Sian Vasey below is used to illustrate how disability can mean escaping the perceived fate of non-disabled women:

> We are not usually snapped up in the flower of our youth for our domestic and child rearing skills, or for our decorative value, so we do not have to spend years disentangling ourselves from wearisome relationships as is the case with many non-disabled women.[362]

Impairment, through disability, thus potentially means abdication from a number of composite life opportunities and this is forwarded as a form of valuable freedom:

> Essentially, impairment which is social death and invalidates disabled people in a non-disabled society, provides a social context for disabled people to transcend the constraints of non-disabled norms, roles and identity and affirm their experiences, values and identity.[363]

To conclude, Swain and French criticise the social model of disability for not explicitly acknowledging the positive aspects of impairment and disability, and even more so those who call for the social model of disability to explicitly recognise impairment as potentially negative.

3.7.2. The role of additional forms of human diversity

The social model of disability and particularly the Disabled People’s Movement have been challenged for not paying sufficient attention to the disadvantage imposed on its intended constituency in connection with forms of human diversity other than impairment.[364] The backdrop of this critique is the assertions that such aspects of human diversity give rise to different requirements and issues *among* persons with disabilities. Each aspect of diversity has two facets, one of which is likely to be seen as the norm, setting the agenda in the name of all persons with disabilities and thus

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[360] Swain and French, 2004, p. 8.

[361] Ibid., p. 7.

[362] Vasey, Sian, Disability Culture: It’s a Way of Life, in Rieser, Richard and Mason, Micheline (Eds.), Disability Equality in the Classroom: A Human Rights Issue, Disability Equality in Education, London, 1992, p. 74, quoted Swain and French, 2004, p. 8.

[363] Swain and French, 2000, p. 576.

[364] This is commonly referred to as an analysis of “intersectionality”, first introduced by critical race theory feminists in the 1980s. See e.g. Crenshaw, Kimberlé, Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics, The University of Chicago Legal Forum, 1989.

ignoring and rendering invisible the requirements and issues of the other facet. The norm is male, heterosexual, white, citizen and/or not too young and not too old, and the 'other' is female, gay/lesbian, black, indigenous, non-citizen and/or a child or an older person. While everyone finds themselves at the intersection between numerous aspects of diversity, those who are visible and who get to set the agenda inside a framework primarily addressing one form of human diversity is thus 'the norm-1', namely those who have *only one* facet setting them apart from the norm, which in the case of persons with disabilities is impairment.

Since each facet not representing the norm is coupled with disadvantage, the combination of such facets give rise not only to different issues and requirements, but a lesser likelihood to have any requirements recognised and fulfilled. The problem is thus both invisible differing requirements and a lesser likelihood to have *any* requirement recognised and fulfilled in the larger social context. In addition, which is the focus here, even the ideological and political frameworks created to address disadvantage connected to diversity reproduce 'the norm-1' fallacy. As expressed by Ayesha Vernon, "[t]he fundamental problem is that each oppressed group is really focusing only on a single system of oppression, the nearest to its heart, believing it to be the primary cause of all human suffering".[365] Among such systems, those most often mentioned as contenders of being added to disability is "ethnicity, gender, sexuality, age and class".[366] The experience of the tendencies noted by Vernon is apparent in the following statement by Millie Hill in relation to racism:

> I got fed up to the back teeth of being told by white disabled people that as black disabled people we shouldn't be concerned with issues of race and disability; that we should be concerned only with issues of disability because that was the fight; that was the most important element in our character.[367]

Michael Oliver recognised in 1996 that "it is certainly true that the social model of disability has not explicitly addressed the issue of multiple or simultaneous oppression but then such issues are only just beginning to be explored in respect of both impairment and disability".[368] Michael Oliver and Jane Campbell noted, also in 1996, that the omitting of issues of intersectionality was to some extent a hesitation born from earlier divisive experiences of categorisation based on impairment as a threat to united efforts, but that there had "never been a policy to focus only narrowly on disability issues and to ignore racism, sexism, ageism and homophobia".[369]

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365 Vernon, Ayesha, Multiple Oppression and the Disabled People's Movement, in Shakespeare, Tom (Ed.), The Disability Reader: Social Science Perspectives, Continuum, London, 1998, p. 207.

366 Enumeration by Ayesha Vernon in Vernon, Ayesha, The Dialectics of Multiple Identities and the Disabled People's Movement [hereinafter Vernon, 1999], Disability & Society, Vol. 14, No. 3, 1999, p. 385.

367 Quoted in Campbell, Jane and Oliver, Michael, Disability Politics: Understanding Our Past, Changing Our Future [hereinafter Oliver and Campbell, 1996], Routledge, London, 1996, p. 132.

368 Oliver, 1996, p. 39.

369 Oliver and Campbell, 1996, p. 132.

In addition to not explicitly addressing such diversity, particular features of the social model of disability are pulled out as rendering it inadequate for certain segments of the constituency. Pointing to the case of children, especially those with "profound impairment", a tendency to write those close to the persons with a disability out of the picture has been questioned:

> […] I would suggest that the social model is inadequate for children with profound impairment as it can be seen to neglect the role of others who come into contact with the profoundly impaired child. […] With its strong emphasis upon self-advocacy and collective action, and given that children with profound impairment may be largely reliant upon others, the social model may be seen to have little 'room' for such children.[370]

Similar critique has also addressed old age through concerns being voiced about how issues of older persons are addressed, such as their comparably higher medical needs as well as lesser likelihood to identify ideologically with the notion of social oppression.[371]

Many of the calls for attention to intersectionality are however explicit on the problem lying not in the social model of disability, but in how it is applied in practice.[372] Jenny Morris, (while making the connection between the social model of disability and the silence on and silencing of experience in the Disabled People's Movement, especially in 'private' spheres of life), direct her criticism of insufficient attention to the domestic sphere of life and its particular effect on women towards the Disabled People's Movement rather than to the social model of disability per se:[373]

> Disabled women want personal assistance which enables them to look after children, to run a home, to look after parents or others who need help themselves. In contrast, the disabled people's movement has tended to focus on personal assistance which enables paid employment and other activities outside the home. These things are of course important for disabled women as well but the disabled people's movement has, so far, failed to give enough prominence to the fact that choice and control which is at the heart of the movement's concept of independent living must also be concerned with the private world of the family and personal relationships. Independent living for both disabled men and women is as much about being able to participate in caring relationships as it is about participating in the public world of work (see Morris, 1995).[374]

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[370] Brett, Jane, The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: Is It Time for an Alternative Model of Disability?, Disability & Society, Vol. 17, No. 7, 2002, p. 831.

[371] See e.g. Pinder, 1996, p. 154.

[372] Ayesha Vernon is explicit on that the fault lies with the movement and not with the social model of disability: "It is imperative to note, however, that the blame does not lie with the social model of disability, as it is sometimes assumed, for that is merely a conceptual tool.". Vernon, 1999, p. 385.

[373] See Morris, 1996, pp. 12-15.

[374] Ibid., pp. 10-11.

Another aspect of life, the lack of attention to which is explored in the previous section, is the issue of health. Nasa Begum adds another dimension to the question of how such lack of attention impacts on different segments of the constituency of the social model of disability by noting that access to and experience of health services differ according to a number of factors other than impairment. Consequently, a lack of attention to issues of health works to the detriment of less privileged segments of the constituency:

> In the past, disabled people have fought so hard to challenge the medicalisation of their lives and experiences that concerns about health needs have tended to be minimised. [D]isabled people, whether as a result of impairment or as a consequence of everyday illnesses, are consumers of health services. [D]isabled people are not a homogenous group and factors such as race, class, age, sexuality, sex and gender often play a significant role in shaping their experiences of health services. […] Much more work remains to be done on how disability interacts with other dimensions of social inequality to influence people's experience of health care.[375]

To conclude, the intended target of this critique as the social model of disability per se *or* as how it is applied in practice is not always clear. This is particularly so when critique makes connections to formative features common to both these dimensions, such as emphasis on self-advocacy, lack of attention to issues of health and a focus on public rather than private dimension of life.

Connections between disability and health are central to the approach to disability explored in the following section: the International Classification of Functioning, Disability and Health (ICF).

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[375] Begum, Nasa, Doctor, Doctor…Disabled Women's Experience of General Practitioners, in Morris, Jenny (Ed.), Encounters with Strangers: Feminism and Disability, The Women's Press Ltd, London, 1996, pp. 169-170.

4. International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) is a revised version of ICIDH and like it, a product of WHO. It is the result of a process to revise ICIDH which was initiated in 1993 and culminated in the endorsement of ICF by the World Health Assembly in 2001.[376]

The main distance travelled between these two approaches to disability is described by WHO as ICIDH depicting the "consequences of disease" and ICF instead depicting the "components of health".[377] The essence of this development is presented as that ICF "takes a neutral stand with regard to etiology". [378] In other words, as opposed to ICIDH, ICF does not predetermine the cause of problems in relation to composite life opportunities as levels and modes of functioning of the body and mind only.[379]

Another novelty is that the universe of ICF is not restricted to covering *problems*. Instead the concept of Disability is situated in a conceptual framework containing its designated opposite, the concept of Functioning. *Disability* is defined as "the *negative* aspects of the interaction between an individual (with a health condition) and that individual's contextual factors"[380] and *Functioning* is defined as its mirror image: "the *positive* aspects of the interaction between an individual (with a health condition) and that individual's contextual factors"[381].

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[376] World Health Organization (WHO), World Health Assembly Resolution 54th Session, 22 May 2001, WHA.54.21. For an account of the revision process see Fougeyrollas et al., 2001, pp. 178-79, 184 and Pfeiffer, 1998, pp. 506-508.

[377] WHO, 2001, p. 4.

[378] Ibid.

[379] This remains the most serious critique launched against ICIDH (see above under 2.7.).

[380] Ibid., p. 213.

[381] Ibid., p. 212.

WHO summarises the function of ICF as follows:

> In sum, ICF is WHO's framework for health and disability. It is the conceptual basis for the definition, measurement and policy formulations for health and disability. It is a universal classification of disability *and* health for use in health and health-related sectors.[382]

Three separate but interrelated functions of ICF can be distilled from the above: *a conceptualisation*, as in a way of understanding and describing health and disability, a *classification*, as in a system to organise information about health and disability, and a tool for *policy development*.

The account of ICF below is based on a manual of ICF published by WHO[383] and a subsequent paper on ICF by WHO[384].

4.1. The universe of ICF

The conceptual framework of ICF is one of considerable detail, even omitting the dimensions which are primarily a part of its classifying rather than its conceptual function. The problems identified by ICF are subsumed under the umbrella concept of Disability, which includes the concepts of Impairment, Activity limitations and Participation restrictions. *Disability* is defined as "the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)".[385] *Impairment* is defined as "a loss or abnormality in body structure or physiological function (including mental functions)".[386] *Activity limitations* are defined as "difficulties an individual may have in executing activities".[387] *Participation restrictions* are defined as "problems an individual may experience in involvement in life situations".[388] These three concepts

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[382] World Health Organization (WHO), Towards a Common Language for Functioning, Disability and Health [hereinafter WHO, 2002], WHO, Geneva, 2002, WHO/EIP/GPE/CAS/01.3, p. 19. Emphasis in original.

[383] WHO, 2001. In 2007, the WHO published a version of ICF adapted to children and youth: International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY). ICF-CY uses the ICF conceptual framework and reproduces the introduction and the annexes of WHO, 2001. References will only be made to ICF-CY regarding questions relating to who ICF covers. World Health Organization (WHO), International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY) [hereinafter WHO, 2007], Geneva, 2007.

[384] WHO, 2002.

[385] WHO, 2001, p. 213.

[386] Ibid.

[387] Ibid.

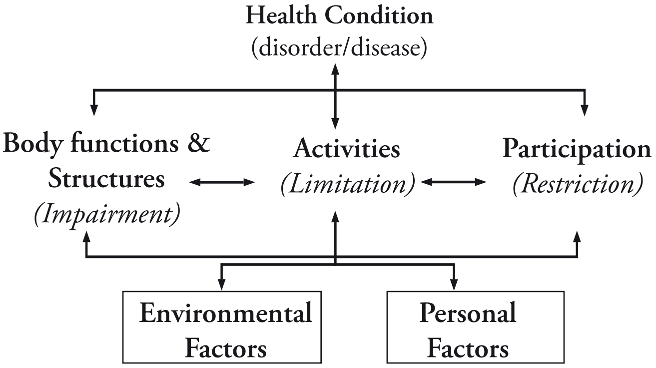
[388] Ibid.

separate "perspectives"[389] or "levels"[390] of Disability: the body (Impairment), the person (Activity limitations) and society (Participation restrictions).

Impairment, Activity limitations and Participation restrictions portray three levels of or perspectives on *interaction* between the Health condition of a person, other Personal factors and Environmental factors. *Health condition* as a concept represents "an umbrella term for disease (acute or chronic), disorder, injury or trauma".[391] *Personal factors* as a concept "are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health state".[392] Such factors "may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics".[393] *Environmental factors* as a concept "includes the physical world and its features, the human-made physical world, other people, other people in different relationships and roles, attitudes and values, social systems and services, and policies, rules and laws".[394]

The interaction between these components and determinants of Disability can be depicted as follows:

ICF: Interaction of Concepts



[395]

The central horizontal line of the diagram above contains (in parentheses) the three components that ICF includes under the umbrella concept of Disability: Impairment, Activity limitations and Participation restrictions. The upper and lower lines illus-

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[389] Ibid., p. 211.

[390] WHO, 2002, p. 10.

[391] WHO, 2001. p. 212.

[392] Ibid., p. 17.

[393] Ibid.

[394] Ibid., pp. 213-214.

[395] Australian ICF Disability and Rehabilitation Research Program, ICF: Interaction of Concepts.

trate the factors interacting to produce Disability: Health condition, Environmental factors and Personal factors.

As mentioned above Disability is conceptualised by ICF in relation to a counterpart, the concept of Functioning. *Functioning* is defined by WHO as "the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)".[396] Like Disability, Functioning has three components depicting different levels[397] of or perspectives[398] on interaction: the body (Body function and structure), the individual (Activities) and society (Participation). *Body functions* are "the physiological functions of body systems, including psychological functions".[399] *Body structures* are "the structural or anatomical parts of the body such as organs, limbs and their components classified according to body systems".[400] *Activity* is "the execution of a task or action by an individual".[401] *Participation* is "a person's involvement in a life situation".[402]

The central horizontal line of the diagram above contains the three components that ICF includes under the umbrella concept of Functioning, namely Body functions and structures, Activity and Participation. The upper and lower lines illustrate the factors interacting to determine Functioning: Health condition, Environmental factors and Personal factors. As Functioning and Disability are constructed as mirror images, it follow that they are portrayed as resulting from the same categories of possible causes.[403] In other words, it is the same factors which, depending whether they are present or absent, and on their nature, cause Disability or Functioning. To illustrate: a law is an Environmental factor which, depending on its content and application, can cause Functioning as well as Disability at the level of the body, the individual or society.

To sum up, ICF portrays and classifies outcomes of the interaction between an individual (with a Health condition) and his or her environment. This outcome is constructed and measured in terms of Disability (negative) and Functioning (positive), which can be described as mirror images.

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[396] WHO, 2001, p. 212. "The components of Functioning and Disability […] can be expressed in two ways. On the one hand, they can be used to indicate problems (e.g. impairment, activity limitation or participation restriction summarised under the umbrella term *disability*); on the other hand they can indicate nonproblematic (i.e. neutral) aspects of health and health-related states summarized under the umbrella term *functioning*)." Ibid., p. 8. Emphasis in original.

[397] WHO, 2002, p. 10.

[398] WHO, 2001, p. 211.

[399] Ibid., p. 213.

[400] Ibid.

[401] Ibid.

[402] Ibid.

[403] "The diagram identifies the three levels of human functioning classified by ICF: functioning at the level of body or body part, the whole person, and the whole person in a social context. Disability therefore involves dysfunctioning at one or more of these same levels: impairments, activity limitations and participation restrictions." WHO, 2002, p. 10.

4.2. What problems does ICF recognise?

The three concepts used in ICF to portray and categorise *problems*[404] are thus Impairment, Activity limitations and Participation restrictions. The lines of division between these concepts according to WHO are that they depict problems on different "levels"[405] or from different "perspectives"[406]: the body, the person and society. ICF does not list the specific problems envisaged as Disability, instead it lists its "positive" counterparts: instances of Functioning.[407] Disability (including Impairment, Activity limitations and Participation restrictions) is thus detectable as "dysfunctioning"[408]; the "negative"[409] aspects of the forms of doing or being listed as dimensions of Functioning in ICF.

In ICF these life opportunities are listed in a structure of Domains. A *Domain* is defined as "a practical and meaningful set of related physiological functions, anatomical structures, actions, tasks, or areas of life".[410] These Domains do not assume to provide an exhaustive list of the life opportunities potentially valuable to an individual.[411] The Domains containing the positive counterparts of Impairment are Body functions and Body structures. The Domains of *Body functions* listed in ICF are: "Mental functions", "Sensory functions and pain", "Voice and speech functions", "Functions of the cardiovascular, haematological, immunological and respiratory systems", "Functions of the digestive, metabolic and endocrine systems", "Genitourinary and reproductive functions", "Neuromusculoskeletal and movement-related functions" and "Functions of the skin and related structures".[412] The Domains of *Body structures* listed in ICF are: "Structures of the nervous system", "The eye, ear and related structures", "Structures involved in voice and speech", "Structures of the cardiovascular, immunological and respiratory systems", "Structures related to the digestive, metabolic and endocrine systems", "Structures related to the genitourinary and reproductive systems", "Structures related to movement" and "Skin and related structures".[413] The Domains contain-

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[404] "The components of [...] Disability [...] indicate problems (e.g. impairment, activity limitation or participation restriction"). WHO, 2001, p. 8. "Having a problem may mean an impairment, limitation, restriction or barrier depending on the construct." Ibid., p. 22.

[405] WHO, 2002, p. 10.

[406] WHO, 2001, p. 211.

[407] WHO, 2002, p. 10.

[408] Ibid.

[409] WHO, 2001, p. 10.

[410] Ibid., p. 3, note 3. These Domains are in turn organised in a nested structure of categories.

[411] In each Domain, the nested categories contains the categories "others specified" and "unspecified".

[412] Ibid., pp. 47-104. These Domains are then branched into levels of categories. For example, one of the categories of "Genitourinary and reproductive functions" is "Genital and reproductive functions" which in turn contains the category "Menstruation functions", which in turn contains the category "Regularity of menstrual cycle". Ibid., pp. 90-91.

[413] Ibid., pp. 105-122. These Domains are then branched into levels of categories. For example, one of the categories of "Structures related to movement" is "Structure of upper extremity", which in turn contains the category "Structure of hand". In turn, the category "Structure of hand" contains the category "Joints of hand and fingers". Ibid., pp. 118-119.

ing the positive counterparts of Activity limitations and Participation restrictions are *Activities* and *Participation.* These Domains are listed in ICF as: "Learning and applying knowledge", "General tasks and demands", "Communication", "Mobility", "Self-care", "Domestic life", "Interpersonal interactions and relationships", "Major life areas" and "Community, social and civic life".[414]

While the forms of doing and being included in the Impairment component (the perspective of the body) is covered by two lists of Domains (Body functions and Body structures), the forms of doing or being included under the other two components of Disability, Activity limitations (the perspective of the person) and Participation restrictions (the perspective of society), are conflated in *one* list of Domains, described as covering "the full range of life areas (from basic learning or watching to composite areas such as interpersonal interactions or employment)".[415] Disability signifies "dysfunctioning" in any of these domains.[416] Applying the terminology of this book, the Impairment Domains cover levels and modes of functioning of the body and mind and the Activities and Participation Domains cover both such levels and models of functioning of the body and mind *and* composite life opportunities.[417] As posited in the introduction, the hallmark of the latter category of forms of doing and being is that they, at least in theory, actualise alternative ways of performance and enjoyment.

Taken together, the lists of Domains above clearly illustrate that the problems in the universe of ICF include both levels and modes of functioning of the body and mind and composite life opportunities. However, this (levels and modes of functioning of the body and mind/composite life opportunities) is not the dividing line applied when constructing Domains of life opportunities and assigning these to the three parallel dimensions of Disability (Impairment, Activity limitations and Participation restrictions). While the lists of Domains assigned to the concept of Impairment represent levels and modes of functioning of the body and mind only, the *singular* list assigned to the concepts of Activity limitations *and* Participation restrictions includes *both* these and composite life opportunities, for example these Domains include both walking and using public transport. ICF thus leaves it open if an instance of Disability is to be designated as a problem at the level of the person (Activity limitations) or society (Participation restrictions). According to WHO, "[t]he definition of "participation" brings in the concept of involvement. Some proposed definitions of "involvement" incorporate taking part, being included or engaged in an area of life, being accept-

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[414] Ibid., pp. 123-171. These Domains are then branched into levels of categories, for example, the categories in the Domain "Major life areas" are "Education", "Work and employment" and "Economic life" and each of these in turn contains additional categories. Ibid., pp. 164-167.

[415] Ibid., p. 14.

[416] WHO, 2002, p. 10.

[417] The differentiation by WHO between the levels and modes of functioning of the body and mind in the Impairment Domains and the levels and modes of functioning of the body and mind in the Activity limitations and Participation restrictions Domains is that the Impairment Domains cover the 'body' level, e.g. what a muscle or an organ can or cannot do or be while the Activity limitations and Participation restrictions Domains covers the 'person' level, e.g. walking or seeing.

ed, or having access to needed resources".[418] The relationship between Activities and Participation is not elaborated further and WHO explicitly recognises the difficulty in separating the life opportunities connected with each concept:

> It is difficult to distinguish between "Activities" and "Participation" on the basis of the domains in the Activities and Participation component. Similarly, differentiating between "individual" and "societal" perspectives on the basis of domains has not been possible given international variation and differences in the approaches of professional and theoretical frameworks.[419]

Finally, to reiterate the main conclusion in this section, the problems recognised by ICF include both levels and modes of functioning of the body and mind and composite life opportunities.

4.3. What causes does ICF recognise as relevant to the problems it identifies?

The three components of Disability in ICF are constructed as effects of the interaction between a (person with a) *Health condition* and *Contextual factors*, categorised further as *Environmental factors* and *Personal factors*.[420] According to ICF, the *causes* of Disability are thus to be found in these three categories of factors. For an image of these causal relationships, see the vertical arrows connecting the central horizontal line (Disability) with these categories in the image of ICF above under 4.1.

The concept of *Health condition* is broadly employed in ICF, including "diseases, disorders, injuries, traumas etc.".[421] *Environmental factors* are defined as "the physical, social and attitudinal environment in which people live and conduct their lives".[422] Environmental factors are elaborated in detail as they are part of those factors which are classified in ICF. The main Domains are: "Products and technology", "Natural environment and human-made changes to the environment", "Support and relationships", "Attitudes" and "Services, systems and policies".[423] Environmental factors are organised in ICF according to two levels, *individual and societal.* Individual factors are factors "in the immediate environment of the individual, including settings such as home, workplace and school".[424] Societal factors are "formal and informal social

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[418] WHO, 2001, p. 15, note 14.

[419] Ibid., p. 16.

[420] Ibid., p. 8.

[421] Ibid.

[422] Ibid., p. 10.

[423] Ibid., pp. 171-207. These Domains are then branched into levels of categories. For example, one of the categories of "Support and relationships" is "Personal care providers and personal assistants". Ibid., pp. 187-188.

[424] Ibid., p. 16.

structures, services and overarching approaches or systems in the community or society that have an impact on individuals".[425] According to ICF, an Environmental factor is either a *Barrier* or a *Facilitator*. Barriers are "factors in a person's environment that, through their absence or presence, limit functioning and create disability".[426] Facilitators are "factors in a person's environment that, through their absence or presence, improve functioning and reduce disability".[427] To illustrate, for a person using a wheelchair the presence of a lift is a Facilitator while its absence is a Barrier and the absence of a threshold is a Facilitator while its presence is a Barrier.

While Personal factors are included in the conceptual framework as a determinant of Disability, they are not part of that which is classified in ICF. In other words, their relationship to Disability is not recorded or graded, only acknowledged.[428] As mentioned above under 4.1., Personal factors are defined as "the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states".[429]

The ICF concept of Disability is thus the result of "dynamic interaction"[430] of a Health condition (disease, disorder, injury or trauma), other Personal factors such as gender, age or social background and Environmental factors such as social relations, attitudes, laws or the built environment. Changes pertaining to any factor have the potential to modify any level of Disability and changes in any level of Disability have the potential of modifying other levels of Disability.[431] For an image of the causal relationships *between* levels of Disability, see the multidirectional arrows on the central horisontal line connecting the three levels of Disability in the graphic depiction of ICF above under 4.1.

According to WHO, "ICF takes a neutral stand with regard to etiology so that researchers can draw causal inferences using appropriate scientific methods".[432] In the

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[425] Ibid., p. 17.

[426] Ibid., p. 214.

[427] Ibid.

[428] Ibid., p. 17. These are not listed in ICF "because of the large social and cultural variance associated with them". Ibid., p. 8.

[429] Ibid., p. 17.

[430] Ibid., p. 8.

[431] This interaction can be portrayed as a 'two level chain reaction', as the respective three components of Disability in ICF are depicted not only as the result of the interplay between the person with a Health condition and Contextual factors (Personal factors and Environmental factors), but also as a result of the interplay with the two other *aspects* of Disability. In other words, Disability at one level (e.g. Impairment) is not only depicted as a result of the interplay of a Health condition, Personal factors and Environmental factors but also as a result of other aspects of Disability (i.e. Activity limitations and Participation restrictions), which are in themselves results of the interplay of a Health condition, Personal factors and Environmental factors. The specific 'cocktail' of interaction which represents Disability on one level thus influences the other two levels and, although it results from the same categories of Contextual factors as the other two, it is metamorphosed into representing a, to some extent independent, influence on these other two levels. In this way, a Contextual factor which does not have a direct effect on the level of Disability in question (e.g. Impairment), may have a direct effect on another level of Disability (i.e. Activity limitations and Participation restrictions), which in turn has an effect on Impairment.

[432] Ibid., p. 4.

words of WHO, ICF does not "model" the process of Functioning and Disability; rather it can be used to "describe" this process.[433] This neutrality is described as ICF providing a "language" open to the creation of different texts, or "building blocks" useful for the creation of different models of Disability:

> It [ICF] provides the building blocks for users who wish to create models and study different aspects of this process. In this sense, ICF can be seen as a language: the texts that can be created with it depend on the users, their creativity and their scientific orientation.[434]

The gist of this is that while ICF broadly determines the factors it sees as relevant to the causality of Disability as those collected in the categories Health condition, Environmental factors and Personal factors, it does not stipulate to what extent factors from these respective categories have causal significance in relation to any particular life opportunity, or how the dynamics of such causality work. WHO expresses this openness as that ICF is "an integration" of "two opposing models" of disability: "the medical model" and "the social model". [435] In relation to these models, ICF "attempts to achieve a synthesis".[436] However, WHO clearly finds these models *on their own* lacking as approaches to disability. While ICF is neutral in the sense that it encompasses the causal connections embraced by *both* models of disability, ("a problem of the person"[437] *and* "a socially created problem"[438]), it remains normative in that it does not accommodate the use of its "language" or "building blocks" in a way that *at the outset* excludes the causal factors of either model, i.e. neither Health condition *nor* Environmental factors:

> On their own, neither model [medical or social] is adequate, although both are partially valid. Disability is a complex phenomena that is both a problem at the level of a person's body, and a complex and primarily social phenomena. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. [...] A better model of disability, in short, is one that synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects. This more useful model of disability might be called the biopsychosocial model. ICF is based on this model, an integration of medical and social. ICF provides, by this synthesis, a coherent view of different perspectives of health: biological, individual and social.[439]

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[433] Ibid., p. 18.
[434] Ibid.
[435] Ibid., p. 20.
[436] Ibid.
[437] Ibid.
[438] Ibid.
[439] WHO, 2002, p. 9.

The "medical model" is described as viewing disability "as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals".[440] The "social model" is described by WHO both as seeing "the issue *mainly* as a socially created problem, and basically as a matter of the full integration of individuals into society"[441] and as "a socially created problem and *not at all* an attribute of an individual".[442] As illustrated in the preceding chapter on the Social Model of Disability, the span between "*mainly* a socially created problem" and "*not at all* an attribute of the individual" is the site of the ambiguity of what this model really claims, and the plausibility of ICF presenting a "synthesis" arguably cannot pre-empt an answer to that question.

Thus, an inquiry settling on a particular problem in relation to employment being overwhelmingly caused by a Health condition is arguably not acceptable to a "social model" which sees such problems as either categorically socially caused or irrelevant, while it remains acceptable to ICF provided that a holistic consideration has been made at the outset of the inquiry. If, as WHO says, the "social model" sees disability as "a socially created problem and not at all an attribute of an individual"[443], then the recognition of a Health condition as a causal factor here, even if flanked by Environmental factors, is not compatible with the social model. Correspondingly, an inquiry holding at the outset that participation restriction in employment is solely dependent on factors external to the person could be depicted using *some* of the causal components of ICF (Environmental factors) but this would not be considered 'correct' according to the holistic idea behind ICF. Consequently, the compatibility between a "social model" and ICF depends on the claims of that "social model". The "biopsychosocial model" of ICF subsumes the causal factors recognised by the "social model" (Environmental factors) and the "medical model" (Health condition) and in this respect it is indeed a synthesis of these two. However, if the key feature of one model is the denial of the relevance of the causal factors recognised by the other model, a "synthesis" of such opposition amounts to a negation.

Irrespective of the validity of these claims of compatibility with other approaches to disability, it can be concluded from the broad approach to causality in ICF that it finds the potential causes of Disability (Impairment, Activity limitations and Participation restrictions) in the individual (Health condition combined with Personal factors) as well as in the environment (Environmental factors).

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[440] WHO, 2001, p. 20.

[441] Ibid. Emphasis added.

[442] WHO, 2002, p. 9. Emphasis added.

[443] Ibid.

4.4. What solutions does ICF recognise as relevant to the problems it identifies?

The targets of the solutions envisaged by ICF correspond to the problems it portrays under the umbrella term Disability: Impairment, Activity limitations and Participation restrictions. The solutions focus on two of its three identified categories of causes: Health conditions and Environmental factors.[444] Like ICIDH, ICF is a classification, a matrix for collecting pieces of information about the person and his or her environment as they relate (directly and indirectly) to "health"[445]; information which in turn can be the basis for finding solutions to the problems ICF identify as Disability:

> ICF can assist in identifying where the principal "problem" of disability lies, whether it is in the environment by way of a barrier or the absence of a facilitator, the limited capacity of the individual himself or herself, or some combination of factors. By means of this clarification, interventions can be appropriately targeted and their effects on levels of participation monitored and measured.[446]

Like ICIDH, the function of information collected and analysed through ICF is not limited to individual or clinical use. Instead, although ICF "looks like a simple health classification" its most important purpose is "as a planning and policy tool for decision-makers"[447]:

> In both the health sectors and other sectors that need to take into account the functional status of people, such as social security, employment, education and transportation, there is an important role that ICF can play. It goes without saying that policy development in these sectors requires valid and reliable population data on functional status. Legislative and regulatory definitions of disability need to be consistent and grounded in a single coherent model of the disability creation process. Whether it is devising eligibility criteria for disability pensions, developing regulations for access to assistive technology, or mandating housing or transportation policy that accommodates individuals with mobility, sensory or intellectual disability, ICF can provide the framework for comprehensive and coherent disability-related social policy.[448]

WHO notes a wide range of "applications of ICF", exemplified by its function as a "statistical tool", a "research tool", a "clinical tool", a "social policy tool" and an "educational tool".[449] Exemplified sectors (in addition to the immediate one of health) include "insurance, social security, labour, education, economics, social policy and

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[444] See more on the third Domain Personal factors above under 4.1.

[445] Compare e.g. WHO, 2001, p. 10 were the definitions of the components of ICF are introduced by the phrase "[i]n the context of health".

[446] Ibid., p. 243.

[447] WHO, 2002, p. 2.

[448] Ibid., p. 7.

[449] WHO, 2001, p. 5.

general legislation development, and environmental modifications".[450] WHO also forwards ICF as "an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation".[451] Yet another aim is to facilitate communication between its "different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities"[452], "across the world in various disciplines and sciences"[453].

To conclude, the main aim of ICF is providing a conceptual framework and a framework for the collection of data, which in turn will improved policy in all areas of life aiming at a "comprehensive and coherent disability-related social policy".[454] Such policy covers solutions to all the problems subsumed under the umbrella Disability, including levels and modes of functioning of the body and mind as well as composite life opportunities. In the words of WHO: "[B]oth medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention.".[455]

4.5. Who is the intended constituency of ICF and by virtue of what characteristics or experiences?

Constituency wise ICF is characterised by inclusiveness, its entry gate being a broad understanding of Health conditions:

> *Health condition* is an umbrella term for disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition.[456]

Adding to this, ICF is not restricted to persons experiencing conditions of certain duration, it covers persons with "acute or chronic"[457] Health conditions alike. Among chronic conditions, no separation of "chronic illness and disability" is made.[458] Furthermore, its intended constituency includes those who have a genetic predisposition for a Health condition, those who have previously experienced a Health condition and also those falsely suspected of having a Health condition.[459]

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[450] Ibid.
[451] Ibid., p. 6.
[452] Ibid., p. 5.
[453] Ibid., p. 3.
[454] WHO, 2002, p. 7.
[455] Ibid., p. 9.
[456] WHO, 2001, p. 212. Emphasis in original.
[457] Ibid.
[458] See e.g. WHO, 2002, p. 19.
[459] WHO, 2001, Annex 4 Case Examples, pp. 238-241.

The fact that "health and health-related states associated with all health conditions can be described using ICF" leads WHO to assert that ICF is not "only about people with disabilities; in fact, it is about *all people*. In other words, ICF has universal application".[460] The inclusive character of ICF is a deliberate strategy to broaden the concept of Disability to equate "universal human experience":

> ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience.[461]

Through the "health" connection, ICF effectively and intentionally disarms the term disability as a criterion for separating out a minority among human beings. WHO notes that "[p]reviously, disability began where health ended; once you were disabled, you where in a separate category. We want to get away from this kind of thinking".[462] Indeed, WHO explicitly states that ICF "should not become a tool for labeling persons with disabilities as a separate group".[463] The choice by WHO of the variable connecting the functioning of the human body and mind with access to life opportunities as "health" builds both on the wish to universalise the problem of restricted life opportunities connected to the functioning of the body and mind and on the idea that this is best done by using the concept of "health":

> We want to make ICF a tool for measuring functioning in society, no matter what the reason for one's impairments. […] By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.[464]

Irrespective of the obvious broad coverage of ICF, the assertion above that that ICF is about "all people" can be understood in different ways. Firstly, since ICF measures *Functioning* and not only Disability, ICF could be said to be about everyone, as everyone is somewhere on the span thus created between 'total' Functioning and 'total' Disability.[465] It remains however that ICF only is applicable to those with a Health condition, which, irrespective of its broad applications outlined above, does not cover everyone.[466] Furthermore, all Health conditions do not have consequences

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[460] Ibid., p. 7. As mentioned above, ICF-CY was developed to increase the relevance of the facts recorded for children, but ICF still applies to everyone.

[461] WHO, 2002. p. 3.

[462] Ibid.

[463] Ibid., p. 14.

[464] Ibid., p. 3.

[465] "ICF is named as it is [International Classification of Functioning, Disability and Health] because of its stress on health and functioning, rather than on disability." Ibid.

[466] "ICF is a health classification and so presumes the presence of a health condition of some kind." WHO, 2001, p. 224.

that amount to Disability (as it is understood in ICF) and so it seems that only those who have Health conditions which create such restriction are, strictly speaking, those ICF 'is about'. To conclude, the *potential* coverage of ICF is indeed everyone, as everyone can experience a Health condition which is coupled with Disability, but the actual coverage is more restricted. Having said that, by virtue of the inclusive approach outlined above, this does not deny the broad coverage of ICF, extending as it does to acute and chronic Health conditions as well as to the genetic predisposition for and history of such conditions and even to imputed conditions. In other words, even if ICF is only applicable to those persons currently implicated by Disability as understood by ICF, this range of person is much wider than the usual understanding of 'persons with disabilities' and indeed broader that the previous two approaches outlined in this book.

To summarise the main points of this section, by collapsing the distinctions between (ill-) health and Disability and between chronic and acute conditions, ICF is inclusive to the point where Disability no longer delimits a distinguishable group (because it equals the consequences of any Health condition); instead Disability (or strictly speaking the potential for Disability) becomes a universal characteristic of the human condition. ICF also includes not only those with current Health conditions, but previous, future and imputed such conditions.

4.6. ICF as a basis for entitlements

The previous four sections have addressed key features of how ICF constructs disability. In this section a summary is provided of these features and their implications for what claims to entitlements ICF can be used as a basis for.

The range of *problems* recognised by ICF is seemingly endless.[467] Each Domain covering life opportunities in ICF, by virtue of signifying both Functioning and Disability, simultaneously indicates both which such life opportunities ICF recognises as valuable to its envisaged constituency and what limitations or restrictions in relation to these it recognises as problematic. These life opportunities are portrayed by WHO as Domains of "*well-being*" which are either "interpreted to be within the "health notion"" or "have a strong relationship to a health condition".[468] "Well-being" is in turn defined by WHO as "the total universe of human life domains, including physical, mental and social aspects, that make up what can be called a "good life"".[469] In short, the life opportunities covered by ICF aim to exhaust areas of a "good life" relevant to persons with a Health condition. As illustrated by the diagram below, ICF includes both levels and modes of functioning of the body and

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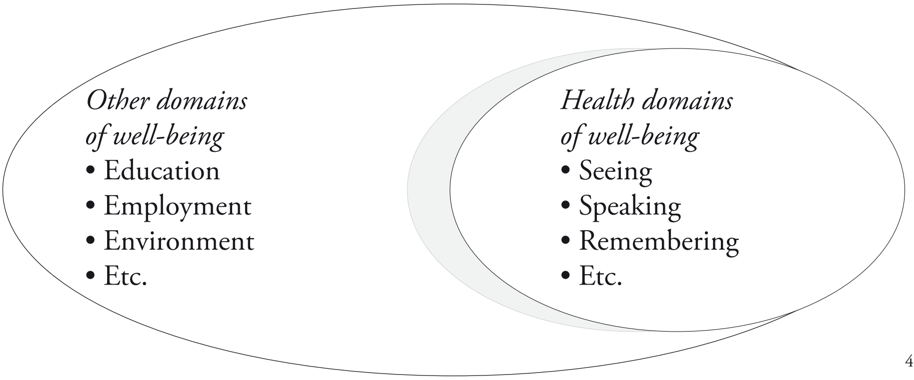
[467] As mentioned above under 4.2. each Domain contains the categories "others specified" and "unspecified", thus opening up for inclusion of any aspect overlooked.

[468] Ibid., p. 212.

[469] Ibid., p. 211.

mind (“health domains of well-being”) and composite life opportunities (“other domains of well-being”) in this “universe of well-being”:



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In line with the assertion by WHO that ICF “takes a neutral stand with regard to etiology”, the scope of potential *causes* of Disability appear unlimited.[471] The three categories of determinants are envisaged broadly. Health condition is defined as “an umbrella term for disease (acute or chronic), disorder, injury or trauma [which] may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition”.[472] Environmental factors in turn “make up the physical, social and attitudinal environment of the individual in which people live and conduct their lives”.[473] Finally, Personal factors are described as that they “may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics”.[474] The determinants of all levels of Disability (Impairment, Activity limitations and Participations restrictions) envisaged by ICF thus include factors intrinsic as well as extrinsic to the individual.

It is the aim of ICF to contribute, both through its conceptual and its classification function, to remedying the problems included in the Disability concept. The *solutions* envisaged by ICF mirror the problems and causes it identifies. In relation to the individual with a Health condition ICF is aimed at identifying the most appropriate interventions for each problem (Impairment, Activity limitations and Participation restrictions). Such interventions include those targeting the Health condition or Impairment of the individual as well as those targeting the environment. In relation to the policy framework of such solutions ICF envisages its conceptual framework as a means for standardising the understanding of problems and solutions. In addition, the information recorded within this framework is to provide detailed guidance for policy

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[470] Ibid., p. 212.
[471] Ibid., p. 4.
[472] Ibid., p. 212.
[473] Ibid., p. 16.
[474] Ibid., p. 17.

in relation to all the life opportunities covered by ICF, which include levels and modes of functioning of the body and mind as well as composite life opportunities.

The wide understanding of Disability as an umbrella concept for problems including both levels and modes of functioning of the body and mind as well as composite life opportunities, combined with the wide entry point to the ICF framework as a Health condition, universalises Disability, thus disqualifying it as a criterion for a minority category. The envisaged *constituency* of ICF is consequently broad, potentially including everyone. It includes not only those with current Health conditions, but also previous, future and imputed such conditions. Likewise, it covers acute and chronic conditions alike.

In sum, the range of claims to entitlements which can be drawn from ICF as an approach to disability includes claims to both levels and modes of functioning of the body and mind as well as to composite life opportunities. The range of persons potentially covered by ICF is universal and even if those actually covered are limited to those with a Health condition and Disability, it remains of broad application. The envisaged solutions include changes targeting the individual as well as the environment. The calling card of ICF is its inclusive and holistic character regarding all the aspects discussed above: problems, causes, solutions and constituency.

4.7. Critique of ICF

Like ICIDH, ICF has been subjected to criticism, both as a tool for classification and as an approach to disability. The aim of this section is limited to introducing in general terms the main strands of the criticism of ICF as a way to understand disability.

Much like the criticism of ICIDH, the most persistent criticism against ICF concerns the fact that it connects disability with health and remains a classification scheme, as well as the questions whether or not it sufficiently implicates the environment as a determinant of restricted composite life opportunities. In addition, it has been questioned in terms of clarity of its conceptual underpinnings.

For some, such as David Pfeiffer, the mere fact that a scheme is the product of WHO "imbues it with a medical identity".[475] As ICF uses the notion of health to forward disability as being of universal concern, it consequently emerges as little better than ICIDH.[476] Similarly, as expressed in the quote by Pfeiffer reproduced above under 2.7., *any* classification scheme remains an evil. According to Pfeiffer any

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[475] Pfeiffer, 1998, p. 509.

[476] Ibid. Recent suggestions to improve the clarity and usefulness of ICF through adapting its graphic representation (see above under 4.1.) includes addressing the risk that it is "read to have a biomedical bias" seen as inherent in the current positioning of Health condition at the top, indicating that this "holds priority" over Contextual factors. In addition, as Body functions and structures are depicted first from the left, these may appear "more important" than Activities and Participation. Ravenek, Michael et al., Perspectives in Rehabilitation: Enhancing the Conceptual Clarity and Utility of the International Classification of Functioning, Disability & Health: The

system for classification can and will be abused, even to the point of facilitating the elimination of those subjected to classification.[477]

Apart from criticism linked to connections with health and ICF being a classification scheme, much of the criticism of ICF is thus based on concerns about *how well it caters for the role of the environment* and to what extent it is susceptible to application bypassing this role. The heart of the criticism is that Activity limitations and Participation restrictions are not separated in ICF. Instead they share one list of life opportunities, dysfunction in relation to which the user can choose to designate as either an Activity limitation or a Participation restriction, or both. Patrick Fougeyrollas and Line Beauregard hold that by mixing what is referred to in this book as levels and modes of functioning of the body and mind (the 'person' level in ICF terms) and composite life opportunities (the 'society' level in ICF terms), common tendencies to attribute blame for dysfunction in relation to composite life opportunities to the individual are accommodated rather than discouraged:

> We assert that the conceptual clarification between capabilities in mental and physical activities (e.g. being able to maintain balance, perceive colors, hear in a noisy environment, understand abstract ideas, and remember) and performance in the accomplishment of socially determined life habits is the fundamental operational issue in response to the demands of people with disabilities. [...] Yet it [ICIDH-2/ICF] perpetuates confusion about what really pertains to the individual and what pertains to the environment [and] reinforces the perception that performance in human activities within one's life context is an intrinsic personal characteristic.[478]

This critique connects the dual function of ICF as a classification and as a conceptual framework. Two constructs are provided in ICF to measure dysfunction in the Domains of life opportunities connected to Activity limitations and Participation restrictions: Capacity and Performance. The former construct measures the "naked"[479], "true"[480] or "environmentally adjusted"[481] ability of the individual by assuming a standard environment. The latter construct measures the ability of the individual in his or her actual environment. The purpose of these two measures is to chart the role of the environment, thus both recognising and operationalising the importance of environmental Barriers and Facilitators:

Potential of a New Graphic Representation [hereinafter Ravenek et al., 2013], Disability and Rehabilitation, Vol. 35, No. 12, 2013, p. 1017.

[477] Pfeiffer refers to "Nazi Germany" as an example of this. Pfeiffer, 1998, p. 520. See also Hahn, 2002a, pp. 8-13, 18-19.

[478] Fougeyrollas et al., 2001, pp. 183-185. See also Whiteneck, Gail, Conceptual Models of Disability: Past, Present, and Future, in Workshop on Disability in America: A New Look, National Academy of Sciences, Washington, 2006, Appendix B, pp. 57-58.

[479] WHO, 2002, p. 11.

[480] WHO, 2001, p. 230.

[481] Ibid., p. 229.

> The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance.[482]

However, the critique holds, the possibility to measure Capacity in relation to composite life opportunities (Participation in ICF terms) operationalises and thereby condones and strengthens the notion that the 'naked' ability of a person is the relevant factor to record:

> The participation dimension […] is a cosmetic choice, as we end up with taxonomies that allow each dominant group to maintain its ideological position: An individual's disability is viewed in terms of impairments of body functions, structures, and activity restrictions of the person as a whole. The immediate effect is to put the weight of the responsibility on the individual, satisfying the biomedical gatekeepers and their mandates to attribute disability status and eligibility to compensation.[483]

It is thus asserted that the possibility to use the ICF scheme in relation to composite life opportunities, calling these Activities and measuring the persons Capacity for them, sanctions and perpetuates continuing ignorance of the role of the environment by playing into the hands of those who are susceptible to do so:

> Far from being integrated, the three domains can be used independently, and the body and activity ones will be well accepted by biomedical, compensation, and program eligibility gatekeepers. Omitting the necessity to use all conceptual domains together to document human functioning and disability process, *ICIDH-2* makes room for continued consideration of the individual unfitness for work, the inability to be educated, or the inability to use certain means of transportation as intrinsic characteristics. This perspective seems unacceptable to the independent living and equalization of opportunities movements.[484]

While some commentators, such as Rachel Hurst, are positive to ICF as a tool for developing policies to change the environment[485], much of the scepticism expressed by others above is based on this requiring a *change* of current policy and on ICF not being sufficiently unequivocal on the role of the environment in order for this change to materialise.

ICF has also been criticised for being "relatively silent about its conceptual underpinnings".[486] According to Rob Imrie, "the ICF fails to specify, in any de-

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[482] Ibid., p. 15.

[483] Fougeyrollas et al., 2001, pp. 185-186.

[484] Ibid., p. 186. Emphasis in original.

[485] Hurst, 2000, p. 1086: "The environmental context covers all areas of life and experience, including attitudes and belief systems, the natural world, services, legislation and policy. If used properly and disabled people involved in the classification, these factors will build up a considerable body of evidence for major social change to ensure the inclusion of disabled people.".

[486] Imrie, Rob, Demystifying Disability: A Review of the International Classification of Functioning, Disability and Health, Sociology of Health and Illness [hereinafter Imrie, 2004], Vol. 26, No. 3, 2004, p. 289.

tail, the content of some of its main claims about the nature of impairment and disability”.[487] Imrie warns that this carries a risk of incoherent practice, as “it is possible that different practitioners will interpret, in quite contrasting ways, some of its theoretical and conceptual content”.[488] Here, he notes the affiliations created with biopsychosocial theory and the principle of universalism.[489]

In relation to biopsychosocial theory, Imrie notes that ICF takes it for granted as “a natural guide, or middle way, through the divergent discourses of disability”.[490] He notes that lacking detail about what biopsychosocial theory is and what potential it has to do the job assigned to it by ICF “creates potential difficulties, for policy makers, medical practitioners, and academic commentators alike, in making judgements about the relevance (or not) of BPS [biopsychosocial theory] in contributing to the understanding of functioning, disability and health”.[491] He also notes the fact that biopsychosocial theory originates in the medical sphere, and although it was created as a call for attention to social dimensions, biopsychosocial theory “for some, implies, potentially, ‘a strengthening of traditional, biological, reductionist medicine’ while maintaining the ‘subsidiary status of the social sciences’ (Armstrong 1987: 1213, also see Fougeyrollas and Beauregard 2001)”.[492] A related critique by Victor Finkelstein questions the assertion that the “’biopsychosocial’ model” of ICF is a “synthesis” between “medical and social models of disability”,[493] particularly as it purports “the view that disability is about problems”:

> The undistorted social model of disability, on the other hand, interprets the constraints imposed upon disabled people as a result of ‘barriers’ to functioning and the issue is the removal of barriers rather than the management of problems.[494]

Consequently, Finkelstein rejects both ICF and the claim that it is compatible with “the undistorted social model”.

Turning back to Imrie, and on to universalism, he notes that in ICF “universalism is based on the recognition that the population as a whole is at risk from acquiring impairment and chronic illness”.[495] He finds ICF’s “commitment to universalism

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[487] Ibid., p. 287.

[488] Ibid., p. 289.

[489] Ibid.

[490] Ibid., p. 297.

[491] Ibid., p. 296.

[492] Ibid., p. 297.

[493] Finkelstein, Victor, The Biodynamics of Disablement? [hereinafter Finkelstein, 1999], Proceedings of the Workshop on Research Informed Rehabilitation Planning in Southern Africa, Harare (29 June-3 July 1998), Department of Public Health, Leids Hogeschool, Leiden, The Netherlands, 1999, p. 4.

[494] Ibid., p. 3. Emphasis in original. This position is however not shared by Rachel Hurst, who sees ICF as equivalent to “the analysis by disabled people of the social model of disability”: “There is still a determination[on behalf of WHO] not to support the analysis by disabled people of the social model of disability- although the ICIDH2 interactive model seems to me to be a rose by another name.”. Hurst, 2000, p. 1085.

[495] Imrie, 2004, p. 299.

[…] laudable and worthwhile" but the discussion and justification of it lacking.[496] Imrie notes especially the failure to address exactly how universalism will cater to diverse needs while downplaying the notion of the particular, as well as the danger of creating a potentially misconceived juxtaposition between the universal and the particular. Here he quotes Simon Thompson and Paul Hoggett:

> [A]ny universalism that makes serious attempts to be sensitive to the differences between particular cases, and particularism with the moral force to adjudicate between differences, are in fact the same theories looked at from opposite points of view.[497]

Continuing on the topic of universalism, Michael Ravenek et al. suggest that ICF use the umbrella term of 'health', rather than Health condition as the entry point of ICF to better connote its universal application.[498] David Pfeiffer questions the operationalisation of universalism by noting that even though ICF *can* categorise everyone, it probably will not be applied that way:

> The ICIDH-2 is a collection of descriptions of impairments, disabilities and participation activities which seem to cover every part of human life. The result is that everyone in the world can be categorized. Probably, it would not happen unless a person had an International Classification of Disease diagnosis connected with an impairment code from the ICIDH-2.[499]

Like Pfeiffer, Harlan Hahn agrees with the premises of universalism but questions its strategic value for policy:

> The notion of universalization, which has been actively promoted by Bickenbach and his cohort at WHO (Bickenbach *et al.* 1999), is founded on the fundamentally accurate premise that nearly everybody now has or will experience some form of disability during their lifetimes. In the short term, this definition could increase the percentage of disabled persons in society. But this sort of expansion could also dilute the message of the disability movement. The orientation might reinforce support for the principle of universal design by augmenting the size of the disabled community, but it may also result in additional neglect of the interests and needs of citizens with major disabilities.[500]

This quote by Harlan Hahn concludes this section on the main strands of the critique launched at ICF. Hahn is the author of the approach to disability explored in the following chapter, the Minority Group Model of Disability. As the name indicates, its viewpoint on disability is the opposite of universalism.

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[496] Ibid.

[497] Thompson, Simon and Hoggett, Paul, Universalism, Selectivism and Particularism: Towards a Postmodern Social Policy, Critical Social Policy, Vol. 16, p. 35, quoted in Imrie, 2004, p. 301.

[498] Ravenek et al., 2013, pp. 1018-1019.

[499] Pfeiffer, 1998, p. 519.

[500] Hahn, Harlan, Adjudication or Empowerment: Contrasting Experiences with a Social Model of Disability [hereinafter Hahn, 2001], in Barton, Len, (Ed.), Disability, Politics and the Struggle for Change, David Fulton Publishers Ltd, London, 2001, p. 72.

5. The Minority Group Model of Disability

The epithet ‘minority’ is routinely used about any approach to disability which emphasises the difference between its envisaged constituency and others, and the commonality within that constituency.[501] It is also used in a narrower sense, to depict approaches to disability linked to the United States (US) legal and political tradition of civil rights legislation and movements. In the following I will focus on one such approach to disability which has claimed the name “‘the minority group model’”, articulated by Harlan Hahn.[502] This choice is prompted both by the fact that it is often by reference to his account that subsequent scholarly work positions itself in relation to such “minority” approaches and that his account is well developed in numerous publications.[503] I will refer to Hahn’s approach to disability as the Minority Group Model of Disability.

In naming his approach to disability “‘the minority group model’”, Hahn was looking to create and strengthen access for disability issues and thus persons with disabilities to the main US framework for conceptualising and combating comparative injustice, namely the civil rights tradition. Especially in his earlier writings, Hahn employs his approach to disability mainly as a tool to illustrate and influence the development and interpretation by the courts of US law, particularly civil rights and anti-discrimination law. He stresses the importance of examining the theoretical background informing the interpretation of anti-discrimination law, since it leaves the judiciary much room to manoeuvre:

> One indication of the importance of examining the association between legal doctrines and social research is revealed by the broad discretion conferred on the judiciary by many legislative efforts to ban discrimination. […] Since most legal provisions prohibiting discrimination on the basis of race or ethnicity, gender, age, or disability also have not included explicit definitions of these characteristics, the courts have been free to

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[501] See further below under 10.2.

[502] For use of this label by Hahn, see e.g. Hahn, 2001, p. 74.

[503] Among Harlan Hahn’s numerous publications I have selected texts which most directly address the Minority Group Model of Disability.

> choose among various social theories that attach different meaning to the phenomena afforded legal protection.[504]

In later writings, much due to disappointment with the way the judiciary had used such discretion in relation to disability, Hahn increasingly emphasises the role of the Minority Group Model of Disability in the achievement of the interrelated goals of political mobilisation of persons with disabilities and the development of "personal and political identity":

> Admittedly, 'the minority group model' was originally conceived both because it comprised the most accurate framework for the study of disability and because it might help the courts comprehend arguments about disability discrimination. But the fact that judges decided instead to embrace the traditional notion of disability as a 'functional limitation' does not comprise an excuse to abandon the paradigm. The model can be employed to promote political mobilisation that might eventually contribute to the growth of a disability constituency that could supplement the quest for civil rights with the exercise of significant political influence in the democratic process. Like many other movements that furnished the major impetus for social change in the second half of the 20th century, women and men with disabilities can transform physical characteristics that were once devalued into a positive source of personal and political identity (Hahn 1997a).[505]

Consequently, the Minority Group Model of Disability is a political tool and a tool to develop "a positive source of personal and political identity" based on one's level or mode of functioning of the body and mind as well as on the responses to it encountered. In addition, Hahn stresses the general value of the Minority Group Model of Disability as a way of understanding disability, as evidenced by the reference just above to this model as "the most accurate framework for the study of disability".

5.1. The Universe of the Minority Group Model of Disability

Hahn refers interchangeably to a "'minority group model'"[506], "the 'minority group' perspective"[507] and "a 'minority group' paradigm of disability".[508] Unlike the previous

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[504] Hahn, Harlan, Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective [hereinafter Hahn, 1996], Behavioral Sciences and the Law, Vol. 14, 1996, pp. 43-44. See also Ibid., p. 43: "[T]he extension of civil rights to oppressed minorities usually has been marked by a tendency to adopt relatively abstract phrases, which arouse little disagreement, rather than precise legal standards.".

[505] Hahn, 2001, p. 74.

[506] Ibid., p. 74.

[507] Ibid., p. 60.

[508] Ibid., p. 62.

approaches analysed in this book, Hahn does not use different concepts to delimit dimensions of the universe of the Minority Group Model of Disability or to illustrate the relationship (or lack of relationship) between these. He sometimes uses "impairment" to signify levels and modes of functioning of the body and mind as opposed to composite life opportunities which he terms "disability", but he also uses "disability" to mean both these things.[509]

Hahn forwards his Minority Group Model of Disability as a reaction to, and the coming successor of, an erroneous "*functional limitations* paradigm, which focuses on the effects of personal restrictions resulting from bodily impairments".[510] This erroneous paradigm is connected to the "medical approach to disability" which "identif[ies] the functional incapacities resulting from organic impairments as the fundamental source of a disabling condition"[511] and with "economic definitions" which "are based on the view that chronic impairments frequently prevent persons from fulfilling qualifications for employment"[512]:

> Both the economic and medical definitions seem to form the cornerstones of the functional limitations paradigm for research on disability. Both of these approaches concentrate on the behavioral or vocational restrictions that stem from bodily impairments as the primary issue to be studied and as the principal problem to be solved. Both also tend to adopt a clinical orientation, which centres on efforts to increase the physical or occupational skills of a specific individual; and little attention is devoted to the task of altering the external environment through collective action.[513]

In opposition to this "functional limitations paradigm", Hahn describes the Minority Group Model of Disability as "founded" on "the socio-political definition" of disability.[514] This definition, which is asserted as a "major source of support" for the Minority Group Model of Disability[515] is described as "defin[ing] disability as the product of interactions between individuals and the surrounding environment"[516] and as "indicat[ing] that stigmatizing attitudes are the primary source of discrimination against disabled individuals"[517].

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[509] See e.g. Hahn, Harlan D. and Belt, Todd, L., Disability Identity and Attitudes toward Cure in a Sample of Disabled Activists [hereinafter Hahn and Belt, 2004], Journal of Health and Social Behavior, Vol. 45, 2004, p. 453. Due to this sliding use of terminology, I will not capitalise "impairment" and "disability" as technical terms of the Minority Group Model of Disability.

[510] Hahn, 1996, p. 41. Emphasis in original.

[511] Ibid., p. 44.

[512] Ibid., p. 45.

[513] Ibid.

[514] Ibid., p. 53. Hahn refers interchangeably to a socio-political "definition", "model" and "perspective". See e.g. Hahn, Harlan, Towards a Politics of Disability: Definitions, Disciplines, and Policies [hereinafter Hahn, 1985], The Social Science Journal, Vol. 22, No. 4, 1985, p. 93.

[515] Hahn, 1996, p. 46.

[516] Hahn, Harlan, Academic Debates and Political Advocacy: The US Disability Movement [hereinafter Hahn, 2002], in Barnes, Colin (Ed.), Disability Studies Today, Polity Press, Cambridge, 2002, p. 168.

[517] Hahn, 1996, p. 41.

5.2. What problems does the Minority Group Model of Disability recognise?

The problems which the Minority Group Model of Disability elaborates and discusses constitute restrictions of composite life opportunities, expressed as "common social, economic and political activities" such as employment and education.[518] Other such restrictions mentioned are those of economic subsistence, housing, transportation, voting and political engagement, general public facilities and participating in the community and being with family, friends and neighbours.[519] By focusing widely on the physical and attitudinal environment, the Minority Group Model of Disability potentially extends to restrictions of all imaginable composite life opportunities.

In the Minority Group Model of Disability, the problems confronting persons with disabilities are, in addition to "disability", categorically termed "discrimination" or lacking "equal rights". According to Hahn, "the primary problems confronting citizens with disabilities are bias, prejudice, segregation and discrimination which can be eradicated through policies designed to guarantee them equal rights".[520] Hahn refers to the idea of equality as "[p]erhaps the most pivotal controversy in the debate concerning disability rights".[521] Exploring equality in relation to education, Hahn designates "equality of result" which at a minimum focuses on the needs of each student related to "participation in a democratic society" and persists until these are met, as "[p]erhaps the most appropriate" standard of equality to aspire.[522] He continues that "an even more desirable proposal" is the idea of "equal shares", ensuring everyone "an acceptable measure of […] material success".[523] He notes, however, that both these standards are likely to be met with political resistance.[524] Hahn emphasises consciousness of "the usual environment that bestows advantages on non-disabled individuals and corresponding disadvantages on disabled people" as central to an adequate conceptualisation of equality.[525] He forwards a related conceptualisation of equality in the context of employment: "Equal Environmental Adaptation". [526] This entails that persons with disabilities should at least be entitled to the same amount of resources that are spent on others:

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[518] Hahn, 1985, p. 94.

[519] See e.g. Hahn, 2002, pp. 171-177, Hahn, 1985, p. 93, and Hahn, Harlan, Civil Rights FOR Disabled Americans: the Foundation of a Political Agenda [hereinafter Hahn, 1987], paper for Independent Living Institute, 1987, p. 11 (source not paginated).

[520] Hahn, 1987, p. 2 (source not paginated).

[521] Hahn, 2001, p. 66. Here, he quotes his earlier work, Hahn, Harlan, New Trends in Disability Studies: Implications for Educational Policy [hereinafter Hahn, 1997], in Gartner, Alan and Kerzner Lipsky, Dorothy, Inclusion and School Reform: Transforming America's Classrooms, Paul H. Brookes Publishing Co., Baltimore, 1997, p. 326.

[522] Hahn, 2001, p. 66, quoting Hahn, 1997, p. 326.

[523] Hahn, 2001, p. 66, quoting Hahn, 1997, p. 326.

[524] Hahn, 2001, p. 66, quoting Hahn, 1997, pp. 326-327.

[525] Hahn, 2001, p. 68.

[526] Ibid., p. 67. See also Hahn, 1996, p. 47.

> After many years, I finally gained the realisation that the non-disabled usually are not considerate enough to bring their own chairs. If fact, the built environment has been designed exclusively for their use. A true standard of equality, therefore, would grant disabled people the same benefits that have always been enjoyed by the non-disabled majority.[527]

In relation to the latter conceptualisation of equality, Hahn notes that it has implications for how such benefits are regarded. He states that "[t]hese actions should be taken as a tangible manifestation of a fundamental belief in human equality rather than as a special concession indicating paternalistic sympathy for the plight of the less fortunate".[528]

In relation to levels and modes of functioning of the body and mind, much of Hahn's work emphasise positive experiences connected to impairment among the constituency of the Minority Group Model of Disability. He explicitly questions the assumption that impairments are 'problems' in and of themselves, or neutral for that matter:

> In fact, many disabled citizens now regard living with their disability as a valuable experience that can yield a positive source of personal and political identity instead of viewing their disability as a negative defect or deficiency that results in a loss or decline of bodily functions.[529]

Based on his research on the position of activists in the U.S. Disability Movement, as well as on his own experience, Hahn consequently warns against an erroneous assumption that the elimination of impairment is a priority, or even a desire, for all or most persons with disabilities.[530] Hahn explicitly links the rejection of "cure" with the emergence of the Minority Group Model of Disability, which in turn is linked to "disability pride":

> Only in the final decades of the twentieth century did Americans with disabilities begin to define themselves as a minority group and to ascribe their problems primarily to attitudinal prejudice and discrimination (Scotch, 1989). Thus, they seem to be divided by a sense of "disability pride" and by the priority attached to the search for a cure for disabilities.[531]

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[527] Hahn, 2001, p. 67.

[528] Hahn, 1996, p. 47.

[529] Hahn and Belt, 2004, p. 453. Note that Hahn is here is using "disability" as meaning "bodily functions", rather than a restricted composite life opportunity.

[530] Hahn, Harlan, Attitudes towards Disabilities: A Research Note on Activists with Disabilities [hereinafter Hahn, 2001a], Journal of Disability Policy Studies, Vol. 12, 2001, p. 45. To the statement "Even if I could take a magic pill, I would not want my disability to be cured." 47% of the activists responding answered affirmatively. Ibid., p. 44. See also Hahn and Belt, 2004 and Hahn, 2002, pp. 178-179.

[531] Hahn, 2001a, p. 41. "Qualitative studies and anecdotal evidence is consistent with such a division [between "pride" and "cure"], suggesting that people with disabilities vary in their attitudes towards

Thus, seeing levels and modes of functioning of the body and mind as a source of pride is portrayed as a consequence of, or at least as connected with, the Minority Group Model of Disability. Still, as noted by Hahn above, some "search for a cure" and he consequently notes that he does not "speak for all disabled people":

> I do not, of course, claim to speak for all disabled people; but I do regard disability as an experience rather than as a disease or a defect. […] I also consider disability, despite the everyday problems that stem from living in a disabling environment, a positive experience and a source of creative insights that may not be as readily available to non-disabled brethren. Furthermore, it is my hope that the candid admission of these facts could eventually aid in the discovery of what many of us call a 'disability culture'. [532]

Hahn emphasises in particular the positive value derivative from participating in the struggle for human rights, which may serve to provide an answer to existential questions:

> In the immediate aftermath of a disability, an individual is compelled to answer two of the most difficult metaphysical questions that can be posed to any human being: why? And why me? In the past, they have been given little assistance in their efforts to grapple with such imponderables. Increasingly, however, disabled Americans are beginning to recognize that they have a unique chance to become involved in an historical struggle to extend and expand the definition of human rights. And there are perhaps few other activities that can provide greater meaning and purpose in life.[533]

To conclude, the problems in focus for the Minority Group Model of Disability are restricted composite life opportunities. Opportunities receiving particular attention are employment and education, as well acquiring "a positive [...] personal and political identity"[534]. Impairments are not presented as problems of relevance to the Minority Group Model of Disability; indeed this approach forwards the celebration of impairment. It is recognised that this position does not resonate with everyone. However, the opposite position is if not contrary to then at least not relevant to the agenda of the Minority Group Model of Disability.

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their impairments, ranging from "bitterness" about their physical condition to "embracing the disability" as a quintessential element of their identity (Weinberg, 1988, pp. 149-153)." Ibid.

[532] Hahn, 2001, p. 60. See also Hahn, 1987, p. 14 (source not paginated).

[533] Hahn, Harlan, Can Disability Be Beautiful? [hereinafter Hahn, 1988], Social Policy, Vol. 18, 1988, p. 31. See also Hahn, 2002, p. 173: "Eventually, a significant proportion of disabled people appeared to begin to consider the struggle to improve their status in society as a more significant aspiration than their own personal rehabilitation.".

[534] Hahn, 2001, p. 74.

5.3. What causes does the Minority Group Model of Disability recognise as relevant to the problems it identifies?

The Minority Group Model of Disability focuses composite life opportunities and in line with the "socio-political approach" it understands "disability as the product of the interactions between humans and their environments".[535] Harlan Hahn locates the *causes* of disability (used here in a general sense to connote 'problems' facing persons with disabilities), "primarily" in the environment, stating that "[d]isability is neither a disease, [n]or does it result exclusively from bodily impairment; in fact, disability is produced primarily by the effects of a disabling environment."[536]

Hahn couples the Minority Group Model of Disability with the position that restrictions emanate from the environment rather than from the individual. However, he sees the exact weighing of these causes as an answer to be arrived at through research:

> While supporters of the "minority group" paradigm generally ascribe greater significance to environmental than to individual traits and the followers of the "functional limitations model" display opposite proclivities, the precise value that would be assigned to each of these considerations probably reflects some as yet unspecified point between the two poles which can only be identified through further research.[537]

The Minority Group Model of Disability accords a pivotal role to the *attitudinal* environment as a cause of restricted composite life opportunities, both in the direct interaction between persons with disabilities and others as well as by shaping the physical environment through public policy. Hahn stipulates "three major postulates" of the Minority Group Model of Disability in relation to causality:

> [T]he minority group paradigm for research on disability is founded […] on three major postulates: (a) that the primary source of the major problems confronted by persons with disabilities can be traced to unfavourable attitudes; (b) that all aspects of the environment are fundamentally shaped by public policy; and (c) that policies tend to reflect pervasive social attitudes and values.[538]

While the first postulate points out unfavourable attitudes to persons with disabilities as the key source of problems, the second and third postulates link these attitudes to the environment by way of public policy. The environment is shaped by policy which is shaped by unfavourable attitudes; thus the environment is a 'secondary' effect of such attitudes. Hahn asserts that "[a]ttitudes restrict opportunities even

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[535] Hahn, 1996, p. 45. In line with the focus on composite life opportunities, the operative *causes* of levels and modes of functioning of the body and mind are not focused on in Hahn's work.

[536] Hahn, 2002, p. 180.

[537] Hahn, 1987, p. 6 (source not paginated).

[538] Hahn, 1996, p. 53.

more blatantly than physical barriers".[539] One of Hahn's main points is the severity and prevalence of negative attitudes to persons with disabilities, that "[a]nimus toward disabled people seems to be an endemic and deep-seated characteristic of most cultures of the world".[540] As a consequence, "[f]eatures of the social environment that impose inequality on disabled citizens cannot be viewed merely as accidental or coincidental".[541] In light of the damage done by such negative attitudes and in order to link these to disadvantaging aspects of the environment, Hahn calls for further research along the lines of his own exploration of attitudes to persons with disabilities as the effects of "existential" and "aesthetic" anxiety:

> Relatively little research has been conducted on the effects of 'aesthetic anxiety', or the tendency to avoid persons with physical appearances that are perceived as unattractive or unpleasant, and 'existential anxiety', or the fear of the eventuality of an immobilising debility; but both factors may be the roots of discrimination against disabled people (Hahn 1988c).[542]

A principal aim of such research into the causes of disability is to uncover similarities with the social reception of other aspects of human diversity, of "groups bearing the visible sign of other physical differences such as race or ethnicity, gender or age".[543] Through such analogies, the causality of disability (understood as restricted composite life opportunities, rather than as "bodily attributes" as it is used below) will be accepted as a form of discrimination, i.e. as disadvantage imposed from the outside:

> Accordingly [referring here to the socio-political perspective] disabilities are regarded as no different from other bodily attributes such as skin color, gender, or ageing which have been used as a means of differentiation and discrimination throughout history.[544]

In addition to negative attitudes, in later writings, Hahn draws attention to capitalism as "a root cause of oppression of disabled people":

> The principal factor which interferes with the capacity of disabled workers to reap the rewards of their labour cannot be ascribed to organic impairments; instead, it can be traced to a capitalist economic system that divorces everyone from goods that are a nat-

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[539] Hahn, 1987, p. 6 (source not paginated). See also Hahn, 2002, p. 171: "[T]here are strong reasons to believe that adverse reactions by non-disabled persons comprise the basic source of the problems of disabled people.". Compare also Hahn, Harlan, The Political Implications of Disability Definitions and Data [hereinafter Hahn, 1999] in Marinelli, Robert P. and Dell Orto, Arthur E. (Eds.), The Psychological and Social Impact of Disability (4th Ed.), Springer Publishing Company, New York, 1999, p. 7: "Whereas the effects of a disabling environment are the penultimate origins of the restrictions encountered by persons with disabilities, an even more fundamental source of their difficulties can be located; it is the social attitudes of the nondisabled majority that may finally be responsible for virtually all types of environmental restraints.".

[540] Hahn, 2002, p. 183.

[541] Hahn, 1985, p. 95.

[542] Hahn, 2001, p. 70. See also Hahn, 1985, p. 103 and Hahn, 1999, pp. 8-9.

[543] Hahn, 1996, p. 54.

[544] Hahn, 1985, pp. 93-94.

> ural extension of their bodies. Hence, elimination of the exploitation of labour under capitalism could provide significant remedies for the oppression of disabled workers.[545]

Such references are not related to his earlier explorations of attitudes as the ultimate genesis of disadvantage and so the additional recognition of material factors as central in this regard is here read as a complementary approach.

To summarise, while the Minority Group Model of Disability does not explicitly define disability (used in the sense of restricted composite life opportunities) as problems *solely* caused by the environment of the individual, it asserts the environment as its primary cause. In addition, the environment is the locus for all causes expressly problematised by Hahn. While recognising the importance of material factors, the principal aspect of the environment in focus is negative attitudes, both in and of themselves and as causes of a generally unaccommodating environment.

5.4. What solutions does the Minority Group Model of Disability recognise as relevant to the problems it identifies?

Mirroring the problems focused on by the Minority Group Model of Disability (composite life opportunities) and the causes thereof (the attitudinal and material environment) its envisaged solutions target attitudinal and physical barriers to enjoyment of composite life opportunities:

> [T]he effects of disability can be attributed primarily to a disabling environment rather than to personal defects or deficiencies. Thus, the principal solutions to the problems confronting disabled citizens are centred on programs to change the environment instead of the individual; and the ultimate objective of such efforts is probably an environment adapted to the needs of everybody, which seems to be in the reach of technological feasibility, even if it might not yet be in the grasp of human imagination.[546]

The particular strategy which gave name to the Minority Group Model of Disability is the striving for political and legal recognition that person with disabilities "may qualify for designation as a minority group".[547] Such recognition is the entry point to a particular legal tradition, namely the civil rights and non-discrimination framework in the US. As a conceptual framework, civil rights acknowledge and condemn prejudice and discrimination against 'minorities'. The mere inclusion of disability here, in addition to creating access to legal rights, reinforces the qualification for entry, namely that the disadvantage of persons with disabilities is caused by discrimination, inequality and prejudice:

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[545] Hahn, 2001, p. 70. See also Ibid., p. 62 and Hahn, 2002, pp. 182-183.

[546] Hahn, 1996, pp. 45-46.

[547] Hahn, 1987, p. 11 (source not paginated).

> Like the plight of other minorities, the problems of disabled persons can be viewed as raising the fundamental issue of the extent to which a society is willing to take compensatory action for the discrimination and inequality imposed upon portions of the population that have become the objects of widespread prejudice.[548]

The recognition of persons with disabilities as “a minority group” is thus the entry point to the legal framework. Access to legal rights in turn serves to reinforce such recognition through strengthening the analogy with e.g. ethnicity:

> The increased emphasis on legal rights has led to a growing recognition that physically disabled people comprise a minority group with many of the same problems as other disadvantaged ethnic or racial segments of the population.[549]

For Hahn, recognising that disadvantage is socially caused and redirecting the quest for an explanation of disadvantage *from* the individual *to* the social context is key. This is so as “[u]nlike other disadvantage groups, citizens with disabilities have not yet fully succeeded in refuting the presumption that their subordinate status in society can be ascribed to an innate biological inferiority.[550]

In early writings, Hahn emphasises the potential of *the judiciary* to improve the self-regard of persons with disabilities and in turn improve the potential for political organisation:

> A clear statement by the courts that discrimination on the basis of devalued characteristics is illegitimate, for example, could be a crucial means of removing the psychological effects of stigma that have previously prevented disabled citizens from forming a strong electoral constituency and from achieving a positive sense of personal and political identity.[551]

In later writings, Hahn expresses disappointment with the judiciary. He asserts that it persisted in interpreting legislation expressing civil rights for persons with disabilities through “a ‘functional limitations’ model”. Rather, such interpretation ought to have been in line with the redirection of questioning that the civil rights traditions demands, namely *from* the individual *to* the context of that individual:

> Moreover, by approaching issues of civil rights within the traditional context of a ‘functional limitations’ model rather than a ‘minority group’ paradigm of disability (Hahn 1982b, 1983, 1984a, 1985a, 1985b, 1985c, 1986a, 1986b, 1987a, 1987b, 1991, 1993a, 1995) non-disabled lawyers and judges abrogated their historic role of defending disadvantaged minorities and seeking to fulfil the promise of equality. […] Hence, disabled Americans appear to be confronted by a difficult choice between either (a) re-educating the judiciary and the public about the nature and meaning about disability

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[548] Hahn, 1985, p. 94.

[549] Ibid.

[550] Hahn, 1996, p. 43.

[551] Ibid., p. 55.

> or (b) pursuing alternative strategies of empowerment which are not as dependent on the legal process.[552]

According to Hahn, in deciding who merits the protection against discrimination, the judiciary focused on the level and mode of functioning of the individual rather than acknowledged his or her potential as a target for wrongful behaviour. As a consequence, the judiciary seriously limited the scope of such protection. Hahn points to the failure of the judiciary to acknowledge the "'existential'" and "'aesthetic'" anxiety felt towards disabled people by non-disabled people.[553] This has led to a reluctance of the judiciary to find wrongful conduct towards disabled people, by invoking "sympathetic feelings toward disabled people in an attempt to discredit arguments for civil rights".[554] According to Hahn, recognising the pervasiveness of "a deep-seated aversion to this minority group"[555], often hidden behind "paternalistic expressions of sympathy"[556] is key to realising that the problems inflicted on persons with disabilities are not the effects of "benign neglect".[557]

> What many judges and lawmakers have failed to realize is that superficial indications of sympathy, and even pity, for the plight of disabled persons frequently conceal a deeper sense of discomfort and resistance that has perpetuated the segregation and inequality of the segment of society.[558]

For Hahn, the judiciary accepting that "the segregation and inequality imposed by the existing environment reflects a deep or even subconscious aversion to disabled people rather than mere coincidence"[559] and that such "attitudes signifying a desire for social and physical separation from persons with disabilities"[560] is thus key to its potential in relation to disability. Lacking such acceptance by the judiciary, Hahn has reappraised his faith in law as an avenue for change, particularly for changing public opinion:

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[552] Hahn, 2001, p. 62.

[553] Ibid., p. 72.

[554] Ibid., p. 63.

[555] Hahn, 1996, p. 52.

[556] Hahn, 1987, p. 5 (source not paginated).

[557] Hahn, Harlan, Disputing the Doctrine of Benign Neglect: A Challenge to the Disparate Treatment of Americans with Disabilities [hereinafter Hahn, 2000], in Pickering Francis, Leslie and Silvers, Anita (Eds.), Americans with Disabilities, Exploring Implications of the Law for Individuals and Institutions, Routledge, New York, 2000, p. 269. This is a very summary account of Hahn's elaboration of the judicial responses to various legal instrument and provisions. For further information on the context of Hahn's position, see e.g. Ibid., pp. 269-274, Hahn, 1996 and Hahn, 2001, pp. 63-69.

[558] Hahn, 1996, p. 43. Comparing US theorising about disability with the UK, Hahn links this failure to the lack of theoretical development of the notion of oppression: "Much of the judicial opposition to disability rights can be attributed to my failure, as an American theorist, to develop a 'minority group model' of disability that adequately encompasses the notion of oppression.". Hahn, 2001, p. 59.

[559] Hahn, 1985, p. 100.

[560] Hahn, 1999, pp. 6-7.

> My earlier hope that the legal prohibition of discrimination might be helpful to the disability movement was founded primarily on my firm belief, after almost 30 years of experience with disability, that the principal problems faced by disabled people were prejudice and discrimination rather than functional impairments. I still believe that this analysis is correct. But, perhaps unfortunately, I no longer think that the bigotry and bias of dominant non-disabled segments of society can be effectively ameliorated by judicial interpretations of the law.[561]

Through this failure of the judiciary, legal rights have according to Hahn not delivered as a strategy for change. This led him to focus increasingly on complementary strategies, notably on *political representation* of persons with disabilities:

> Disabled people must not abandon the possibility of achieving progress through litigation; but they also need to explore alternative strategies to attain their objectives. Perhaps the most fruitful of these approaches is represented by the concept of empowerment. Permanent systemic changes need to be made to give disabled people increased influence in the decision-making process in communities as well as nations. In particular, attention might be devoted to the possibility of granting disabled residents as well as other disadvantaged minorities continuing representation on local councils.[562]

Hahn emphasises the mutually reinforcing strategies of "efforts to organise a permanent disability constituency capable of exerting decisive influence on crucial political decisions"[563] and the emergence of "an equivalent to the "Black is beautiful" phenomenon of the 1960s that would allow disabled persons to redefine their identity in a positive manner"[564]:

> This plan would impose a major responsibility on disabled citizens themselves to join other movements that have embraced identity politics by transforming a personal attribute which was previously viewed as stigmatising and shameful into a positive source of dignity and pride. The defining element of disability is 'difference'. This approach would seek to translate disability into a kind of difference that can be honoured and even celebrated.[565]

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[561] Hahn, 2001, p. 65. "The treatment of disabled people by lawyers and judges also seems to indicate that the disability movement might appropriately refrain from placing additional reliance on the legal system." Ibid., p. 77.

[562] Ibid., p. 78. The closest Hahn comes to defining "empowerment" (subject to the limitations of this research) is that it "is often characterized by an increase in the social, economic and political influence of disadvantaged groups in relation to privileged segments of society". Hahn, 2002, p. 186.

[563] Hahn, 2001, p. 74.

[564] Hahn, 1988, p. 27. See also Hahn, 1987, p. 14 (source not paginated).

[565] Hahn, 2001, p. 74. While political organisation thus requires a positive identity, it simultaneously strengthens it: "Perhaps one of the most important of these [strategies that disabled people can pursue to enhance their political influence] is the effort to redefine disability as a positive source of identity instead of a trait enveloped by feelings of shame or inferiority.". Hahn, 2002, p. 182. See also Hahn, 1985, p. 100: "In fact, the delineation of positive values derived from the disability experience may be essential to overcome the understandable reluctance of many disabled individuals to mobilize politically around that aspect of their identity – the disability – which is

In addition to political organisation, education is identified as a tool towards positive self-regard. Hahn calls for "both disabled and non-disabled students" to be "provided with appropriate instruction that would allow the former group to develop a sense of dignity and pride in themselves and in the minority community in which they are a part".[566] In line with this call for the celebration of particularity as a minority Hahn, based on his research on the position of activists in the US disability movement, as well as his own experience, explicitly questions the assumption that persons with disabilities see their levels and modes of functioning of the body and mind as 'a problem' which they wish to eliminate.[567]

> [T]his group of people with disabilities identifies closely with their disabilities and seems to adhere to a minority-group perspective. Many identified so closely with their disabilities at a personal level that they indicated that they would not choose to be cured even if this were "magically" possible.[568]

In addition to questioning the desirability of elimination of impairment, Hahn distinguishes "cure" from "medical rehabilitation" and questions "cure" (as differentiated from "medical rehabilitation") as a generally viable prospect:

> By definition, of course, impairments are usually permanent. The purpose of medical rehabilitation is not to eradicate a functional problem. Despite the desire of many physicians to 'fix' what they view as unacceptable bodily anomalies, often the most that can be expected from a lengthy process of rehabilitation is the arrest of a steady deterioration of physical or mental attributes. 'Cure', or even the amelioration of chronic conditions, is usually not a viable prospect.[569]

Hahn emphasises that the environment is a much more likely target for successful alteration:

> Disability may be, in part, a chronic or persistent condition; but, since environmental configurations are seldom unalterable, it can be mitigated and ameliorated especially through improvements in the architectural and communications milieu.[570]

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most negatively stigmatized by the remainder of society. [...] Politics not only provides a vehicle for the attainment of important objectives such as the eradication of discrimination, but it also seems to comprise an indispensable process for transforming individual and societal images of the self.". See also Hahn, 1987, pp. 13-14 (source not paginated).

[566] Hahn, 1987, p. 16 (source not paginated).

[567] Hahn, 2001a, p. 45. See also Hahn and Belt, 2004 and Hahn, 2002, pp. 178-179.

[568] Hahn, 2001a, p. 40.

[569] Hahn, 2002, p. 174. See also Hahn, 1985, p. 89: "Since this goal [complete recovery] is obviously impossible for many disabled persons, the domination of the treatment of disability by the medical profession can be seriously questioned.".

[570] Hahn, 2002, p. 180.

Hahn also categorically emphasises the dangers connected with ideas of 'solutions' targeting impairment and refers to prior abuse such as those during the 2nd World war[571], as well as current rationing of health care and assisted suicide.[572]

To conclude, the solutions to the problems recognised by the Minority Group Model of Disability target the environment and not the individual. The envisaged avenues towards change include a mix of interrelated and mutually reinforcing strategies, both feeding and feeding off increased attitudinal and environmental adaptation: public acknowledgement as a minority group, legal rights, development of a positive self-regard and the formation of a political collective source of power.[573] Early accounts of the Minority Group Model of Disability have a clear focus on legal measures while more recent accounts emphasise a complementary strategy of political measures.[574] A related trend, infused by disappointment in the judiciary as well as in the public, is a shifting emphasis from a former (albeit qualified) faith in professionals as agents for change and onto the centrality of the political organisation of its constituency.[575] Overall, Hahn's resulting strategy can be summarised as engendering "a positive feeling of self-esteem and a critical appraisal of society as a dual foundation for political activism".[576]

5.5. Who is the intended constituency of the Minority Group Model of Disability and by virtue of what characteristics or experiences?

The constituency of the Minority Group Model of Disability is referred to by Harlan Hahn as e.g. "disabled people"[577], "disabled citizens"[578], "disabled individuals" [579],

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[571] Hahn, 1987, p. 15 (source not paginated).

[572] Hahn, 2002, p. 163.

[573] When addressing specific composite life opportunities, Hahn suggests particular solutions such as quotas in relation to employment, compensation for costs of living in an unaccommodating society and government sponsored plan of medical care. Hahn, 1987, pp. 16-17 (source not paginated).

[574] Simultaneously with expressing his disappointment in the working of the law so far, Hahn emphasises its importance, were it to improve: "Without judicial recognition of the importance of weighing the effects of a barrier-ridden physical environment and a stigmatizing social environment in deciding whether equality between the disabled and nondisabled portions of the population has been achieved, the aptness of the minority model for the effective political conceptualization of disability may remain an unrealized opportunity.". Hahn, 2000, p. 273.

[575] Accordingly, "[p]eople with disabilities, therefore, might be appropriately advised to avoid depending on legal, medical or other professionals in the pursuit of their goals". Hahn, 2001, p. 68.

[576] Hahn, 1999, p. 9.

[577] Hahn, 2001, p. 59.

[578] Ibid., p. 61.

[579] Hahn, 2002, p. 178.

"disabled persons"[580] , "people with disabilities"[581], "citizens with disabilities"[582] and "[p]eople with chronic conditions"[583]. Hahn expressly includes people with diverse impairments in the constituency of the Minority Group Model of Disability, such as "persons with sensory, mobility, and other types of disability"[584] and "physical, mental, emotional, and learning disability"[585]. On the individual level the only categorical criterion discussed by Hahn as relevant to inclusion is the "chronic", even definite, character of conditions; that "disabilities represent chronic conditions that cannot be cured through therapeutic interventions".[586]

According to Hahn, like the minorities constituting the civil rights tradition Hahn taps into, the constituency of the Minority Group Model of Disability share "bodily attributes".[587] The 'glue' of the constituency of the Minority Group Model of Disability is however being at the receiving end of prejudice and discrimination. Based on the research of others, Hahn held already in 1988 that "a major proportion of disabled citizens" consider themselves as part of a "minority group" in the Minority Group Model of Disability sense.[588] Hahn notes three additional "means" by which "deprived and disadvantaged segments of the population" can be regarded as qualifying as a minority.[589] These three means are the willingness of others to describe such a segment as a minority, the disadvantageous position of such a segment compared to "dominant portions of the population on crucial social and economic indicators" and the subjection to "similar experiences which include ascriptions of biological inferiority, segregation, stigmatizing, stereotyping, bias, prejudice, discrimination, and overt bigotry".[590] The latter criterion illustrates the oppositional focus inherent in Hahn's approach, where emphasis is put on the centrality of straightforwardly recognising the dangerous attitudes of individuals who are part of the majority population:

> Many disabled people have privately expressed the fear that the paternalistic attitudes displayed by the non-disabled may actually conceal unacceptable feelings of hostility

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[580] Hahn, 2001, p. 59.

[581] Hahn, 1996, p. 41.

[582] Ibid., p. 43.

[583] Hahn, 2002, p. 178.

[584] Hahn, 1987, p. 9 (source not paginated).

[585] Ibid. Notwithstanding this, most of the examples of and reasoning around problems, causes and solutions address physical impairments. See e.g. Hahn, 1985, pp. 90-93. Hahn here refers repeatedly to "physical disabilities" and categorically discusses a focus on "manual labour" and "physical capabilities" as negative to persons with disabilities.

[586] Hahn, 1999, p. 4.

[587] Hahn, 1985, p. 93.

[588] "According to a recent Harris survey, a major proportion of disabled citizens consider themselves to be members of a minority group; and many are beginning to recognise that their principal problems stem from discriminatory attitudes and behavior rather than from their own functional limitations." Hahn, Harlan, Review of Disabled Policy: America's Programs for the Handicapped by Berkowitz, Edward D., The American Political Science Review, Vol. 82, No. 3, 1988, p. 985.

[589] Hahn, 1987, p. 11 (source not paginated).

[590] Ibid.

> and repugnance that, if they were ever to be exposed, might be related to a repressed desire even to kill disabled people.[591]

Despite the oppositional character of the categories "disabled" and "non-disabled", Hahn explicitly recognises the potential fluidity of this relationship by giving recognition to the "notion of universalization".[592] However, while recognising the universal relevance of disability, this idea is dismissed on strategic grounds for fear that such an inclusive approach would divert attention from the concerns and messages of "citizens with major disabilities".[593]

5.6. The Minority Group Model of Disability as a basis for entitlements

The previous five sections have addressed key features of how the Minority Group Model of Disability constructs disability. In this section, a summary is provided of these features and their implications for what claims to entitlements the Minority Group Model of Disability can be used as a basis for.

The problems recognised by the Minority Group Model of Disability are restricted composite life opportunities. The majority of attention in the texts reviewed in this book is devoted to employment, education and enjoying a positive self-regard. However, the Minority Group Model of Disability categorically asserts a broad coverage summarised by Harlan Hahn as "common social, economic, and political activities"[594], covering "community participation"[595] as well as "social interaction with family, friends and neighbours"[596]. In addition to the concept of disability, Hahn emphasises the importance of the concepts of discrimination and inequality for problematising the situation of persons with disabilities. Impairments are not presented as problems of relevance to the Minority Group Model of Disability, instead the latter embraces and encourages the celebration of impairment. While it is recognised that this position does not resonate with the entire constituency intended by the Minority Group Model of Disability, the opposite position emerges as contrary to its agenda.

The *causes* of restrictions of composite life opportunities identified by the Minority Group Model of Disability reside "primarily" in the environment.[597] While also recognising other aspects of the environment such as economic systems and physical

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[591] Hahn, 2002, p. 180.
[592] Hahn, 2001, p. 72. For a quote of this entire passage, see above under 4.7.
[593] Ibid.
[594] Hahn, 1985, p. 94.
[595] Hahn, 2002, p. 177.
[596] Ibid.
[597] Ibid., p. 180

barriers, the principal aspect of this environment is negative attitudes, both in and of themselves and through causing policy resulting in a generally unaccommodating environment. Hahn emphasises the importance of exploring the severity and extent of the underlying mechanism of such attitudes for understanding and eliminating the problems inflicted on persons with disabilities.

In line with the causal connections drawn by the Minority Group Model of Disability, the *solutions* it envisages target the environment, and not the individual. In the words of Hahn, the goal is "to change a disabling environment rather than to 'fix' disabled individuals".[598] The envisaged mechanisms towards such change include a mix of interrelated and mutually reinforcing strategies, both feeding and feeding off increased environmental adaptation: public acknowledgement as a minority group facing discrimination, legal rights, development of a positive self-regard and the formation of a political collective source of power. Earlier accounts of the Minority Group Model of Disability have a clear focus on legal measures while more recent accounts, due to the perceived failure by the judiciary, emphasise political measures. A parallel trend, similarly infused by disappointment particularly with the legal profession, represents a move from a former (albeit qualified) faith in professionals as agents for change to a focus on the political organisation of the constituency.

According to Hahn, elimination of impairment (to the (questioned) extent that it presents itself as an option) is if not always unwelcome so seriously over-rated. While a role for medical interventions in the form of rehabilitation is recognised, this is separated from 'cure', meaning the eradication of impairment. Furthermore, Hahn cautions against the forms of abuse which historically as well as currently follow the problematisation of impairment.

The key aspect in common among the *constituency* of the Minority Group Model of Disability is being the target of discrimination and prejudice, and the individual markers are inclusively depicted.

To conclude, the claims to entitlements flowing from the Minority Group Model of Disability are claims to an altered environment. Mechanisms to this end include particularly collective organisation, political representation and legal avenues. A positive self-regard is seen as a key means towards, as well as aim of, all such action. A claim to medical interventions cannot reasonable be made with reference to the Minority Group Model of Disability, due to the general silence on the role of such interventions, the juxtaposition of such intervention and interventions targeting the environment and the warning against the abuse coupled with such interventions. While medical rehabilitation is mentioned, it is so in the context of downplaying its potential. Efforts to eliminate impairment are questioned both regarding their possibility and regarding if such efforts are generally desired among persons with disabilities. To conclude, medical intervention (except for striving for the elimination of impairment) does not emerge as contrary to the Minority Group Model of

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[598] Hahn, 2001, p. 76.

Disability. However, such interventions cannot be *demanded* with explicit reference to this ideological and political platform of disability.

5.7. Critique of the Minority Group Model of Disability

The main strand of criticism of the Minority Group Model of Disability concerns the latter's emphasis on persons with disabilities as a minority who can and should meaningfully and purposefully be conceptually divorced from the majority population. Additional criticism focuses on subsuming the problems facing persons with disabilities under the concept of discrimination and the connection made with civil rights and anti-discrimination law.

Jerome Bickenbach et al. hold that the Minority Group Model of Disability builds on a "forced analogy between racial minorities and disabled people that breaks down at many important points".[599] Because of the wide variation of implicated levels and modes of functioning of the body and mind as well as societal responses to these, there is "almost no commonality of experience, or feelings of solidarity, between people with diverse disabilities" and "no unifying culture".[600] Based on such diversity of experience and lack of common culture and solidarity, Bickenbach et al. problematise representation:

> The leaders of the disability movement tend to be highly educated, white middle-class males with late-onset physical disabilities and minimal medical needs, a group that is hardly representative of the population of people with disabilities in the world.[601]

Bickenbach et al. furthermore mean that any efforts to define the demarcations around the constituency are futile due to "the spread of disability and its discontinuous nature" and due to such efforts necessarily reverting to "the medical conception of disability" as eligibility requirements will reflect levels and modes of functioning of the body and mind:[602]

> [A]nd here the irony is the thickest, the minority group approach finds itself requiring a fixed and dichotomous sense of disability precisely in order to define the minority group of people with disabilities. One cannot engage in identity politics without establishing clear eligibility requirements for membership in the group.[603]

Bickenbach et al. note that this catch 22 of identity politics is translated into anti-discrimination law. Such law embodies in just the wrong way what has become

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[599] Bickenbach et al., 1999, p. 1181.

[600] Ibid.

[601] Ibid.

[602] Ibid., p. 1182.

[603] Ibid.

known, through the words Martha Minow, as "the dilemma of difference".[604] This dilemma entails that by emphasising difference one risks invoking and cementing popular conceptions about that difference; however silence entails that needs are not met and injustices remain invisible.[605] Bickenbach elaborates how anti-discrimination law enforces conceptions of such difference as medical:

> [A] potential complainant must also claim membership in the disability minority group and, to prove membership, is forced to rely on medical or rehabilitative conceptions of disability, thereby falling back on precisely the models of disability the human rights approach rejected. There is no choice but to medicalize disability because, in an adversarial context, self-identification would be immediately dismissed as self-serving, and a functional but non-medical definition would be opened to the charge that the complainant was malingering.[606]

Additional problems with anti-discrimination law discussed by Bickenbach are political compromises based on 'virtue' concerns, entailing that categories such as alcoholism or gambling are habitually excluded from protection.[607] Generally, those who benefit from such laws are only the least disadvantaged among the constituency, namely those who can enjoy composite life opportunities 'but for' a single tangible, identifiable barrier:

> It might even be argued that the antidiscrimination approach tends to produce another class of "inferior" people – namely, those people with disabilities for whom the absence of discrimination offers no benefit and for whom the kind of equality of opportunity that antidiscrimination legislation protects affords no relief. Their impairment-related needs go unmet, and they remain unemployed, uneducated, and powerless.[608]

Moving away from the law, Bickenbach questions the adequacy of the concept of *discrimination* as a depiction of the problematic social responses to impairment. He questions the reliance on this concept because "*neutral* forces such as economic factors create real disadvantages for persons with disabilities [and] because there is no insult and no insulter":[609]

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[604] Ibid., p. 1177, referring to Minow, Martha, Making All the Difference: Inclusion, Exclusion and American Law, Cornell University Press, Ithaca, New York, 1990. See also Liggett, Helen, Stars are Not Born: An Interpretative Approach to the Politics of Disability, Disability, Handicap & Society, Vol. 3, No. 3, 1988, pp. 271-272.

[605] Bickenbach et al., 1999, p. 1177.

[606] Bickenbach, Jerome E., Disability Human Rights, Law, and Policy [hereinafter Bickenbach, 2001], in Handbook of Disability Studies, Albrecht, Gary L. et al. (Eds.), Sage Publications, London, 2001, p. 577. For an account of the difficulty of such law to sever the ties with medicine, see Donoghue, Christopher, Challenging the Authority of the Medical Definition of Disability: An Analysis of the Resistance to the Social Constructionist Paradigm, Disability & Society, Vol. 18, No. 2, 2003.

[607] Bickenbach, 2001, p. 578.

[608] Ibid.

[609] Ibid. Emphasis added.

> There is a social evil; there is injustice and inequality. But of a different sort. Around the world, people with disabilities face non-accommodating physical and organizational environments, lack of educational or training programming, impoverished or non-existent employment prospects, confused and inadequate income support programs, underfinanced research for assistive devices technologies, lack of resources to meet impairment-related needs, policy neglect and minimal political influence. These are all social ills brought about by a maldistribution of power and resources. However, they are not forms of discrimination.[610]

Central to Bickenbach et al.'s critique are the limits they attribute to the idea of discrimination, amounting to that "[t]he condition of inequality that people with disabilities face can not always fit into the mould of discrimination".[611] Instead, these conditions entail "distributive injustice".[612] Bickenbach et al. emphasise that the recognition of injustice cannot be dependent on identifying an intention driven actor, instead "[d]istributional injustice is created, not intentionally by those in power, but systematically: institutionally, structurally, as a product of impersonal economic factors. The injustice persists because of the variation in impairment-related needs and disability accommodations".[613] This is illustrated further by Bickenbach et al. referring to the problems of persons with disabilities as a limitation of "positive freedom" ("the freedom to achieve, through the provision of resources and opportunities, what it is that one wishes to do or become") rather than "discrimination" which amounts to a restriction of "negative freedom" ("the creation of an obstacle or barrier to full participation or some other benefit to which the wronged party has a prima facie claim, based on an irrelevant feature of that individual").[614] In other words, the problem here is not 'being' hindered, but rather 'not being' facilitated. Kay Schriner and Richard Scotch forward a similar point when they question if "the commonly held notion of discrimination must be so stretched to include the various barriers faced by people with disabilities that the concept loses some of its precision and thus its utility as a guide to policy":[615]

> It may be more useful, both politically and conceptually, to look beyond discrimination to characterise the nature and consequences of a constructed environment that ignores the presence of people with disabilities.[616]

Finally, the critique of the Minority Group Model of Disability gets the loudest in relation to the basis of its 'us and them' approach. Through the assertion of the universality of impairment, it is held that for the majority of humanity impairment is

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[610] Ibid.

[611] Bickenbach et al., 1999, p. 1181.

[612] Ibid.

[613] Ibid.

[614] Ibid.

[615] Scotch, Richard K. and Schriner, Kay, Disability as Human Variation: Implications for Policy, Annals of the American Academy of Political and Social Science, No. 549, 1997, p. 152.

[616] Ibid.

not a question of 'if', but rather of 'when'. This particular opposition to the minority approach is habitually ascribed to Irving Kenneth Zola. In his words, not embodying "bodily differentness [...] is only temporal: if all of us live long enough, we will inevitably age, and according to all existing data we will all possess one or more of the physical differences commonly labeled chronic illness or disability, if we do not do so already".[617] While Zola notes that seeing persons with disabilities as "an oppressed minority" and using a civil rights strategy have produced important gains[618], he none the less argues for "a corrective-a reorientation of the general thinking of disability (Milio 1981)"[619] building on the conclusions drawn just above:

> By seeing people with a disability as "different" with "special" needs, wants and rights in this currently perceived world of finite resources, they are pitted against the needs, wants and rights of the rest of the population (Stone 1984)[.] Only when we acknowledge the near universality of disability and that all its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated will it be possible fully to appreciate how general public policy can affect this issue.[620]

This 'universality' view is espoused by others such as Bickenbach et al. and is eloquently expressed here by Gareth Williams:

> However imperative it may be politically to define people with disabilities as a minority group, it is a curious minority that will include us all – if not today, then tomorrow, or the day after that.[621]

For these reasons, critics such as Jerome Bickenbach mean that the Minority Group Model of Disability is mistaken about what "disablement" is and consequently will not work as the basis for policy:

> [W]hatever its successes, the minority group analysis and the civil rights approach to advocacy misconceive the nature of disablement and will likely have to give way eventually to a more inclusive, and more stable, political analysis that can more effectively serve the political and social needs of disabled persons in the future. [622]

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[617] Zola, Irving Kenneth, Bringing Our Bodies and Ourselves Back In: Reflections on a Past, Present and Future "Medical Sociology", Journal of Health and Social Behaviour, Vol. 32, No. 1, 1991, p. 8.

[618] Zola, Irving Kenneth, Toward the Necessary Universalizing of a Disability Policy [hereinafter Zola, 1989], The Milbank Quarterly, Vol. 67, Suppl. 2, 1989, p. 420.

[619] Ibid., p. 401. Further into the article, Zola refers to this redirection in less radical terms, as "an additional complementary strategy". Ibid., p. 420.

[620] Ibid., p. 420.

[621] Williams, Gareth, Theorizing Disability, in Albrecht, Gary L., et al. (Eds.), Handbook of Disability Studies, Sage Publications, London, 2001, p. 141.

[622] Bickenbach, Jerome E., Minority Rights or Universal Participation: The Politics of Disablement, in Jones, Melinda and Basser Marks, Lee Ann, Disability, Divers-Ability and Legal Change, Martinus Nijhoff Publishers, The Hague, 1999, p. 106.

To sum up, the main strand of criticism of the Minority Group Model of Disability comes from those questioning the conceptual ‘setting apart’ of persons with disabilities inherent in this approach to disability. In addition, its use of the concept of discrimination to describe the disadvantage facing persons with disabilities is questioned, as is its reliance upon civil rights and anti-discrimination law.

This account of the critique launched at the Minority Group Model of Disability concludes Part I of this book, in which answers to the questions ‘what is disability?’ and ‘who are persons with disabilities?’ have been sought after in four approaches to disability: ICIDH, the Social Model of Disability, ICF and lastly the Minority Group Model of Disability. In relation to each approach a central focus has been which entitlements it explicitly and implicitly recognises as legitimate, and for whom. In Part II of this book the focus will be on a human rights convention addressing disability, the CRPD. In the following the entitlements and obligations the CRPD creates and how it generally understands and portrays disability and persons with disabilities will be compared to the four approaches to disability hitherto explored.

PART II

6. Introduction to Part II

6.1. From approaches to disability to a convention on human rights

In comparison with the approaches to disability explored in Part I, the CRPD has the added function of serving as an international human rights convention. All of the above approaches, as well as the CRPD, function as platforms to both depict reality and support particular demands. The CRPD is however different as it is crafted through the negotiation process of international law making. It is the product of negotiations; a patchwork quilted from various proposals from different actors and reflecting a compromise between these. In addition, it is formulated as enforceable *law*, i.e. with the intention of serving as the basis for the adjudication of competing legal claims.

However, while the specific purposes of the CRPD and the approaches to disability explored in Part I differ (as do the latter approaches among themselves), they all unite in their aim to profess what 'disability' is and who 'persons with disabilities' are. Importantly, they also unite in their aim to stipulate and aid the realisation of a particular range of entitlements for a particular range of persons subsumed under the umbrella of 'disability'. Like the approaches to disability explored in Part I, the CRPD consequently gives one, out of many possible answers to the larger question *what the problem is and whom it affects, and consequently what is to be done about it, why, how, when, for whom and by whom?* Furthermore, all the approaches explored in Part I save ICIDH explicitly call upon if not "human rights"[1] so "rights"[2].

Taken the elasticity of the concept of disability illustrated through the divergence between the approaches to disability explored in Part I, the fact that a UN human rights convention is labelled "Convention on the Rights of Persons with *Disabilities*"[3] does not say very much about how it understands disability and the people it implicates, nor, consequently, what entitlements it carries and for whom. In light of this, the following chapters present the entitlements and obligations created by the

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[1] See e.g. WHO, 2001, pp. 6, 170, Oliver, 1996, pp. 44, 82, Hahn, 1987 (source not paginated), p. 16 and Hahn, 1988, p. 31.

[2] See e.g. UPIAS, 1974, paras. 9, 25.

[3] Emphasis added.

CRPD and the concerns and positions expressed in the negotiations through which is was created. These are compared with the principled positions and strategic considerations of, as well as points of contention between, the approaches to disability explored in Part I, including the critique of the latter presented there.

Regarding the modalities of comparison, in contrast to the approaches to disability explored in Part I, the CRPD, as a human 'rights' instrument, expresses the connections it makes almost solely in the language of entitlements and obligations. The task in Part II of this book is thus somewhat different from that in the previous part. It is not primarily to draw out the implications for entitlements and obligations of statements on causality, what is a problem, whom it concerns and how it should be solved. Instead, statements expressing entitlements and obligations are used to infer, in addition to their legal consequence, the view of the CRPD on principled points, strategic concerns and key controversies identified among the approaches to disability explored in Part I. These include questions of where the causes of restricted composite life opportunities are found, if impairment is valued or regretted and what represents the commonality of the constituency.

By situating the final product (as in the CRPD) and the negotiations preceding it in the context of the points of divergence between the approaches to disability explored in Part I, the CRPD and thus the 'human rights' approach to disability is shown to be the product of choices explicitly or implicitly made in the negotiations. These choices concern not only the actual entitlements and obligations which can be distilled from the CRPD by legal means. It also concerns choices of words and expressions which send messages about what disability is and who persons with disabilities are.

The following four chapters will each apply to the CRPD one of the four questions answered in relation to the approaches to disability in Part I. Consequently, Chapter 7 explores the *life opportunities* drawn out as valuable and relevant to the constituency of the CRPD through demands for these or problems identified in relation to these, Chapter 8 explores the position of the CRPD on the *causality* of the problems it identifies, Chapter 9 explores the *solutions* called for by the CRPD and Chapter 10 explores *whom* the CRPD envisages as its constituency. This organisational principle will thus be more accommodating of disability theory than of the structure of a human rights convention. However, this choice is made to facilitate the comparison of the CRPD with the approaches to disability explored in Part I on points of principle, through creating an accessible bridge conducive to 'translating' between disability theory and the CRPD in relation to such points.

In these chapters the provisions of the CRPD will be introduced, organised according to the above. While the aim is to draw out the essence of each provision, the focus of thorough interpretation of the CRPD will be on principles points, strategic concerns and key controversies identified in Part I.[4] While some references are made

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[4] For an introduction to the CRPD see e.g. Lawson, Anna, The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?, Syracuse Journal of International

to previous UN human rights law, the focus is on comparing the CRPD with the approaches to disability explored in Part I. Following these four chapters, Part II is closed by Chapter 11 which provides a distilled comparison between the approaches to disability analysed in Part I and the CRPD, exploring which features of the CRPD resonate the most with each approach and which features of the CRPD are most alien to each approach. In addition, the understanding in the negotiations on the CRPD of the two approaches most visible there (the Social Model of Disability and ICF) is explored here.

The remainder of this chapter sets the scene for the following five chapters by providing a cursory recapitulation of the points of divergence between the four approaches in Part I (6.2.) and an introduction to the CRPD and the process by which is was negotiated (6.3.).

6.2. A distilled account of the comparison of ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

The approaches to disability analysed in Part I diverge on how they construct the ideological and political platform for which the term 'disability' is used as shorthand. They diverge on what they identify as relevant problems, what the salient causes of and solutions to such problems are, as well as whom such problems implicate. Before moving on to the CRPD, a distilled account of the comparison of these approaches is provided here.

Beginning with the question of *what is a relevant problem*, all approaches recognise the importance of composite life opportunities to their constituencies and have an open-ended approach towards which these may be. Instead they diverge on the question whether the levels and modes of functioning of the body and mind they implicate are to be regarded as valuable or problematic. ICIDH and ICF approach these as problematic while the Minority Group Model of Disability and the Social Model of Disability (in as much as it is attributed to Michael Oliver rather than to UPIAS) rather call for the celebration of these.

Moving on to the question what these approaches recognise as *relevant causes* of the problems they recognise, the disagreement concerns composite life opportunities.

Law and Commerce, Vol. 34, 2007, Kayess, Rosemary and French, Phillip, Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities [hereinafter Kayess and French, 2008], Human Rights Law Review, Vol. 8, No. 1, 2008, Quinn, Gerard, Disability and Human Rights: A New Field in the United Nations [hereinafter Quinn, 2009], in Krause, Catarina and Scheinin, Martin (Eds.), International Protection of Human Rights: A Textbook, Åbo Academy University Institute for Human Rights, Åbo, 2009, or Schulze, Marianne, Understanding the UN Convention on the Rights of Persons with Disabilities: A Handbook on the Human Rights of Persons with Disabilities (3rd Ed.), [hereinafter Schulze, 2010], Handicap International, New York, 2010.

The Social Model of Disability categorically and explicitly delimits relevant causes of restricted composite life opportunities as those residing in the environment. The Minority Group Model of Disability displays an, although less categorical, focus on the environment as the relevant cause of restricted composite life opportunities. ICIDH amounts to the opposite of these two approaches, as it categorically (albeit not entirely consistently) depicts the relevant cause of restricted composite life opportunities as the individual level or mode of functioning of the body and mind. ICF in turn explicitly recognises causes of restricted composite life opportunities as encompassing both environmental factors and levels and modes of functioning of the body and mind. None of the approaches linger on the causality of impairment.

Turning to the question of what *solutions* these approaches identify as relevant to the problems they recognise, such solutions mirror the positions of these approaches regarding causality. The Social Model of Disability categorically asserts that relevant solutions to restricted composite life opportunities are limited to those targeting the environment. The Minority Group Model of Disability displays an, although less categorical, focus on the environment as the locus for solutions to restricted composite life opportunities. ICIDH, conversely, categorically depicts the solutions to such restrictions as those targeting the individual level or mode of functioning of the body and mind. ICF in turn explicitly depicts solutions to restricted composite life opportunities as encompassing those targeting the environment *and* those targeting levels and modes of functioning of the body and mind. ICIDH and ICF also depict solutions targeting impairment as valuable irrespective of the effect of such solutions on composite life opportunities, i.e. as addressing impairments in the latter's own right.

Finally, on the question *whom* these approaches envisage as their constituencies, ICF stands out by virtue of including not only chronic but also acute levels and modes of functioning of the body and mind. The other approaches envisage their constituencies as having levels and modes of functioning of the body and mind of a certain chronicity. While the Social Model of Disability and the Minority Group Model of Disability both emphasise that the central feature of their constituencies is being the target of socially imposed disadvantage, this does not alter the answer to the question whom their constituencies encompass, just by virtue of what. A possible limitation of the Social Model of Disability is that Michael Oliver posits that it is only about those who identifies with its ideological position (which would omit what he refers to as "people with impairments" as opposed to "disabled people").[5] A similar limitation made by the Minority Group Model of Disability is inherent in the assertion that its constituency is largely identifiable through the non-existence of the possibility (as different from the desire) to eliminate impairment. However, this does not read as a criterion intended to delimit the constituency, but rather to make the point that solutions targeting the existence of impairment are not relevant from the platform of disability.

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[5] Oliver, 1996, p. 5.

By virtue of these differences, these approaches function differently as *the ideological basis for the launching of claims to entitlements* from the ideological, political and legal platform of disability. While all approaches recognise the value of composite life opportunities, ICIDH only functions as support for measures towards this end which target the individual impairment. Conversely, the Social Model of Disability and the Minority Group Model of Disability function only as support for measures towards this end which target the environment. ICF, in turn, functions as support for both these categories of measures. ICIDH and ICF, contrary to the Social Model of Disability and the Minority Group Model of Disability, recognises impairments as problematic irrespective of their role as causes of restricted composite life opportunities. Hence, the former two function as support for entitlements to measures addressing impairment in the latter's own right.

6.3. The genesis and structure of the CRPD

As mentioned in the Introduction to this book, the CRPD was adopted on 13 December 2006 after five years of negotiations and entered into force 3 May 2008. After initial deliberations, a Working Group was tasked with drafting a convention in January 2004, between the 2nd and the 3rd sessions of the Ad Hoc Committee.[6] Based on the Working Group Draft, negotiations started in earnest during the 3rd session in 2004 and after numerous readings of the Working Group Draft a redraft was made in 2005 between the 6th and the 7th session by the Chair of the Ad Hoc Committee (the Chair), attempting to consolidate proposals thus far.[7] Further negotiations followed and the CRPD was adopted during its 8th session in 2006, along with it an Optional Protocol (OP-CRPD) containing additional monitoring mechanisms.[8]

Turning to the content of the CRPD, it is the first UN human rights instrument to label its articles, a practice which greatly facilitates overview as well as navigation. The terms used to signify each article below are the official ones and will be capitalised as in the CRPD throughout the text for easy identification.

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[6] Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [hereinafter the Working Group Draft, 2004], Annex I to Report of the Working Group to the Ad Hoc Committee [hereinafter Working Group Report, 2004], 27 January 2004, UN doc: A/AC.265/2004/WG/1, p. 7.

[7] Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [hereinafter Chair's Draft, 7th Session, 2005], Annex 1 to Letter dated 7 October 2005 from the Chairman to all members of the Committee [hereinafter Letter from the Chair to the Ad Hoc Committee, dated 7 October 2005, 7th Session], 14 October 2005, UN doc: A/AC.265/2006/1. When I hereinafter refer to "the Chair" it up until the 6th session signifies Luis Gallegos (Ecuador) and after that Don MacKay (New Zealand). References to "the Coordinator" signify Don McKay, as this was his position prior to him being appointed Chair.

[8] Optional Protocol to the Convention on the Rights of Persons with Disabilities [hereinafter OP-CRPD]. Adopted 13 December 2006. Entered into force 3 May 2008. UN doc: A/RES/61/606.

After a relatively long and detailed Preamble, Article 1 contains the Purpose of the CRPD. Article 2 is titled Definitions and contains concepts that are central to many of the subsequent provisions: "Communication", "Language", "Discrimination on the basis of disability", "Reasonable accommodation" and "Universal design". Article 3 is titled General principles and seeks to distil and present the value basis of the CRPD. Article 4 is titled General obligations and stipulate obligations that are of general relevance to the implementation of the areas and aspects of life protected in the CRPD. Article 5 is titled Equality and non-discrimination and represents a parallel framework for standard setting: complementing each of the minimum standards protecting particular areas and aspects of life. Articles 6 and 7 deal with particular sub-groups among persons with disabilities and are titled Women with disabilities and Children with disabilities respectively. Article 8 titled Awareness-raising and Article 9 titled Accessibility also have general relevance: they have an instrumental character towards the fulfilment of other provisions protecting a particular area or aspects of life. Articles 10-30 cover particular aspects or areas of life, Articles 31-40 cover provisions relating to implementation and monitoring and Articles 41-50 cover issues relating to the CRPD as a legally binding instrument, such as entry into force, reservations and amendments.[9] The following is a list of the provisions of the CRPD by titles, to facilitate overview.

Preamble
Article 1 Purpose
Article 2 Definitions
Article 3 General principles
Article 4 General obligations
Article 5 Equality and non-discrimination
Article 6 Women with disabilities
Article 7 Children with disabilities
Article 8 Awareness-raising
Article 9 Accessibility
Article 10 Right to life
Article 11 Situations of risk and humanitarian emergencies
Article 12 Equal recognition before the law
Article 13 Access to justice
Article 14 Liberty and security of person
Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 16 Freedom from exploitation, violence and abuse
Article 17 Protecting the integrity of the person
Article 18 Liberty of movement and nationality
Article 19 Living independently and being included in the community
Article 20 Personal mobility
Article 21 Freedom of expression and opinion, and access to information
Article 22 Respect for privacy

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[9] This book will not deal with Articles 41-50.

Article 23 Respect for home and the family
Article 24 Education
Article 25 Health
Article 26 Habilitation and rehabilitation
Article 27 Work and employment
Article 28 Adequate standard of living and social protection
Article 29 Participation in political and public life
Article 30 Participation in cultural life, recreation, leisure and sport
Article 31 Statistics and data collection
Article 32 International cooperation
Article 33 National implementation and monitoring
Article 34 Committee on the Rights of Persons with Disabilities
Article 35 Reports by States Parties
Article 36 Consideration of reports
Article 37 Cooperation between States Parties and the Committee
Article 38 Relationship of the Committee with other bodies
Article 39 Report of the Committee
Article 40 Conference of States Parties
Article 41 Depositary
Article 42 Signature
Article 43 Consent to be bound
Article 44 Regional integration organizations
Article 45 Entry into force
Article 46 Reservations
Article 47 Amendments
Article 48 Denunciation
Article 49 Accessible format
Article 50 Authentic texts

As mentioned above, the following chapter will address the question which life opportunities the CRPD recognises as valuable against the background of the approaches to disability explored in Part I: their principled points, their strategic concerns and points of divergence between these. This account will include the critique launched at these approaches explored there, and in addition to the final text of the CRPD the analysis will address the negotiations preceding it (over and above the role these play in legal interpretation).[10]

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[10] A note on how I reference the negotiation materials is in place here. The official documents issued by the Ad Hoc Committee are referenced primarily through which session they adhere to. Written contributions by States and other actors are referenced as close as possible to the way these are introduced in the documents in which they are contained, while balancing traceability against readability. Some proposals come without further introduction, in which case I refer to the Article they pertain to. Each document is connected to the session in which it was discussed, and if the document contains a more specific date, this is provided. In the list of sources at the end of the book, each document is linked to where it is posted on the UN website. Some contributions are posted directly on the UN website, while others are contained in Word of PDF files. If the latter documents are not paginated, in order to facilitate navigations within them, I refer to page numbers while

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noting that the source is not paginated. In addition to official documents and written contributions, they daily proceedings of the sessions were recorded and summarised by NGO's present. These are referenced through date and session and are available through the UN website, to which links are provided in the list of sources at the end of the book. Finally, a potential cause of confusion is that the sequence of the articles of the CRPD changed in the 7th session and so in earlier references the issue and the article number will not correspond with the final version of the CRPD. When need arises to make clear that a reproduced text is not the final text of the CRPD, I will refer to the articles as they stood at different times during the drafting procedure as "draft" articles (e.g. Draft Article 25 on Health, as it was known during the 7th and 8th sessions and Draft Article 21 on Health and rehabilitation as it was known before that).

7. Valuable life opportunities according to the CRPD compared to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

The aim of this chapter is to present the life opportunities forwarded as valuable by the CRPD and discuss these against the backdrop of those forwarded by the approaches to disability and the critique of these explored in Part I. While some comparisons to earlier human rights law will be made, the focus remains on comparing the CRPD with the approaches to disability explored in Part I. What is recognised as valuable forms of doing or being, ‘a good life’, and threats to it?

At its most general, the CRPD, as a part of the human rights legal tradition, expresses the life opportunities it protects as “human rights and fundamental freedoms” in Article 1. As visible from the spectrum of areas of life covered in the CRPD, it was the ambition of the negotiations to stitch a quilt of protection which was comprehensive, covering the entire web of doings and beings which make up ‘a good life’. In the terminology used in this book, the list below covers composite life opportunities (such as education and work) as well as levels and modes of functioning of the body and mind (through the recognition of health and habilitation and rehabilitation):

Article 10 Right to life
Article 11 Situations of risk and humanitarian emergencies
Article 12 Equal recognition before the law
Article 14 Liberty and security of person

Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 16 Freedom from exploitation, violence and abuse
Article 17 Protecting the integrity of the person
Article 18 Liberty of movement and nationality
Article 19 Living independently and being included in the community
Article 21 Freedom of expression and opinion, and access to information
Article 22 Respect for privacy
Article 23 Respect for home and the family
Article 24 Education
Article 25 Health
Article 26 Habilitation and rehabilitation
Article 27 Work and employment
Article 28 Adequate standard of living and social protection
Article 29 Participation in political and public life
Article 30 Participation in cultural life, recreation, leisure and sport

Being part of a long line of human rights conventions, the framers of the CRPD sought their main inspiration for determining valuable forms of doing and being as well as threats to these in previous human rights law, notably the International Covenant on Civil and Political Rights (ICCPR)[11], the International Covenant on Economic Social and Cultural Rights (ICESCR)[12], the Convention on the Elimination on All Forms of Discrimination against Women (CEDAW)[13] and the Convention on the Rights of the Child (CRC).[14] As in the development of the latter two instruments, such generic inspiration was wed with attention to the particular situation envisaged as facing the potential beneficiaries of the instrument: here persons with disabilities. Consequently, the majority of titles covering 'clusters' of life opportunities in the CRPD mirror those of preceding instruments (such as politics, expression, education, health, adequate standard of living and social protection, culture and privacy) while others titles are innovations targeting the particular situation envisaged as facing the intended constituency of the CRPD (such as living independently and being included in the community and rehabilitation).

In human rights terms, the CRPD covers 'civil and political' as well as 'economic, social and cultural' rights. The CRPD arguably recognises all these life opportunities on par, i.e. it does not rank them. While it is true that Article 4 (2) explicitly attaches obligations of a more qualified standard to economic, social and cultural rights, the

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[11] International Covenant on Civil and Political Rights (ICCPR). Adopted 16 December 1966. Entered into force 23 March 1976. 1999 UNTS 171.

[12] International Covenant on Economic, Social and Cultural Rights (ICESCR). Adopted 16 December 1966. Entered into force 3 January 1976. 993 UNTS 3.

[13] Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). Adopted 18 December 1979. Entered into force 3 September 1981. 1249 UNTS 13.

[14] Convention on the Rights of the Child (CRC). Adopted 20 November 1989. Entered into force 2 September 1990. 1577 UNTS 3. Much of the language in CRPD, albeit in an adapted form, is traceable to theses instruments. Compare the relationship between CRPD Article 5 on Equality and non-discrimination and ICCPR Article 26 discussed below in note 361, Part II.

rationale for this language was not discussed in terms of any difference in *importance* compared to civil and political rights, but rather in terms of a perceptions of difference in *what it takes to realise* the life opportunities contained in these respective categories.[15] In additional support of the position that the CRPD recognises all life opportunities it covers therein on par, Preamble (c) reaffirms "the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms".

As noted above, the ambition of the drafters was to be comprehensive, to cover all aspects of life. Without knowing the exact ambit of the forms of doing and being which will be interpreted as included under the provisions of the CRPD, and noting controversial issues (such as e.g. abortion) as well as general limitations of human rights law, the CRPD holds the potential to cover the majority of life situations.[16] Regarding potential coverage of life opportunities it should also be mentioned here that Article 1 sets the Purpose of the CRPD as "the full and equal enjoyment of *all* human rights and fundamental freedoms", thus extending its potential coverage outside the areas of life explicitly covered in the articles of the CRPD.[17]

Before delving into the provisions covering life opportunities in the CRPD, a potential source of confusion requires addressing: the dual meaning attributed to the term "disability" in the CRPD. Paragraph (e) of the Preamble addresses what this "concept" entails:

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[15] In relation to the structure of the CRPD, the Chair noted in his report from the 6th session the importance of avoiding "creating the appearance of a "hierarchy" of rights". Report by the Chairman [hereinafter 6th Session Report by the Chairman, 2005], Annex II to the Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Sixth Session [hereinafter 6th Session Ad Hoc Committee Report, 2005], 17 August 2005, UN doc: A/60/266, p. 7, para. 8. He also stressed this in the negotiations during the 6th session (Daily Summaries 11 August 2005, 6th Session) as well as the 7th session (Daily Summaries 26 January 2006, 7th Session). It should also be noted here that compared to CRC and ICESCR (Articles 4 and 2 respectively), the qualification of obligations relating to economic, social and cultural rights is explicitly diminished in Article 4 (2) of the CRPD: "With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, *without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law*." Emphasis added.

[16] General limitations of human rights law include the qualification of obligations attached to economic, social and cultural rights mentioned just above and the question how far State obligations relating to private actors reach. For an analysis of these aspects and others in the CRPD see Mégret, Frédéric, The Disabilities Convention: Towards a Holistic Concept of Rights [hereinafter Mégret, 2008], The International Journal of Human Rights, Vol. 12, No. 2, 2008. For the question of abortion see below under 7.1.1. and 7.2.1.

[17] Emphasis added. Similarly, Article 5 on Equality and non-discrimination provides, trough the definition of "[d]iscrimination on the basis of disability" in Article 2 on Definitions, such protection in relation to "*all* human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field." Emphasis added.

> *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[18]

"[D]isability" is depicted as restricted composite life opportunities: hindered "full and effective participation in society". The necessary prerequisites are defined as "persons with impairments" and "attitudinal and environmental barriers", and the genesis of disability is the "interaction" between these.

A discrepancy between the way "disability" is depicted in Preamble (e) and how it is used in the remainder of the instrument needs to be noted here. The term "disability" is depicted in Preamble (e) as restricted composite life opportunities, more precisely restricted participation in society, and "impairments" is the term used to depict the individual level and mode of functioning of the body and mind. In the remaining provisions of the CRPD however, the term "impairments" is not used again. Instead, the term "disability" is used in the sense attributed "impairments" in Preamble (e), namely to connote levels and modes of functioning of the body and mind.[19]

An illustrative example is Article 21 (a) on Freedom of expression and opinion, and access to information, which calls for information in "accessible formats and technologies appropriate to different kinds of disabilities". The use of the term "disabilities", according to Preamble (e), indicates that what is sought after here are different kinds of restricted participation. However, the context indicates that it is the individual diversity which is to be accommodated in the provision of information, not 'different kinds of restricted participation'. Similarly, Article 25 (b) on Health calls for "health services needed by persons with disabilities specifically because of their disabilities". Again, the use of the term "disabilities" in Article 25 (b), according to the meaning explicitly attributed to "disability" in Preamble (e), indicates that the health services in 25 (b) are to target restricted social participation and not impairment. However, the reference to "their" disabilities connotes the individual level and the context indicates that the goal is not primarily to provide health services to address restricted participation, as opposed to impairment.[20]

Disability is also used in this sense when import is *not* to be accorded levels and modes of functioning of the body and mind, e.g. when Article 14 on Liberty and

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[18] Emphasis in original.

[19] Rosemary Kayess and Phillip French make the same observation in Kayess and French, 2008, pp. 21-22.

[20] A similar reading can be done of Article 30 (5b) on Participation in cultural life, recreation, leisure and sport, when it calls for "disability-specific sporting and recreational activities". Other examples of instances where the use of "disability", in its context, connotes levels and modes of functioning of the body and mind are Article 7 (3) on Children with disabilities calling for "disability[...]-appropriate assistance" and Article 16 (2) on Freedom from exploitation, violence and abuse calling for "protection services" that are "disability-sensitive". Also, Article 28 (2a) on Adequate standard of living and social protection speaks of "disability related-needs" and (2c) of "disability-related expenses". While it is clear that restricted participation causes needs and costs as well, it is plausibly not those that are to be accommodated here, at least not as a long-term solution, which remains remedying the root causes of such restrictions, not 'assisting' in handling them.

security of person stipulates that "the existence of a disability shall in no case justify a deprivation of liberty".[21] Again, it is arguably not deprivation of liberty as a response to *additional* forms of restricted participation that is outlawed here, but deprivation of liberty as a response to impairment. Another illustration of this dual use of the term "disability" is that this term, rather than the term "impairment", is used to point out levels and modes of functioning of the body and mind as a prohibited ground for discrimination: "discrimination on the basis of *disability*".[22]

Finally, the clearest example of this dual use of "disability" in the negotiations is the adoption of Draft Article 3 (d) in the 8th session as calling for "[r]espect for difference and acceptance of *disability* as part of human diversity and humanity".[23] Clearly, the intention was not for the CRPD to call for acceptance of restricted participation (as "disability" is depicted in Preamble (e)). The Drafting Committee pointed this out,[24] and the final version of the CRPD was changed during a reopening of the 8th session to the effect that the final text of the CRPD calls for the acceptance of "persons with disabilities", rather than of "disability".[25] This last example is the only one where the dual use of the term "disability" gave rise to a potential contradiction, and one concerning the core of the CRPD at that (as restricted social participation is to be eliminated, not accepted). To my knowledge this dual use of "disability" in the CRPD to connote both "disability" (as depicted in Preamble (e)) and "impairment" (in the sense used in Preamble (e)) was not subject to a general, principled discussion in the negotiations.[26]

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[21] Other articles use "on the basis of disability" in a similar vein. See Article 18 (1a, c-d) on Liberty of movement and nationality, Article 23 (4) on Respect for home and the family, Article 24 (2a) on Education and Article 25 (f) on Health. Article 23 (4) reads "on the basis of *a* disability". Emphasis added.

[22] See e.g. Article 5 on Equality and non-discrimination, Article 27 (1a) on Work and employment and Article 28 (2) on Adequate standard of living and social protection. Emphasis added.

[23] Draft Convention on the Rights of Persons with Disabilities [hereinafter Interim Draft, 8th Session, 2006], Draft Article 3 (d) on General Principles, Annex II to Interim Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Eighth Session [hereinafter 8th Session Ad Hoc Committee Interim Report, 2006], 1 September 2006, UN doc: A/AC.265/2006/4, p. 9. Emphasis added.

[24] "Since [what became Preamble (e)] states that disability results from interaction which hinders full participation in society, the acceptance of "disability" in this para. seems tantamount to accepting such discrimination." Ad Hoc Committee 8th Session Drafting Committee, First Revised Text [hereinafter First Revised Drafting Committee Text, 8th Session, 2006], 13 September 2006, 8th Session, p. 5, note 13. For a discussion on the potential effect of this change on the valuation of impairment in the CRPD, see below under 7.1.1.

[25] Draft Resolution, Convention on the Rights of Persons with Disabilities, Annex to Final Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [hereinafter 8th Session Ad Hoc Committee Final Report, 2006], 6 December 2006, 8th Session, UN doc. A/61/611, p. 8.

[26] On this topic it should be noted that Thailand is recorded during the 6th session as calling for changing a reference to "severe and multiple disabilities" in Draft Article 23 (1c) on Social security and an adequate standard of living of the Working Group Draft to severe and multiple "impairments". This was suggested "as impairments can be diagnosed while disability is socially constructed" (Daily Summaries 9 August 2005, 6th Session). In summing up, the Chair is recorded as noting this proposal as suggesting impairment as a "more measurable term". Ibid. The topic

In the following account, levels and modes of functioning of the body and mind (7.1.) will be discussed separately from composite life opportunities (7.2.). In 7.3. *generic* life opportunities (represented by Article 3 on General principles) will be explored.

7.1. Levels and modes of functioning of the body and mind

Two of the clusters of life opportunities covered in the CRPD qualify as that which is categorised in this book as levels and modes of functioning of the body and mind, namely Article 25 on Health and Article 26 on Habilitation and rehabilitation. They do so as they create entitlements to manage, avoid, minimise and eliminate impairment. By now it would have escaped no one that the largest gap between the approaches to disability explored in Part I remains the valuation of impairment as neutral, positive or negative and the proper role of, and thus attention due impairment from the ideological, political and legal platform of disability. Should levels and modes of functioning of the body and mind such as walking, hugging, conceiving and bearing children, gripping items with hands, hearing, being free from pain, being free from anxiety, not hearing voices, seeing, producing hormones, speaking, producing human rather than synthetic voice and so on be assumed to have an intrinsic value, or should they not, and should restrictions consequently be perceived and portrayed as prima facie problematic, or should they not? Should approaches to disability, in as much as they have an implicated constituency experiencing disproportionate restrictions in relation to these forms of doing and being, assume these to be and depict these as neutral, negative or positive? And as a consequence, should they make or support demands alternatively condemn demands towards entitlements aiming at such forms of doing or being? It is over these questions that the approaches to disability analysed in Part I, as well as disability discourse in general, split open.

7.1.1. Article 25 on Health

Article 25 starts by declaring that States "recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability". States are to take "all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation". Elaborating further such measures, Article 25 (a) creates an entitlement to "the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in

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concerned qualification for assistance from the state in situations of poverty and the proposal by Thailand was as a response to critique that "severe and multiple disabilities" was hard to define. Ibid.

the area of sexual and reproductive health and population-based public health programmes".

The reference to "sexual and reproductive health" remained controversial, due mainly to its debated relationship to abortion. In the end, this provision gained acceptance as being limited to requiring the State to extend existing services ("the same range") to persons with disabilities and consequently not requiring the State to provide additional services.[27]

The reference in 25 (a) to "population-based public health programmes" was not introduced until after the 6th session.[28] Suggestions to this end were made throughout the negotiations, such as the proposal by New Zealand to insert the obligation to "[e]nsure [that] public health programmes, and programmes concerned with the underlying determinants of health, benefit persons with disabilities on an equal basis with all others".[29] Due to the term "same", 25 (a) does not require such programmes per se, but states that in as much as these are available to others, they should be likewise to the constituency of the CRPD. This relative dimension of 25 (a) was repeatedly underscored in the negotiations, such as in the following call by DPI in the Working Group discussions for language on "the rights of PWD [persons with disabilities] to have equal access to and benefit from, public health programs such as those aimed at preventing diseases like HIV AIDs or polio, or to those related to sanitation and safe drinking water".[30] DPI is recorded as substantiating this call by noting that "[m]any such programs are not designed to include PWD; failing to target PWD in this is a form of discrimination".[31]

The relationship between the concept "population-based public health programmes" (as used in 25(a)) and "the underlying determinants of health" (as in

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[27] See e.g. record of statement by the Chair during the 6th session: "There was no intention to create any new rights; nothing of the kind had been suggested. The rules of societies will not be changed. The text merely states that applicable laws should apply to PWD [persons with disabilities] on an equal basis with others.". Daily Summaries 9 August 2005, 6th Session. For an account of the debate on the use and meaning of the term "sexual and reproductive health" in the elaboration of the CRPD see Yoshihara, Susan, Lost in Translation: The Failure of the International Reproductive Rights Norm, Ave Maria Law Review, Vol. 11, No. 2, 2013, pp. 392-399.

[28] The Chair noted in the 6th session Report by the Chairman, 2005 (p. 17, para. 86) that "there was general agreement to include the concept of population-based public health programmes". For the language as it read then in Draft Article 21, see Ibid., p. 18, para. 93. This concept was then included in Draft Article 25 (a) on Health in Chair's Draft, 2005, p. 28.

[29] Compilation of Proposed Revisions and Amendments Made by the Members of the Ad Hoc Committee to the Draft Text Presented by the Working Group as a Basis for Negotiations by Member States and Observers in the Ad Hoc Committee [hereinafter Compilation of Proposals before the 4th Session, 2004], Annex II to Report of the Third Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [hereinafter 3rd Session Ad Hoc Committee Report, 2004], 9 June 2004, 3rd Session, UN doc: A/AC.265/2004/5, p. 54. New Zealand further called for "[e]qual access to public health programmes e.g. programmes aimed at preventing HIV/AIDS, ensuring provision of safe and potable water and sanitation and cervical and breast screening for women". Ibid., p. 53.

[30] Daily Summaries 12 January 2004, Working Group Session.

[31] Ibid.

the proposal by New Zealand above) was on the table during the 7th session. For example, the UN Special Rapporteur on Health, Paul Hunt, in an oral as well as written intervention during the 7th session, questioned the adequacy of the reference to "population-based public health programmes" in 25 (a). Consequently, he "respectfully suggest[s] that further consideration is given to ensuring that article 25 is clearly understood to cover, not only health care services, but also the underlying determinants of health that constitute such a vital part of the right to the highest attainable standard of health".[32] His concern was that "population-based public health programmes" may not be conceptualised broadly enough to cover every aspect of life which has an impact on health.[33] Irrespective of the outer markers of the entitlements included under "population-based public health programmes", the upshot is that the instigation of such programmes cannot be demanded based on the CRPD but that existing measures in the area of public health that amount to "programmes" must be accessible to persons with disabilities.

Some such programmes (e.g. sanitation, water and immunisation) overlap with what is generally referred to as, among other things, 'prevention' of impairment.[34] Prevention equates measures which precede and pre-empt certain levels and modes of functioning of the body and mind, i.e. make them 'not happen'. However, the entitlements created by Article 25 (a) in relation to public health do not target the impairment by which the subject of the CRPD qualifies as such, as it only addresses access to such programs by *those already covered by the CRPD*, i.e. those who already have an impairment.

Suggestions to include a general entitlement to the prevention of impairment (which would create entitlements towards the prevention of the impairment by virtue of which one qualifies as a subject of the CRPD *or* reparation if the State had faltered in this respect) were made throughout the negotiations,[35] but remained ex-

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[32] Hunt, Paul, United Nations Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Intervention of the Special Rapporteur on Right to Health, A Note on Article 25 (Health), [hereinafter Submission by Paul Hunt, 7th Session], 7th Session, 24 January 2006, para. 21. See also intervention by WHO during the 7th session: "There are two fundamental elements of health. The first is the social determinants of health and the second is health services and health care.". Daily Summaries 25 January 2006, 7th Session. See also Intervention by Mental Disability Rights International (MDRI) on Draft Article 25 (Right to health), 7th Session, 2006.

[33] Submission by Paul Hunt, 7th Session, paras. 19-21.

[34] Compare the following exchange recorded in the 6th session: "The Chair asked for an explanation of the term 'population based health program'. New Zealand responded that this includes any program aimed at the health and fitness of the whole population, e.g. immunization, clean water.". Daily Summaries 8 August 2005, 6th Session.

[35] Diverging views are indicated in footnote 77 to Draft Article 25 on Health (then Draft Article 21) in the Working Group Draft, 2004, p. 26: "There were conflicting views among members of the Working Group on the issue of the prevention of disability. For some, the Convention has to do with the rights of *existing* persons with disabilities, and should mention only the minimization of the effects or progression of their disability, and the prevention of further, secondary disabilities. Others felt that the prevention of disability per se should be included.". Emphasis in original. Propositions and rebuttals to this effect did not disappear but continued throughout the negotiations, see e.g. Daily Summaries 25 January 2006, 7th Session.

plicitly and overwhelmingly rejected and were never part of a draft of the CRPD. Rejections of including general language on prevention in the CRPD were mostly phrased to the effect that this was "not necessary" as the CRPD was to be "a convention on the rights of PWD [persons with disabilities]".[36] Some rejections explicitly recognised the value of prevention in principle, such as the following statement by European Disability Forum (EDF) submitted prior to the Working Group, stating that "[w]hile there is no doubt that Member States should undertake actions to prevent disability, including public health campaigns, road security and other measures, the proposed Convention addresses the rights of persons with disabilities, and is not the appropriate instrument to focus on prevention concerns".[37] Others warned explicitly against the 'signals' an entitlement to prevention would send, such as in the following record of a statement made by the representative of New Zealand during the Working Group session, which reproduces her as stating that "prevention issues should not be mentioned because it could send conflicting messages, that is, that disability is something that is not wanted, and that PWD [persons with disabilities] themselves are not valued".[38] The upshot is that Article 25 (a) does *not* amount to a general entitlement concerning the prevention of impairment and thus does not extend to the creation of the impairment by which one qualifies as a "[p]erson[...] with disabilities"[39], i.e. as covered by the CRPD. Instead, 25 (a) is limited to creating an entitlement for the constituency of the CRPD to existing programmes of prevention, here meaning prevention of *additional* impairment.

Article 25 (b) concerns health services targeting the impairment by which one qualifies as a "[p]erson[...] with disabilities", i.e. as covered by the CRPD. Article 25 (b) obliges States to "[p]rovide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate". It is thus an entitlement aiming at health *services* only, and does not implicate actors within the larger context of public health. "[E]arly identification and intervention" is a term the ordinary meaning of which connotes catching levels and modes of functioning perceived as undesirable, as well as environmental factors instrumental to these early and thus limiting them to the largest extent pos-

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[36] Record of intervention by IDC during the 7th session (Daily Summaries 25 January 2006, 7th Session). Additional statements to this effect were recorded as made during e.g. the Working Group session by Canada and Germany (Daily Summaries 5 January 2004, Working Group Session).

[37] EDF, in Compilation of Proposals for Elements of a Convention [hereinafter Compilation of Proposals before the Working Group, 2004], Working Group Session, 15 January 2004, p. 96. World Blind Union (WBU) is recorded during the Working Group session as noting that "[p]revention remains a "strong objection" for the purposes of this process, while this issue is important it should be addressed by other UN Agencies with a health specific mandate". Daily Summaries 12 January 2004, Working Group Session.

[38] Record of intervention by New Zealand during the Working Group session (Daily Summaries 5 January 2004, Working Group Session). Japan is similarly recorded as noting during the 6th session that "the prevention of disability was controversial and such a provision could send the wrong signals". Daily Summaries 8 August 2005, 6th Session.

[39] Article 1 on Purpose.

sible.[40] The concept posits itself somewhere between 'cure' and 'care', the former entailing intervention which change, halt or eliminate impairment while the latter connotes 'management' of impairment. The original language from the Working Group Draft stopped short at calling for "services needed by persons with disabilities specifically because of their disabilities" and did not contain any reference to 'early identification and intervention'.[41] Calls for more explicit language were made from the beginning of the negotiations.[42] The final language, "early identification and intervention, as appropriate" was inserted after a suggestion from New Zealand during the 6th session[43] and was thus included in the draft text provided by the Chair as a basis for the negotiations of the 7th session.[44] Following this, IDC advocated during the 7th session for the removal of this language, calling for the return to a more general formulation by suggesting language requiring "health services and services which are disability specific including provision of support to persons with disabilities of all age groups".[45] By contrast, the submission by WHO during the same session contains a call for language more explicitly aiming at 'cure'. They suggested 25 (b) call for the State to "initiate programmes run by multidisciplinary teams of health personnel for early detection of disabilities and early intervention, to prevent and reduce avoidable disability in all age groups, and at the same time extend comprehensive rehabilitation services to enhance abilities".[46]

There is of course no strict demarcation between 'care' and 'cure'. However, entitlements to elimination or 'cure' imply a negative valuation of impairment, more so than entitlements to management or 'care'. If management is the outer limits of the entitlements created by the reference to "early identification and intervention", this would necessitate the establishment of a frontier as a matter of principle based on the intervention becoming too close to 'curing' impairment, as opposed to 'caring' for it, as decisive for which entitlements 25 (b) carries.[47] Consequently, including 'cure'

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[40] See e.g. Blackman, James A., Early Intervention: A Global Perspective, Infants and Young Children, Vol. 15, No. 2, 2002, p. 11: "The goal of early intervention is to prevent or minimize the physical, cognitive, emotional, and resource limitations of young children disadvantaged by biological or environmental risk factors.".

[41] Working Group Draft, 2004, Draft Article 21 on Right to health and rehabilitation, pp. 26-27.

[42] See e.g. record of statements during the Working Group session by India (Daily Summaries 12 January 2004, Working Group Session) and Lebanon (Daily Summaries 14 January 2004, Working Group Session).

[43] Daily Summaries 8 August 2005, 6th Session.

[44] The chair noted in the 6th Session Report by the Chairman, 2005, that "there was support to include the concept of early detection and treatment" (p. 18, para. 87), although this section was still kept in brackets on account of the current status of the language as still subject to discussion (p. 18, para. 93). The final language was then presented without brackets in Chair's Draft, 2005, p. 28, as part of Draft Article 25 on Health.

[45] IDC, Chairman's Text as Amended by the International Disability Caucus [hereinafter IDC Amendments to Chair's Draft, 7th Session], 7th session, 2006, p. 52 (source not paginated).

[46] WHO, Proposal for the Seventh Session of the Ad Hoc Committee on Article 25 on Health [hereinafter WHO Proposal Article 25, 7th Session], 7th Session, 2006, p. 2 (source not paginated).

[47] In addition, any entitlement to minimisation or elimination of impairment is naturally limited both by current knowledge (what is medically possible) and general limitations of obligations attached to Article 25 by virtue of this aspect constituting a "social" right, and thus being subject to the

as implicated by "early identification and intervention" makes the substantive difference that entitlements to halting progression and reverting development towards elimination of the original impairment are created and consequently both can be claimed *and* are accepted as a goal worth aspiring to.

The term "early identification and intervention" comes from the area of medicine, where a principled division between 'care' and 'cure', for fear of the former approaching the latter, appears foreign. There is no principle, or practice, to stop a medical intervention due to it coming too close to eliminating, as opposed to managing, impairment. Thus, as a matter of interpretation, and as there is no indication that the negotiating parties established a special meaning of this term in accordance with VCLT 31 (4), the ordinary meaning of this term stands, leaning toward covering both the management and the minimisation or elimination of impairment. However, as this is controversial in the lager disability discourse (including the section of it explored in Part I) further interpretation to confirm this result is merited.

Beginning thus with the purpose of the CRPD, this is expressed in Article 1 on Purpose as "the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". This provides little guidance as to the meaning of "early identification and intervention". The general reference to "human rights" does not help as the question here is what is included in one such human right, namely the right to health. The reference to dignity is similarly general. While dignity clearly requires the valuation of each *person,* the question here is if this includes the valuation of *impairment per se* (which would contraindicate an entitlement to the minimisation or elimination of impairment in Article 25 (b)), an answer to which does not flow from an interpretation of the ordinary meaning attributable to "dignity" as a purpose of the CRPD. It can also be noted here, by allowing myself to pre-empt the order of interpretative sources, that the drafting history of the reference to dignity of the CRPD is not informative in this regard. Although I am here conducting an analysis of the purpose of the CRPD, and thus cannot yet turn to the preparatory works, I can here pre-empt the conclusion that will be reached further down the line: the preparatory works of the CRPD do not indicate that "dignity" was attributed a meaning which negates efforts to minimise and eliminate, as opposes to just manage, impairment.

Having discarded Article 1 as a tool for interpretation of "early identification and intervention" in 25 (b), a contextual interpretation leads to Preamble (m), Article 3 (d) on General Principles, the remainder of Article 25 and Article 26 on Habilitation and rehabilitation. If we begin with Preamble (m) it notes that persons with disabilities make "valued […] contributions" to the "diversity of their communities".[48] These valued contributions are logically connected to impairment, either per se or

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limitations of obligations inherent in Article 4 (2) on General obligations. See above under 7.

[48] Except for the word "valued", this expression was present already in the Working Group Draft, in Draft Preamble (j). Working Group Draft, 2004, p. 8. To my knowledge, this provision was not discussed in relation to the valuation of impairment per se.

through the experiences and perspectives it engenders and as such speaks against entitlements to minimisation or elimination, as well as prevention, of impairment.

Article 3 (d) on General principles stipulates "[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity". The text as such does not answer the question if 3 (d) conveys a message not only on the level of *the person* with the impairment, but on the level of *the impairment per se*, nor what "[r]espect" and "acceptance" would entail in terms of valuation of impairment, positioning themselves as these terms do somewhere between 'celebration' and 'regret'. Again, Article 1 on Purpose does not solve the question any more in relation to 3 (d) than it did in relation to 25 (b). Furthermore, a contextual interpretation of 3 (d) does not yield a straightforward answer as 1) Preamble (m) implies a positive valuation of impairment, and 2) Article 25 (a) (calling as it does for access to public health programmes), the second section of Article 25 (b) (calling as it does for the prevention of further impairment, see below) and Article 26 on Rehabilitation and habilitation (as elaborated below) all imply a negative valuation of impairment. Although I am here conducting a contextual interpretation of Article 25, and thus cannot yet turn to the preparatory works, I can here pre-empt the conclusion that will be reached further down the line: an analysis of the preparatory works as they relate to Article 3 (d) indicates that this provision was not intended by negotiating States as, by virtue of principle, limiting the obligations based on Article 25 to management rather than minimisation or elimination of impairment.

If we return to Article 25 (b), the object of this interpretative exercise, I conclude that a positive valuation of impairment, potentially speaking against an entitlement to minimisation and elimination of impairment being inherent in the right to "early identification and intervention" in 25 (b), is inferable from Preamble (m). However, the straightforward entitlements to "minimize and prevent further disabilities" in 25 (b) (see below), to "population-based public health programmes" in 25 (a) and to "full physical [and] mental […] ability" in Article 26 on Habilitation and rehabilitation (see below) all imply a negative valuation of impairment and call for its minimisation and elimination through the context in question, namely health. Against this background, a contextual interpretation of the right to "early identification and intervention" in 25 (b) does not support it being, by virtue of principle, limited to the management as opposed the minimisation or elimination of impairment.

Turning to the preparatory works of Article 25 to sustain this conclusion, the clear decision not to include an entitlement to prevention of the initial impairment could be read as implying a positive valuation of impairment generally. However, as noted just above arguments against prevention were mainly framed as the CRPD needing to be about actual rather than prospective persons with disabilities and needing to avoid the negative connotation regarding the valuation of impairment flowing from prevention, and not in terms of prevention being wrong because impairment is unlikely to be perceived as a problem. On the whole, the discussion of the avoidance of impairment in relation to Article 25 after the inclusion of the term "early identification and intervention" centred on whether to explicitly include such an entitlement to prevention, rather than on the implications of the term "early identification and intervention" for minimisation or elimination of impairment.[49] In an earlier session, Sudan is recorded as explicitly positing "cure" as the purpose of detecting impairment, through stating that "in countries plagued by severe poverty some disabilities can be cured with early detection".[50] It remains that the term "cure" was used in dismissive terms by a number of actors in the negotiation, including States, as foreign to "the social model" (designated as the proper ideological underpinning of the CRPD).[51] However, this was in a context which leaves it open if the negativity was directed at "cure" as such, or at a focus on "cure" as an inappropriate substitute for changes to the environment.[52]

The preparatory works of Article 3 (d) are informative towards the valuation of impairment and the position on the elimination or minimisation of impairment in the CRPD. Article 3 (d) was present already in the Working Group Draft and remained unchanged throughout the negotiations, save the last minute alteration to refer to "persons with disabilities" rather than to "disability". As discussed above under 7., the text read "acceptance of disability" until the Drafting Committee pointed out that "disability" was depicted in (what became) Preamble (e) as restricted participation in society and that it would thus be misleading to call for the "acceptance" of disability.[53] Replacing "disability" with "persons with disabilities", as was subsequently done, changes the focus to the person rather than the impairment. In other words, the acceptance of *the person* should be unhampered by the impairment, but this acceptance does not necessarily need to extend to *the impairment as such*. However, this change was called for by virtue of the reasons just explained. Furthermore, keeping the text calling for acceptance of the individual level and mode of functioning of the body and mind would have necessitated replacing the word "disability" with the word 'impairment', a term systematically avoided in the negotiations.[54] Hence, as such, the change from "disability" to "persons with disabilities" is not indicative as to if this acceptance reaches past the acceptance of the person to the acceptance of the impairment as such. The negotiations preceding Article 3 (d) show that the question of valuation of impairment actualised a discussion of the choice of verb to

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[49] See e.g. Daily Summaries 25 January 2006 from the 7th session where the Chair is recorded as responding to a suggestion by Morocco and others to include obligations of prevention in Article 25 by noting that "early identification and intervention were dealt with in 25(b) and encourage[ing] informal discussion to find other language that could be generally agreed upon".

[50] Daily Summaries 8 August 2005, 6th Session.

[51] The following statement is recorded by Costa Rica during the 7th session: "The most important point was that since this process started there has been a consensus on the fact that the medical model of disability, which looks at disability as a defect or a disease that needs to be cured through medical intervention, has been completely left behind. The model that now prevails is the social model, in which the problem is defined as interaction between the setting in which the person with impairment lives and the person.". Daily Summaries 24 January 2006, 7th Session.

[52] See further below under 12.1.2.

[53] First Revised Drafting Committee Text, 8th Session, 2006, p. 5.

[54] See above under 7. and below under 12.1.1.

be used, such as “valuing”, “accepting” or “respecting”. Morocco is recorded during the Working Group discussions as calling for “avoiding subjective terms as in “valuing diversity” to which India is recorded as making the suggestion to “[r]eplace valuing with the more objective “respecting ... diversity””.[55] Venezuela is recorded as “call[ing] for the elimination of Article 2d, because it was ambiguous to say “valuing of disability” because one does not choose to be a PWD [person with disabilities]”.[56]

This discussion was linked to whether this provision should explicitly recognise a “right to be different”, a proposal which did not make it into the Working Group Draft or the final text of the CRPD.[57] The meaning of a “right to be different” generated different interpretations. Germany is recorded as stating during the Working Group discussions that “a “right to be different” was not to say that disability is beautiful, but related to a question of whether PWD [persons with disabilities] had a duty of assimilation into culture and should be thought of in the context of human dignity”.[58] In contrast, the meaning of such a right as implicating a positive valuation of impairment, as well as the importance of this, was emphasised in the negotiations in particular by Inclusion International (II). In a submission before the 3rd session of the Ad Hoc Committee, II notes that “[n]on-disabled people still need to recognise the importance of this issue [acceptance of difference] for those of us with a disability as acceptance of our disability leads to acceptance of who we are as a person”.[59] II also emphasised, in the context of prenatal screening and under the heading “Right to Life-Valuing the life of all people and their right to be different[,] the richness through diversity that a person with a disability can bring to the life of their family and community”.[60] The question of valuation of impairment inherent in 3 (d), as well as its implications for the acceptability of prevention and minimisation or elimination of impairment was addressed again in the 7th session. The Islamic Republic of Iran noted that it “supported the acceptance of disability as part of “humanity” in principle, however it was concerned that “as part of human diversity” may suggest that it is not permissible to prevent or take measures to reduce disability”.[61] Consequently, while the drafting history of Article 3 (d) is not conclusive on the valuation of impairment in general, the statements by States recorded above indicate that it was not intended to, in principle, negate entitlements to the minimisation or elimination of impairment (as part of the entitlements in the CRPD or otherwise). To conclude this account on the implications of “early identification and interven-

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[55] Daily Summaries 6 January 2004, Working Group Session.

[56] Ibid. Draft Article 2 (d) under discussion here became Article 3 (d) in the final text of the CRPD.

[57] Objections to a “right to be different” mainly referred to that such a right does not exist in human rights law and rebuttals of such objections to a “right to be different” emphasised the importance of this issue and/or stated that it was specific to the constituency of the CRPD. See Daily Summaries 5 January 2004, Working Group Session.

[58] Daily Summaries 6 January 2004, Working Group Session.

[59] Inclusion International’s Position on the Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [hereinafter II Proposal for the 3rd Session], 3rd Session, April 2004, p. 2 (source not paginated).

[60] Ibid., pp. 3-4 (source not paginated).

[61] Daily Summaries 30 January 2006, 7th Session.

tion", the upshot is that the statements made by States during the negotiations sustain the conclusions drawn by the interpretation through the means indicated by VCLT Article 31: Article 25 creates entitlements not only to 'care' or management of impairment but also to 'cure' (minimisation or elimination) of impairment.

In addition to addressing health services relating to the impairment by virtue of which one is covered by the CRPD, 25 (b) like 25 (a) addresses the creation of *additional* impairments among the constituency of the CRPD, this time more narrowly in the context of health services. It obliges States to "[p]rovide services designed to minimize and prevent further disabilities, including among children and older persons". This provision appeared already in the Working Group Draft as "programmes and services to prevent and protect against secondary disabilities, including among children and the elderly".[62] In his report from the 6th session, the Chair notes that there were "divergent views" on whether the reference could be deleted "on the grounds that its provisions were already covered adequately by preceding subparagraphs".[63] The final language ("to minimize and prevent") was introduced in the Chairs Draft as a basis for negotiations during the 7th session, an additional change being that it was phrased as "further disabilities", rather than "secondary disabilities".[64] During the 8th session, IDC proposed the deletion of the reference to "minimize and prevent further disabilities", noting that "IDC is of the opinion that this convention has the purpose to protect the rights of PWD [persons with disabilities], not deal with prevention of disability, which is a WHO issue and should be dealt with by this UN body".[65] This call was however not heeded and the upshot is that 25 (b) creates an unequivocal entitlement to health services to minimise and if possible prevent that persons who are covered by the CRPD develop additional impairments.

Article 25 (c) concerns the proximity of services and obliges States to "[p]rovide these health services as close as possible to people's own communities, including in rural areas".

Article 25 (d) concerns the quality of care, as well as measures to this end. Accordingly, States shall "[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent". Measures to be taken include "raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care". The provision on "free and informed consent", in addition to stipulating a guarantee of being properly informed about health interventions, actualises the controversial questions if health interventions may ever be performed against the express will of a person,

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[62] Working Group Draft, 2004, p. 26.

[63] 6th Session Report by the Chairman, 2005, p. 18, para. 89.

[64] In addition, "the elderly" had been replaced by "older persons". Chair's Draft, 7th Session, 2005, p. 28.

[65] IDC, Working Text as Amended by the International Disability Caucus [hereinafter IDC Amendments to CRPD Working Text, 8th Session], 8th Session, 18 August 2006, p. 43.

i.e. when the person withholds such consent. This was one of the most controversial questions in the negotiations of the CRPD and its answer requires an interpretative exercise far exceeding the scope of this book, by reading Article 25 (d) together with particularly Articles 12 on Equal recognition before the law and Article 17 on Protecting the integrity of the person. It can be noted, however, that the references to care of the "same" quality as well as the prohibition of "discrimination on the basis of disability" in the chapeau of Article 25 indicates that a reference to impairment as such is not a permissible criteria for disregarding consent. Instead, the question if the withheld consent of a person covered by the CRPD can ever be disregarded will pivot on the interpretation of whether general criteria for disregarding consent which overlap disproportionately with particular impairments equals care of the "same" quality as provided others or amount to "discrimination on the basis of disability". It should be noted here that the CRPD Committee holds categorically in its Draft General Comment on Article 12 that such overlap is discriminatory as "denials of legal capacity violate Article 12 if they are either discriminatory or disproportionately affect the right of persons with disabilities to equality before the law".[66] With reference to Article 25, the Committee categorically holds that reading it together with Article 12 means that all health professionals must obtain free and informed consent from persons with disabilities and that such consent cannot be given on behalf of person with disabilities by another person.[67]

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[66] Committee on the Rights of Persons with Disabilities Draft General Comment on Article 12 of the Convention – Equal Recognition before the law [hereinafter CRPD Draft General Comment on Article 12], Advanced Unedited Version, 10th session, 2013, para. 21. This statement does however leave loose ends to be tied up, as the prohibition of indirect discrimination (the term commonly used for disproportionate disadvantage flowing from neutrally framed criteria for treatment) is not absolute; such overlap remains subject to further consideration of, inter alia, the 'reasonableness' and 'objectivity' of measures (which in turn emanates from conclusions about some persons with disabilities being relevantly different from others or not). This 'objective and reasonable formula' is widely used among other UN human rights treaty bodies and has likewise been reiterated by the CRPD committee, albeit not yet in relation to Article 12. See Committee on the Rights of Persons with Disabilities, H.M. v. Sweden, [hereinafter H.M. v. Sweden, 2012], Communication No. 3/2011, Views adopted by the Committee at its 7th session, 16-27 April 2012, UN doc: CRPD/C/7/D/3/2011, 21 May 2012, para. 8.3. For the coverage of indirect discrimination by Article 5 on Equality and non-discrimination see below under 7.3.4.

[67] CRPD Draft General Comment on Article 12, para. 37. This position is overwhelmingly endorsed in post CRPD doctrine regarding decision-making in general. For early standard setting contributions see Dhanda, Amita, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future? [hereinafter Dhanda, 2007], Syracuse Journal of International Law and Commerce, Vol. 34, 2007 and Minkowitz, Tina, the United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions [hereinafter Minkowitz, 2007], Syracuse Journal of International Law and Commerce, Vol. 34, 2007. Some, while agreeing in principle, however urge caution, at least until it has been established how the provision of support in decision-making while never disregarding the withheld consent of an individual affects the effective realisation of human rights generally. See e.g. Bartlett, Peter, The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law [hereinafter Bartlett, 2012], The Modern Law Review, Vol. 75, No. 5, 2012, p. 759: "[T]here will be times when those conditions make a difference that cannot be equalised by merely supportive social responses. […] The CRPD does not address the question of what response is appropriate when

Article 25 (e) covers health insurance (and if applicable life insurance) and obliges States to "[p]rohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law". Such insurance "shall be provided in a fair and reasonable manner". The requirement of 'reasonableness' and non-discrimination attempts to strike a balance between the need of everyone for insurance and the centrality to the insurance system of notions of 'risk' in relation to ill-health and/or death (which may or may not overlap with a particular impairment), as a determinant deciding both provision and conditions of insurance. Irrespective of what is regarded as "fair and reasonable" and as not amounting to "discrimination" relating to general criteria which overlap with a particular impairment, it flows from the prohibition of discrimination that impairment per se is not an acceptable criterion for denying, or stipulating disadvantageous conditions for, insurance.[68]

Finally, according to 25 (f) States shall "[p]revent discriminatory denial of health care or health services or food and fluids on the basis of disability". This provision will be addressed further below under 7.2.1. in relation to Article 10 on Right to life.

7.1.2. Article 26 on Habilitation and rehabilitation

The second article in the CRPD addressing levels and modes of functioning of the body and mind is Article 26 on Habilitation and rehabilitation, covering (re)habilitation in "the area[...] of health". Article 26 (1) opens by obliging States to "take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life". To reach this goal, States "shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes". Four areas are singled out for their importance: "the areas of health, employment, education and social services". 26 (1a-b) characterise further these services and programmes. According to (a) they shall "[b]egin at the earliest possible stage, and [be] based on the multidisciplinary assessment of individual needs and strengths". According to (b) they shall "[s]upport participation and inclusion in the community and all aspects of society,

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supportive social interventions do not in practice make rights real for the person with disabilities.". See also Carney, Terry and Beaupert, Fleur, Public and Private Bricolage – Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-making, University of New South Wales Law Journal, Vol. 36, No. 1, 2013, p. 179: "It is argued that the social benefits (and unintended costs or risks) of supported decision-making to people with cognitive disabilities (such as people with dementia, acquired brain injury and developmental disability), psychosocial disability (including some severe episodes of mental illness), and the public at large, are too significant to be based solely in abstract normative analysis. Instead, supported decision-making, in all its different social and legal forms, should first be empirically tested through research and pilot programs before an optimal approach is selected.". See further below under 7.2.3. and 7.2.7.

[68] See further below under 7.3.4.

[be] voluntary, and [be] available to persons with disabilities as close as possible to their own communities, including in rural areas".

Article 26 (2) deals with training and stipulates that States "shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services".

Article 26 (3) covers assistive devices and technologies, obliging States to "promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation".

In sum, the core of Article 26 is that all (re)habilitation should be geared towards independence, social participation and inclusion and be provide as close to the person as possible. Such services are to focus not only on the requirements of the person but also on his or her strengths and they must be voluntary.

The relationship to levels and modes of functioning of the body and mind in Article 26 is constituted through the entitlement to (re)habilitation in "the area[...] of health". Such an entitlement is created both in Article 26 (1) as well as in the chapeau of Article 25. The chapeau of Article 25 obliges States to "take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, included health-related rehabilitation". Article 26, as quoted above, is more specific of what is required of such health-related rehabilitation.

Article 26 was introduced as an off-spring to Article 25 due to calls driven by the urge to explicitly emphasise aspects of (re)habilitation other than medical ones, often noting the inappropriateness of overemphasising the role of medicine in the lives of the constituency of the CRPD. To illustrate, IDC submitted a statement to the 6th session noting that "[t]o place habilitation and rehabilitation strictly within the paradigm of health risks supporting the outdated medical model of disability in which disability is seen as an illness or health problem that must be cured. This is direct violation of the dignity and rights of an individual".[69] The final decision to create a separate article on (re)habilitation was recorded by the Chair in his report after the

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[69] IDC, Information Sheet on Draft Article 21bis Habilitation and rehabilitation, 6th Session, 2005, p. 1 (source not paginated). Similar calls were made throughout the negotiations. Already the Working Group Draft had a footnote to Draft Article 21 on Right to health and rehabilitation which read: "Some members of the Working Group considered that grouping "rehabilitation" with "health" was inappropriate, and that it would be better dealt with in a separate article, because "rehabilitation" includes more than "medical rehabilitation", and should not be "medicalized"." Working Group Draft, 2004, p. 26, note 74. For further interaction in the negotiations on the separation of health and rehabilitation see in particular Daily Summaries 8 August 2005, 6th Session and 25 January 2006, 7th Session. The Chair is paraphrased as summarising the discussion during the 7th session as characterised by "a desire to draw a distinction between health and health-related rehabilitation on the one hand, and general habilitation and rehabilitation on the other hand". Daily Summaries 25 January 2006, 7th Session.

6th session.[70] Such an article first appeared in the Chair's Draft as a basis for discussion during the 7th session, and included a reference to health-related rehabilitation.[71]

The main reason for this dual attention to rehabilitation in the area of health was that only Article 25 explicitly proclaims a "right", as opposed to only recognising State obligations. Due to the resistance to frame (re)habilitation generally as a "right" in Article 26, the only way to express health-related rehabilitation as a 'right' was to keep a reference to it in Article 25, framing as it does an established 'right', namely "health".[72] Notwithstanding the desire to compartmentalise entitlements relating to health, Articles 25 and 26 both thus create entitlements to minimise or eliminate impairment, aiming at, in the words of Article 26, "full physical [and] mental [...] ability".

While Articles 25 and 26 thus create entitlements to interventions aimed at impairment, the individual's right to accept or discard such interventions is emphasised. As mentioned above, interventions provided for in Article 25 require "free and informed consent" and Article 26, in turn, provides a similar emphasis by stating that all services of (re)habilitation "are voluntary". As these are life opportunities which involve the individual as a target for change the centrality of the position of the individual towards such change is underscored. As a recognition of this, and reflecting concerns towards tendencies to force 'corrective' procedures upon the envisaged constituency of the CRPD, Draft Article 21 (k) on Right to health and rehabilitation in the Working Group Draft expressly obliged States to "[p]revent unwanted medical and related interventions and corrective surgeries from being imposed on persons with disabilities".[73] Similarly explicit provisions to this effect continued to receive support throughout the negotiations, albeit are not included in the final text of the CRPD.[74]

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[70] The Chair noted that "[t]here was general agreement in the Committee that draft article 21 should address the right to health and that a separate draft article 21 bis should address habilitation and rehabilitation. The Committee did not resolve, however, whether to retain medical, or health-related, rehabilitation in article 21, or to delete all references to it and deal with it in article 21 bis". 6th Session Report by the Chairman, 2005, p. 16, para. 77.

[71] Chair's Draft, 7th Session, 2005, p. 29.

[72] See e.g. recorded intervention to this effect by Thailand (Daily Summaries 8 August 2005, 6th Session) and by MDRI (Daily Summaries 25 January 2006, 7th Session).

[73] Working Group Draft, 2004, p. 27.

[74] The latest language to this effect was included in the working text of the CRPD after the 7th session, in Draft Article 17 (2) on Protecting the integrity of the person: "States Parties shall protect persons with disabilities from forced interventions or forced institutionalization aimed at correcting, improving or alleviating any actual or perceived impairment.". International Convention on the Rights of Persons with Disabilities, Working Text [hereinafter CRPD Working Text after 7th Session, 2006], 7th Session, 2006, Annex II to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Seventh Session [hereinafter 7th Session Ad Hoc Committee Report, 2006], 13 February 2006, UN doc: A/AC.265/2006/2, p. 15. The final version of Article 17 on Protecting the integrity of the person is limited to reading: "Every persons with disabilities has a right to respect for his or her physical or mental integrity.". See below under 7.2.7.

7.1.3. The valuation of impairment in the CRPD compared to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

To summarise the above, a contextual interpretation of the entitlements in Article 25 (b) in relation to *the impairment by which one becomes covered by the CRPD* ("early identification and intervention") includes entitlements implicating not only 'care' but reversal and 'cure' as well. The entitlement to health-related (re)habilitation in Articles 25 and 26 similarly create entitlements aiming at the elimination of impairment and/or its effects, the goal being, as expressed by Article 26, "full physical [and] mental [...] ability". Relating to *further impairment* among the constituency of the CRPD, Article 25 (b) creates explicit entitlements toward avoidance and elimination ("to minimize and prevent") and 25 (a) implicitly does so by demanding access to "public health programmes" (as such programmes (generally understood) do not exclude impairment from their broad conception of 'ill-health'). The upshot is that Articles 25 and 26 through the entitlements they create conceive of and forward impairment as something problematic meriting solving. By doing so, they attach a negative value to impairment. If the avoidance of impairment was not recognised by the framers of the CRPD as of potential value, such entitlements would logically not be included in the CRPD.

The only aspect of the above open to interpretation is the entitlements regarding *the initial impairment by which one becomes covered by the CRPD* in 25 (b) ("early identification and intervention"). If the reference to "intervention" in 25 (b) is interpreted as aiming at only a degree of change stopping short of elimination of impairment or even any reversal of it, i.e. aiming at 'care' rather than 'cure', this would mean that the provision does not imply a negative valuation of impairment as such. Instead, 25 (b) would stop at recognition that particular forms of health services are needed to 'manage' impairment (much like certain health services are needed to manage e.g. pregnancy). By way of such an interpretation, 'cure' (change to a point approaching or reaching elimination) can be denied as an acceptable goal under Article 25 in relation to the initial impairment by which one became part of the constituency of the CRPD. However, the negative valuation flowing from entitlements regarding *"further" impairments* would still remain and the two categories ('initial' and "further" impairment) only differ in relation to in *what order* they appear. One person's 'initial' impairment is another person's "further" impairment.[75] The *same* kind of impairment in relation to which 'cure' may be denied as relevant by such an interpretation (if it constitutes a person's 'initial' impairment) remains explicitly responded to with entitlements "to minimize and prevent" in 25 (b) as well as implicitly targeted by the "public health programmes" called for in 25 (a), if it constitutes a

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[75] It should be noted here that it may not always be entirely clear, and to my knowledge was not discussed, how you draw the line between the progress of an initial impairment (calling for "identification and intervention") and the emergence of a further impairment (calling for "prevention and minimization").

person's "further" impairment. Consequently, a negative valuation of impairment is still undeniably implied by the entitlements created by Articles 25 and 26.

However, on the level of the CRPD as a whole, the negative valuation of impairment implied by Articles 25 and 26 (flowing from the entitlements created there) stands in contrast to the positive valuation of impairment flowing from statements speaking directly to the question of how impairment is to be valued. As discussed above in the contextual interpretation of Article 25 (b) in relation to the initial impairment, Preamble (m) (noting that persons with disabilities make "valued […] contributions" to the "diversity of their communities") convey a message not only on the level of *the person* with the impairment, but on the level of *the impairment per se*; it calls for its positive valuation and rejects its negative valuation. On balance, the CRPD thus both forwards and discourages the perception of the avoidance of impairment as a valuable life opportunity.

Turning to the approaches to disability explored in Part I of this book, a major point of divergence between these remains the position on impairment as neutral, positive or negative. Article 25 on Health and Article 26 on Habilitation and rehabilitation actualise this gap as they create entitlements amounting to altering impairment. Exploring the consequence of this for the compatibility between the approaches to disability explored in Part I and the CRPD, and beginning with UPIAS, the analysis of the valuation of Impairments in their texts leans towards the recognition of these as problematic. Impairments are referred to by UPIAS as "problems" to be "accepted" and nowhere are any positive aspects of Impairment explicitly recognised.[76] Victor Finkelstein recognises that, even though this is foreign to him as an individual, part of the implicated constituency sees Impairment in terms of "tragedy"[77] and Michael Oliver holds that "the social model" has never denied "the pain of impairment"[78]. However, accounts by Oliver in particular, urging that "difference not be merely tolerated and accepted but that it is positively valued and celebrated", qualifies the conclusion the Social Model of Disability recognises Impairment as potentially problematic.[79] This echoes the principled statements in the CRPD entailing a positive valuation of impairment, particularly Preamble (m).

At the same time, while the above indicates an ambiguity towards measures aimed at preventing, minimising or eliminating Impairments (initial and well as further), the importance of medical intervention to manage Impairments is recognised. Oliver notes that "the social model of disability [...] acknowledges that in many cases, the suffering associated with disabled lifestyles is due primarily to the lack of medical and other services".[80] UPIAS similarly calls for "skilled medical help to treat our physical impairments – operations, drugs and nursing care [...] and therapists to

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[76] UPIAS, 1974, para. 15.
[77] Finkelstein, 2001, p. 2.
[78] Oliver, 1996a, p. 48.
[79] Oliver, 1996, p. 89.
[80] Oliver, 2004, p. 22.

help restore or maintain physical function".[81] Additionally, this reference by UPIAS to "restore physical function" recognises the value of minimisation or elimination of Impairment and/or its effects.

Irrespective of the position taken on the valuation of Impairment, the relevance of Impairment (and solutions of which it is the target) to policy from the platform of disability remains categorically refuted, by Oliver and Finkelstein as well as by UPIAS. Widespread recognition of this position has in turn been the main thrust of those who wish to reformulate the 'social model'.[82] Again, a certain inconsistency in relation to UPIAS should be noted here, as they include in their Aims and Policy Statement a call for "medical help" and "therapists to help restore or maintain physical function". On balance, it is questionable to what degree it is compatible with the Social Model of Disability to include explicit language calling for the "prevention and minimization" and "early identification and intervention" relating to impairment in Article 25 and calling for "full physical [and] mental […] ability" in Article 26. The Social Model of Disability, in general terms, advocate for less rather than more attention to issues concerning the management, and particularly the prevention, minimisation or elimination, of Impairment. In any event, the purposeful ambiguity in the expression of the Social Model of Disability analysed for the purpose of this book would implicate that the explicit language in Articles 25 and 26 referred to just above is unwelcome. This is so as the preferred strategy of the Social Model of Disability emerges as downplaying problematic aspects of the individual. The purpose of this is to steer the focus towards the environment in order to limit the influence of the medical profession in the lives of persons with disabilities, to facilitate collective organisation as well as positive self-regard and to steer clear of the atrocities which have flowed from the desire to eliminate Impairment.[83] For these reasons, it can be concluded that the omission of a reference to the general prevention of impairment in the CRPD is well compatible with the Social Model of Disability.

Moving on to the Minority Group Model of Disability, Harlan Hahn puts strong emphasis on the positive valuation of life as a disabled person. He regards it as "a positive experience"[84] and holds that, albeit while recognising that this is not true about everyone, "many disabled citizens now regard living with their disability as a valuable experience that can yield a positive source of personal and political identity".[85] This echoes the principled statements in the CRPD entailing a positive valuation of impairment, particularly Preamble (m). For Hahn, forwarding and promoting a positive valuation of impairment is central to his mission to enable disabled persons to develop a positive self-regard and to form a movement able to wield political power. Consequently, it can be concluded that for the Minority Group Model of Disability, impairment is not a problem. From this it follows that Hahn pays little attention to

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[81] UPIAS, 1974, para. 14.

[82] See above under 3.7.1.

[83] See above under 3.4.

[84] Hahn, 2001, p. 60.

[85] Hahn and Belt, 2005, p. 453.

the entitlements created by Articles 25 and 26 in the CRPD. While he pays occasional attention to issues of care (such as the call for disabled people to be "included in a government sponsored plan of medical care"[86] and the note that rehabilitation can lead to "the arrest of a steady deterioration of physical and mental attributes" rather than "[c]ure"[87]) he refutes the possibility as well as the desirability of "[c]ure", noting that it is usually not a viable prospect[88], nor is it as a rule desired by disabled people[89].

As a platform of disability, it is thus questionable to what degree including explicit language calling for the "prevention and minimization" and "early identification and intervention" relating to impairment in Article 25 and calling for "full physical [and] mental [...] ability" in Article 26 is compatible with the Minority Group Model of Disability. The Minority Group Model of Disability emphasises impairment as positive as well as recognises the engendering of this perspective as crucial for enabling individuals to adopt this position. Through this, in turn, a political movement of consequence can emerge. Against this background, the explicit language in Articles 25 and 26 referred to just above emerges as unwelcome, in the sense that this language connotes both the viability and the desirability of eliminating impairment. For these reasons, and for the designation by the Minority Group Model of Disability of the decisive feature of persons with disabilities as being a 'minority', it can be concluded that the omission of a reference to the general prevention of impairment in the CRPD is along the lines of the Minority Group Model of Disability. This is so as such a reference both universalises the concerns of the CRPD and implies a negative valuation of impairment.

Turning to ICF, it explicitly and unequivocally recognises impairments as prima facie relevant problems meriting solutions by medical means, underscoring as it does the need for "both medical and social responses [to] the problems associated with disability".[90] The entitlements to avoid impairment created in Articles 25 and 26 are thus as central to the mission of ICF as are provisions targeting a changed environment. As regards the explicit language calling for the "prevention and minimization" and "early identification and intervention" relating to impairment as in Article 25 and calling for "full physical [and] mental [...] ability" in Article 26, this explicitness can similarly be assumed to be seen positively rather than negatively, by virtue of it clarifying different aspects of important entitlements.[91] Obviously, ICF sees no problem with the connection between the platform of disability and the area of health in general. This applies to the CRPD as well, as WHO had explicitly suggested in the negotiations that ICF be the basis for the understanding of disability

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[86] Hahn, 1987, pp. 16-17 (source not paginated).

[87] Hahn, 2002, p .174.

[88] Ibid.

[89] Hahn, 2001a, pp. 40, 45.

[90] WHO, 2002, p. 9.

[91] See intervention by WHO quoted above under 7.1.1. and referenced in note 46, Part II.

in the CRPD.[92] In addition, ICF does not make the same connections as the two approaches above, linking as the latter do a negative valuation of impairment and the acknowledgement of and attention to this with issues of self-regard, the creation of a political movement, undue influence of the medical profession in the lives of persons with disabilities and the atrocities committed in the name of eliminating impairment. Furthermore, it can be concluded that ICF would have no quarrels with the inclusion in the CRPD of a general entitlement to the prevention of impairment, as one aspect of its avoidance.[93] In addition, as ICF forwards a universality view of disability, a general call for prevention can be assumed to be welcome as it illustrates the universal relevance of that which is addressed in the CRPD; anyone can (and probably will, irrespective of any preventive efforts at that) become part of the constituency of the CRPD.

Turning to ICIDH, it in no uncertain terms forwards impairments as inherently negative, referring to these as "disturbances"[94] and to those concerned as "sufferers"[95]. The importance of medical responses to impairment (as well as to composite life opportunities) and the centrality of health interventions amounting to the management as well as the elimination of impairment and/or its effects is the raison d'être of ICIDH. From this can be concluded that, from the vantage point of ICIDH, the entitlements created by Articles 25 and 26 to avoidance of impairment are welcome, and the negative valuation of impairment flowing from these correct and otherwise unproblematic. As regards the explicit language calling for the "prevention and minimization" and "early identification and intervention" relating to impairment in Article 25 and for "full physical [and] mental […] ability" in Article 26, this explicitness can similarly be assumed to be seen positively, in the sense that it clarifies different aspects of important entitlements. This is particularly so as ICIDH does not make the same connections with a negative valuation of impairment (enumerated just above in relation to ICF) as do the Social Model of Disability and the Minority Group Model of Disability. Furthermore, based on all of the above, it can be concluded that ICIDH would have no quarrels with the inclusion in the CRPD of a general entitlement to the prevention of impairment, as prevention rests on the assumption that impairments are negative and ICIDH does not find this assumption incorrect or strategically problematic.

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[92] See e.g. submission by WHO to the 8th session, WHO, The International Classification of Functioning, Disability and Health (ICF) [hereinafter WHO Submission ICF, 8th Session], 8th Session, 2006 and submission by WHO to the 3rd Session, WHO Position Statement on Working Group Draft [hereinafter WHO Position Statement on Working Group Draft, 3rd Session], 3rd Session, 2004, p. 2 (source not paginated).

[93] See e.g. the submission by WHO to the 8th session, noting that ICF, with its "comprehensive approach is useful for *prevention*, rehabilitation, social policies and other interventions". WHO Submission ICF, 8th Session, p. 1 (source not paginated). Emphasis added.

[94] WHO, 1980, p. 14.

[95] Ibid., p. 25.

7.2. Composite life opportunities

All but the two provisions of the CRPD presented in the previous section amount to what I refer to in this book as composite life opportunities. In the following, these will be presented in the order in which they appear in the CRPD and related to the approaches to disability explored in Part I (7.2.1.-7.2.17.). As emerged in Part I there is little controversy among the approaches to disability explored in Part I in relation to which composite life opportunities are recognised as valuable forms of doing and being. However, some differences, at least in focus, are discernible and so the final section below (7.2.18.) will bring out and discuss discrepancies between the CRPD and these approaches or critique forwarded against these.

7.2.1. Article 10 on Right to life

Due to its brevity, the entire article is quoted here:

> States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

The last part of the sentence constituting Article 10 emphasises the need for measures, connoting that safeguarding the right to life requires action on behalf of the State. Consequently, it is not enough for the State not to arbitrarily take life; it must in addition actively protect life. The negotiations centred on whether Article 10 should address in more explicit terms threats to life connected to perceptions of quality of life affecting particularly persons with disabilities. For example, the US proposed during the 5th session that this article contain language to the effect that "disability, or perceived quality of life, shall not serve as a basis for infringement of the right to life".[96]

Other proposals were more explicit on such threats, addressing in particular abortion of foetuses suspected to have or develop impairment and medical decisions the effects of which terminate life. Customary debates on when life begins bewildered the issue of abortion based on impairment, and the discussion rarely got past the controversy surrounding abortion per se to how abortion reflects and reinforces the valuation of impairment and what measures or regulations this may call for. Proposals which merely obliged the State not to force or encourage parents to abort foetuses on the ground of suspicion of impairment, or to take measures to inform or encourage parent in a way counteracting popular perceptions that impairment

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[96] US Proposal for Draft Article 8 on Right to life, 5th Session, 2005. See also e.g. the recorded rationale by IDC for its proposal to add "Disability is not a justification to terminate life." to Article 10: "IDC's objective was to highlight the fact that PWD [persons with disabilities] often are isolated, starved and neglected because some regard terminating life a better alternative than living with the disability.". Daily Summaries 17 January 2006, 7th Session. The proposal is contained in IDC Amendments to Chair's Draft, 7th Session, p. 25 (source not paginated).

equals tragedy, were caught up in this web. An example of such a proposal is the following by New Zealand during the 3rd session, stating that "the text could prohibit the promotion of abortion on the grounds of disability. This is a useful formulation, as it does not suggest that women do not have the right to choose".[97] The reluctance to regulate matters relating to the time before birth is evident from the discussion following a proposal by IDC during the 7th session to add, inter alia, "at all stages of life" to Article 10. Relating to this, Japan is recorded as intervening that "if "all stages of life" included the life of an unborn child, it would be difficult to accept the proposal".[98] The upshot of the silence on these issues in the text of Article 10 and the diametrically different positions in the negotiations preceding it is that no conclusion regarding abortion generally can be drawn from Article 10.[99] However,

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[97] Daily Summaries 13 January 2004, Working Group Session. See also proposal from IDC for the 5th session: "States Parties shall undertake effective measures to the prohibition of compulsory abortion at the instance of the State based on the pre-natal diagnosis of disability.". IDC, Updated Contribution on the Draft Text of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 5th Session, 23 January 2005, p. 3. A stronger and more detailed proposal was submitted by a coalition of Australian organisations during the 4th session:

"3. States Parties to this convention shall take immediate and effective measures to discourage termination of pregnancy on the basis of actual, suspected, imputed, assumed or possible future disability. This shall include:

(a) Establishing ethical standards and guidelines for genetic information and counselling services;

(b) Ensuring that information and support provided to parents during the pre-natal period provides a positive orientation to the child with disability;

(c) Ensuring the availability of all necessary post natal information and support to parents and the child with disability;

(d) Prohibiting State and non-State actors from limiting or refusing social assistance on equal terms with others on the basis of a parental decision to bear a child with disability.". People with Disability Australia (PWDA), Australian Federation of Disability Organisations (AFDO), (Australian) National Association of Community Legal Centres (NACLC), Contribution in Relation to Articles 1 to 15 [hereinafter PWDA et al., Contribution Articles 1 to 15, 4th Session], 4th Session, 24 August 2004, p. 14. Among civil society notably II emphasised the need to regulate abortion based on impairment, such as in the following submission from the 3rd session: "Inclusion International holds an unequivocal position on the valuing of the life of all people and their right to be different. [...] The lives of future people with a disability are also at risk from developments in prenatal tests that test for the presence of a disability. Most people with a disability are born in developing counties and the result of a positive test is perhaps obvious. In the more affluent countries parents do come under pressure to terminate the pregnancy after a positive test. This decision is reinforced by the assumption that such a person being born will lead to greater social, health and care needs.". II Proposal for the 3rd Session, pp. 3-4 (source not paginated).

[98] Daily Summaries 17 January 2006, 7th Session. The proposal is contained in IDC Amendments to Chair's Draft, 7th Session, p. 25 (original not paginated). This issue predominantly arose in relation to the reference to "sexual and reproductive health" in Article 25 (a) on Health. See e.g. Daily Summaries 25 January 2006, 7th Session.

[99] As Carole J. Petersen puts it, negotiating States "essentially agreed to disagree on the subject of abortion". Petersen, Carole J., Population Policy and Eugenic Theory: Implications of China's Ratification of the United Nations Convention on the Rights of Persons with Disabilities [hereinafter Petersen, 2010], China: An International Journal, Vol. 8, No. 1, 2010, p. 108. For a thorough account of the issue of abortion in the negotiations of Article 10 see Shaffer, Bret, The Right to Life, the Convention on the Rights of Persons with Disabilities, and Abortion, Penn State International Law Review, Vol. 28, No. 2, 2009, pp. 272-286.

it remains that State behaviour such as providing biased or one-sided information to prospective parents of children with disabilities or encouraging or even enforcing abortion comes into conflict with other provision of the CRPD.[100]

The regulation of termination of life after birth due to impairment was discussed in general as well as specifically in relation to medical decisions on withholding or discontinuing different forms of treatment.[101] The latter issue was discussed in relation to Article 10 but also in relation to Article 25 on Health, where it resulted in 25 (f) which obliges States to "[p]revent discriminatory denial of health care or health services or food and fluids on the basis of disability". This provision was not codified until the 8th and last session of the Ad Hoc Committee, after such a proposal received wider support during the 7th and 8th sessions.[102] The background of this provision concerned how assumptions about the quality of life of the implicated constituency of the CRPD are used as a basis for deciding if a life is worth continuing as well as to decide how scarce resources are to be divided.[103]

Article 25 (f) does not, as indeed it could not, outlaw prioritisation in health services, nor does it say that there is not a point when the suffering of a human being makes death preferable to life. What it does posit is that that decisions based on the existence of a particular impairment per se are not acceptable. A harder question is how to evaluate general rules for prioritising which disproportionately overlap with particular impairments, in other words, when a criterion does not explicitly refer to impairment generally or specifically, but persons with such impairments are over-represented among those implicated. Irrespective of if a particular decision actualises

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[100] See Lord, Janet E., Screened Out of Existence: The Convention on the Rights of Persons with Disabilities and Selective Screening Policies [hereinafter Lord, 2013], International Journal of Disability, Community & Rehabilitation, Vol. 12, No. 2, 2013. See further below note 1134, Part II.

[101] As such general recognition, Thailand is recorded as noting during the Working Group session in relation to the right to life that "[m]any PWD [persons with disabilities] are also deprived of life after birth (they are killed by their families or by others in the case of WW2)". Daily Summaries 15 January 2004, Working Group Session. Regarding discontinuation of treatment, see the following statement from National Right to Life during the 6th session: "Because people with disabilities are often perceived by others as having a lower quality of life, they are in the greatest danger of being denied life-preserving medical treatment on an equal basis with others. They are also in great danger of being denied nutrition and hydration, food and fluids. […] We hear the statement, the "right to die", but it is important to remember that this so called right is only available to persons with disabilities. Death is not a medical treatment, and the "right to die" for people with disabilities will soon become a "duty to die". In a time of limited medical resources, it is persons with disabilities toward whom euthanasia will be directed.". Statement by Cockfield, Wayne, National Right to Life, Society of Catholic Social Scientists, Article 21, 6th Session, 8 August 2005, p. 1 (source not paginated).

[102] The Chair noted after the 6th session that "[a] proposal was made that persons with disabilities should not be denied food, water or life support, which was supported by a number of delegations." 6th Session Report by the Chairman, p. 16, para. 79. The original proposal was widely attributed to Qatar. Daily Summaries 25 January 2006, 7th Session.

[103] A proposal submitted by Qatar during the 8th session explicitly made this connection with quality of life: "Prevent discriminatory denial of medical treatment or food and fluids, regardless of the method of administration, necessary to preserve life based on present or predicted disability or perceived quality of life.". Proposal by Qatar on behalf of Bahrain, Kuwait, Oman, Saudi Arabia, Yemen and United Arab Emirates, 8th Session, 2006.

the issue of resources or not, the common core of the decisions targeted by 25 (f) is that they turn upon valuation of impairment, or rather, of life with impairment.

Turning to the approaches to disability explored in Part I of this book, it goes without saying that they see 'life', largely understood, as a valuable life opportunity. ICIDH and ICF emanate from WHO, where saving life is of course a central aim of health interventions. Turning to the specific threats discussed in the negotiations, both Michael Oliver and Harlan Hahn emphasise the relationship between the valuation of impairment and the valuation of the lives of disabled people, and the ensuing threat of death connected with a low valuation of life. Oliver addresses this as it relates to before as well as after birth:

> As far as disabled people are concerned, our very lives are threatened not just by physical attacks from neo-fascist movements but also from policies developed by our governments. Compulsory abortions in China, euthanasia in Holland, and quality of life debates all over the world pose threats to our very existence.[104]

Michael Oliver also sets the current situation against the backdrop of historical abuse, here the systematic elimination of disabled people during the Holocaust and notes how such practices are made possible through the silence of those not affected:

> We know that the Nazis killed 200,000 disabled people in Germany but we still practise death making in the here and now and still hidden from view. We avert our eyes just like the Germans did all those years ago. There are no gas chambers but there are things going on that we talk about in hushed tones using terms like 'euthanasia', 'mercy killing' and 'termination'.[105]

Harlan Hahn as well emphasises that dangers connected with ideas about a low value of life with impairment fuelling the idea that life with impairment is not worth living, with the ensuing blessing of eliminating the person as an appropriate response. Identification of impairment as a potential problem as well as a focus on solutions targeting impairment is discouraged against the backdrop of (at best) historic instances. It is emphasised that such recognition has produced solutions where the elimination of *the person* became the outcome of a focus on prevention and elimination of impairment. Hahn notes below that this is relevant to "every stage of the life cycle":

> From a vantage point that emphasizes the difficulties posed by functional limitations in the exiting environment, seemingly legitimate concerns might be expressed about the "quality of life" available to disabled individuals at every stage of the life cycle. By contrast, from a minority group perspective, these arguments might be interpreted differently. Along with the prevalence of telethons and the massive resources allocated to medical research, they seem to denote a widespread belief that the principal solution to

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[104] Oliver, 1996, p. 124.

[105] Oliver, Michael, Disabled People and the Inclusive Society, Public Lecture at Strathclyde Centre for Disability Research, 1999. Quoted in Campbell, 2002, pp. 473-474.

> the problem of disability is to eradicate it. As witnesses to a historical tradition which has included the widespread practice of genocide as well as the extermination of one million disabled persons in Nazi Germany, people with disabilities are understandably loath to grant others the power to determine their fate.[106]

Hahn also notes that persons with disabilities are in a position to provide valuable insight into these questions, as "disabled persons may possess a valuable though previously unrecognized culture that can inform these complex moral questions".[107]

Efforts to measure quality of life are thus denoted by Oliver and Hahn, due to the habitually low quality of life widely assumed to come with impairment and the consequences of this for decisions on life and death. Conversely, the ICF manual implicitly recognise the place for such frameworks in the health context as it calls for "establishing links with quality of life concepts and the measurement of subjective well-being".[108] To conclude, all approaches depart from an ambition to safeguard lives but take different positions on if ideas of and constructs relating to measuring quality of life is a threat or a means to this end.

7.2.2. Article 11 on Situations of risk and humanitarian emergencies

Article 11 addresses the protection and safety of persons with disabilities in situations of risk, such as "situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters". To this end, "States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities". Article 11 was elaborated following the tsunami in December 2004, which had illustrated the need for measures suited to persons with disabilities in times of natural disasters.[109]

Turning to the approaches explored in Part I, not much controversy can be expected in relation to the topic of Article 11. The heart of Article 11 is to extend the

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[106] Hahn, 1987, p. 15 (source not paginated). See also Hahn, 2002, pp. 174, 180-181.

[107] Hahn, 1987, p. 16 (source not paginated).

[108] WHO, 2001, Annex 8 Future Directions for ICF, p. 251. The footnote to this passage reads: "Links with quality of life: It is important that there is conceptual compatibility between "quality of life" and disability constructs. Quality of life however, deals with what people "feel" about their health condition or its consequences; hence it is a construct of "subjective well-being". On the other hand, disease/disability constructs refer to objective and exteriorized signs of the individual.".

[109] See e.g. Daily Summaries 24 January 2005, 5th Session. It was first introduced as an off-spring to the article on the Right to life, see Report of the Coordinator to the Ad Hoc Committee at its Fifth Session [hereinafter 5th Session Report by the Coordinator, 2005], Annex II to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Fifth Session [hereinafter 5th Session Ad Hoc Committee Report, 2005], 23 February 2005, UN doc: A/AC.265/2005/2, p. 6, paras. 12-14. Draft Article 11 on Situations of risk was first included in the working text of the CRPD through Chair's Draft, 7th Session, 2006, p. 22. It was here still in brackets, indicating the lack of negotiations thus far on specific language.

safety net in situations which make people vulnerable to persons with disabilities as well. It is a call for public policy regarding these situations to extend its attention to persons with disabilities and provide an inclusive framework, including accessible services. On a general level, this rhymes well with all the approaches explored in Part I. The particular situation in focus in Article 11 is explicitly included in ICF as an Environmental factor: "Civil protection services, systems and policies".[110]

7.2.3. Article 12 on Equal recognition before the law

Article 12 (1) starts by reaffirming the right of persons with disabilities to "recognition everywhere as persons before the law" and 12 (2) recognises that "persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life". 12 (3) introduces the crucial concept of support: "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.". Safeguards to prevent abuse regarding "all measures that relate to the exercise of legal capacity" are stipulated in 12 (4) to ensure that measures "respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body". A proportionality requirement is also stipulated between the level of safeguards required and "the degree to which such measures affect the person's rights and interests". Finally, 12 (5) obliges States to "[s]ubject to the provisions of this article […] take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property".

This text is not unequivocal, to say the least, on the core question it seeks to address: are there ever factors disproportionately affecting persons with psychosocial or intellectual disabilities which legitimise circumscription of legal capacity, either by explicitly tying restricted legal capacity to impairment or to factors which overlap with a diagnosis? The reference to legal capacity having to be "equal" in 12 (2) merely "restates the question"[111]; in as much as some persons with disabilities are regarded as similar to others they are to be accorded legal capacity and in as much as they are regarded as dissimilar they can be denied legal capacity. While the reference to "equal" would seem to prohibit tying restricted legal capacity to an explicit reference

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[110] WHO, 2001, p. 197. Such services include, inter alia, those "safeguarding people and property" such as "emergency and ambulance services". The events causing situations protected under Article 11 are included as Environmental factors as well: "Natural events" such as "earthquakes and severe or violent weather conditions" and "Human-caused events" such as "events and conditions linked to conflict and wars". Ibid., p. 184.

[111] Quinn, 2009, p. 249.

to impairment, the difficult question concerns to what extent criteria which do not explicitly equate an impairment but which are overrepresented among persons with that impairment are allowed to justify limitations of legal capacity.[112] Article 3 (a) on General principles recognises the centrality of "individual autonomy including the freedom to make one's own choices", thus indicating that great weight is to be accorded the interest of autonomy and choice. However, the CRPD is the first UN human rights convention to include General principles and it is arguably a riddle, and a riddle exceeding the scope of this book, to what extent the reach of a General principle is determined by the interpretation of the sum total of the provisions in which such interests are weighed against other concerns, or whether these principles simply add to the weight of the interest it protects in the interpretation of particular provisions.[113] Other provisions which actualise the reach of "individual autonomy including the freedom to make one's own choices" are as open-ended as is Article 12, and thus provide little guidance for the interpretation of Article 12.[114]

The question of systems determining the decision-making capacity of a person and, if found wanting, transferring the power to make legally effective decisions to another person (substituted decision-making) was without comparison the most explicitly controversial issue in the negotiations of the CRPD.[115] All agreed that the primary response to a situation where a person is perceived as having difficulties in making or communicating decisions is to offer support and that it is the obligation of the State to ensure access to such support (supported decision-making). Similarly, no one disagreed that current systems for substituted decision-making have led to unfathomable abuse, by disregarding, ignoring or just not bothering to ascertain the will of a person as well as by outright exploitation, financial and otherwise; hence the explicit safeguards in 12 (4). The disagreement instead regarded whether there are

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[112] As noted above in note 66, Part II, this concerns how far the prohibition of indirect discrimination reaches. For the coverage of indirect discrimination by Article 5 on Equality and non-discrimination, see below under 7.3.4.

[113] While the ideological import of Article 3 is undeniable, the legal role of Article 3 is thus unclear. The CRPD found its inspiration from CRC, however in CRC these principles are distilled by the Committee on the Rights of the Child (CRC Committee) from the particular provisions after their adoption, rather than present parallel sources of law. Committee on the Rights of the Child General Comment No. 5 on General Measures of Implementation of the Convention on the Rights of the Child (Arts. 4, 42 and 44, para. 6), 2003, UN Doc: CRC/GC/2003/5. The question thus arises how e.g. autonomy as a principle adds to the balance arrived at by interpreting the text of Article 12, which in its essence is a manifestation of the balance between protection and autonomy. Conversely, can individual provisions be use as the 'sum', putting 'flesh on the bones' of Article 3, or is Article 3 to guide the interpretation of particular provisions and not the other way around? A principled answer to question how the principles in Article 3 interplay with individual provision which have them at their core fall outside the scope of this book, but remains a salient question for the interpretation of the CRPD.

[114] See above under 7.1. and below under 7.2.4.-7.2.5., 7.2.7. and 7.3.2.

[115] Article 12 on Equal recognition before the law was the last Article to be agreed upon; indeed it was not until the reconvening of the 8th session after the work of the Drafting Committee that a footnote with substantive content was removed. See 8th Session Ad Hoc Committee Interim Report, 2006, p. 13 for the footnote and Letter from the Chair to the Ad Hoc Committee, dated 29 November 2006, 8th session, 2006 for the proposal for its deletion.

"extreme situations" where supported decision-making is not enough to protect the interests of the person and where it is called for to transfer the legal decision-making power to another person.[116] Such situations appeared to involve both when those around a person (after every effort being made) is unable to detect the preferences of that person *and* when such preferences are detectable but disapproved of (i.e. when one is perceived to be in need of 'protection from oneself'); these two situations were habitually conflated in the negotiations.[117] IDC were unequivocal on the termination of substituted decision-making[118], however several States were reluctant to close the door to substituted decision-making.[119] The upshot of Article 12 is at face value inconclusive, as it hinges on a situated interpretation of the prohibition of discrimination. An answer to the question if Article 12 in any situation falling within the two categories described above allows for the transfer of decision-making power from a person will require careful interpretation well beyond the scope of this book. As noted above under 7.1.1., the CRPD Committee holds categorically in its Draft General Comment on Article 12 that denial of legal capacity which disproportionately affects the constituency of the CRPD violates Article 12. It explicitly states that "mental capacity" is not a valid criterion for restricting legal capacity:

> Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of an individual, which naturally vary among individuals and may be different for a given individual depending on many factors, including environmental and social factors. Article 12 does not permit perceived or actual deficits in mental capacity to be used as justification for denying legal capacity.[120]

The Committee explicitly calls for the wholesale abolition of "substitute decision-making regimes", including as a complement to "supported decision-making systems".[121]

In sum, the point of departure remains that the support required to arrive at the expressed will of the individual is to be provided, and this will is to be exercised. Furthermore, the ambiguities in the text of Article 12 affecting the 'frontier cases' have been interpreted by the CRPD Committee as requiring that legal capacity can never be restricted with reference to the perceived or actual decision-making abilities of a individual.

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[116] Recorded statement by the Chair, Daily Summaries 18 January 2006, 7th Session.

[117] See e.g. Daily Summaries 18 January 2006, 7th Session and 3 February 2006, 7th Session.

[118] See e.g. recorded statement by IDC, Daily Summaries 18 January 2006, 7th Session.

[119] See e.g. recorded statements from Russian Federation, Brazil and the Chair, Daily Summaries 18 January 2006, 7th Session and recorded statements from Serbia and Montenegro, Australia, Syrian Arab Republic, Yemen, Kenya, Costa Rica and Singapore, Daily Summaries 3 February 2006, 7th Session.

[120] Draft General Comment on Article 12, para. 12.

[121] Ibid., para. 24.

Turning to the approaches to disability explored in Part I, a comparison is, at the outset, made difficult by the fact that both the Social Model of Disability and the Minority Group Model of Disability although they forcefully embrace autonomy in decision-making as a principle, focus on physical impairment (in the case of UPIAS explicitly so), rather than psychosocial and intellectual ones which emerged as the crunch question regarding Article 12. However, the point of departure attributed to Article 12 just above resonate strongly with the general position of these approaches.

Beginning with UPIAS, it is clear that making one's own decisions and taking control of one's own life by loosening "the stranglehold that professions have over disabled people"[122] and taking back the power of professionals acting as "social controllers"[123] of disabled people, is central:

> Both inside and outside institutions, the traditional way of dealing with disabled people has been for doctors and other professionals to decide what is best for us. […] Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withholding information from us, or take decisions behind our backs.[124]

Applied across the categories of persons with disabilities covered by the CRPD, this is a strong rejection of any substituted decision-making. Michael Oliver similarly categorically rejects the transfer of decision-making to professionals of different categories and states the need "to alter professional practice so that it is the disabled person who is in control and not the social worker or another professional".[125] A possible caveat here is that Oliver in extending the Social Model of Disability to groups other than persons with physical disabilities noted that "[s]imilarly mental handicap can be seen as *less* the problem of the intellectual impairment of certain individuals but *more* related to general expectations about levels of social competence".[126] While this statement does not address decision-making, it does depart from his general position that Impairment is without relevant consequence for the enjoyment of composite life opportunities.

Similarly to UPIAS and Oliver, the focus of Harlan Hahn is on persons with physical disabilities. Hahn does however explicitly deplore, albeit in a general manner, "the establishment of programmes sought by nondisabled professionals and fam-

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[122] UPIAS, 1975, p. 8.

[123] Ibid., p. 18.

[124] UPIAS, 1974, para. 14. UPIAS addresses in particular the curtailing of decision-making in relation to persons in residential institutions and states that they will support the struggles for persons in residential institutions for "full control over their personal affairs, and for a democratic say in the management of their Home, Centre or Unit. The Union strongly opposes all attempts by the authorities to impose restrictions on visiting; to fix times for getting into and out of bed; to limit resident's freedom to come in and go out when they wish; to enforce medical and nursing opinions, or to transfer residents to other institutions against their will". Ibid., para. 8.

[125] Oliver, 1983, p. 136.

[126] Oliver, 1981, p. 30. Emphasis added.

ily members rather than by mentally retarded citizens themselves", stating that this is "paternalism" and calling for "self-determination".[127]

Moving on to ICF, autonomy and choice are also explicitly noted in relation to the valuable life opportunities recognised within the scheme of ICF, i.e. as valuable aspects of Functioning in terms of Activities and Participation. The category "Human rights" includes "the right to self-determination or autonomy; and the right to control over one's destiny".[128] In Annex 6 Ethical Guidelines for the Use of ICF, the manual explicitly calls for its scheme to be used "so as to respect the inherent value and autonomy of individual persons".[129] At the same time, it is obvious that it is assumed that limitations of "cognitive capacity" are a reality that professionals must relate to. Under the heading "Respect and confidentiality", it is noted that "ICF should always be used with the full knowledge, cooperation, and consent of the person whose levels of functioning are being classified. If limitations of an individual's cognitive capacity precludes this involvement, the individual's advocate should be an active participant".[130] Involvement with the professional as regards ICF is subsequently referred to as calling for engagement with "the individual or the individual's advocate".[131] Finally, under the heading "Social use of ICF information", it is stated that "ICF information should be used, to the greatest extent feasible, with the collaboration of individuals to enhance their choices and their control over their lives."[132] To conclude, ICF explicitly recognises the value of control over one's own life but simultaneously recognises that "cognitive capacity" qualifies the attainment of this. This resonates with the right to assistance in decision-making, but does not address who, in every case, wields that decision-making. Furthermore, the interventions by WHO in the negotiations on what became Article 12 of the CRPD indicate that WHO, albeit they forward that the assumption should be that all persons have "capacity", envisage that sometimes consequence should be given "evidence to the contrary established by appropriate legal due process".[133]

Turning to ICIDH, the issue of decision-making does not receive any explicit attention in the ICIDH scheme or manual. The focus is on aiding medical and social professionals in taking decisions that are assumed to be conducive to the enjoyment of life opportunities by its constituency, and it does not address the individual recipient of services as an active part in the taking of such decisions.[134]

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[127] Hahn, 2000, p. 271.

[128] WHO, 2001, p. 170.

[129] Ibid., p. 244.

[130] Ibid.

[131] Ibid.

[132] Ibid., p. 245.

[133] WHO Position Statement on Working Group Draft, 3rd Session, p. 3 (source not paginated).

[134] Compare under Article 14 on Liberty and security of person below, where it is noted that ICIDH seems to assume civil commitment, in other words it assumes substituted decision-making in that particular context.

7.2.4. Article 14 on Liberty and security of person

According to Article 14 (1a) States are to ensure to persons with disabilities the enjoyment of the right to liberty and security of person "on an equal basis with others". 14 (1b) specifies this by stating that it entails that persons with disabilities "[a]re not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty". The traditional focus of human rights provisions on liberty and security of person is criminal incarceration. Article 14 however was crafted with particularly civil commitment in mind, i.e. the practice of detaining persons against their will unrelated to criminal allegations, often with reference to the person being attributed a diagnosis designating him or her as a person with a psychosocial disability and/or with reference to him or her being perceived as a danger to him- or herself or others. Much like in the case of Article 12, the legality of such measures in relation to the constituency of the CRPD hinges upon a situated interpretation of what a decision being based on "the existence of a disability" entails. While the express prohibition of "the existence of a disability" as the justification for deprivation of liberty seems to prohibit explicitly using impairment as a criterion for civil commitment, it arguably leaves the question open to what extent general criteria may overlap with features disproportionately overlapping with a particular impairment. In contrast to Article 12, the analysis will focus on interpreting "on the basis of disability" rather than the reach of the prohibition of indirect discrimination. The core question, however, remains the same: the permissibility of neutrally shaped measures which disproportionately affect the constituency of the CRPD. Like Article 12, as noted there and for the same reasons, a contextual interpretation of Article 14 yields little.[135] There was no consensus in the negotiations on explicitly outlawing civil commitment.[136] In line with the reasoning of the CRPD Committee accounted for above under 7.1.1. and 7.2.3., the Committee holds that when constituents of the CRPD "are denied legal capacity and are detained in institutions against their will, either without regard to obtaining consent or on the consent of a substitute decision maker", this practice violates Articles 12 and 14.[137] In other words, in light of the reasoning by the Committee on the implications of Article 5 on Equality and non-discrimination discussed above under 7.1.1., civil commitment per se violates the CRPD if it is explicitly linked to impairment or if it disproportionately affects constituents of the CRPD.

Article 14 (2) addresses the process through which liberty is deprived and the situation of persons who are deprived of their liberty. Thus, "if persons with disabilities are deprived of their liberty through any process", States Parties shall ensure that they are "on an equal basis with others entitled to guarantees in accordance with

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[135] See above under 7.2.3.

[136] See e.g. Daily Summaries 26-27 January 2005, 5th Session.

[137] CRPD Draft General Comment on Article 12, para. 36.

international human rights law". In addition, they are to be "treated in compliance with the objectives and principles" of the CRPD, including through the provision of "reasonable accommodation". To conclude, while this article thus addresses procedural safeguards for and the living conditions during deprivation of liberty, the main target and the main controversy remains the relationship between civil commitment per se and impairment.

Article 14 thus focuses a particular kind of control of one's own life, namely not to be incarcerated against one's will due to predictions of the future related to impairment. Again, the principled positions expressed by UPIAS and Michael Oliver quoted above under Article 12 would, applied unconditionally across all categories of persons with disabilities, outlaw any civil commitment as it is currently practiced worldwide targeting persons with psychosocial and intellectual disabilities. Similarly, the rejection of "paternalism" and the call for "self-determination" by Harlan Hahn quoted above in relation to Article 12 speaks against civil commitment on a principled level.[138]

ICF recognises as valuable life opportunities in terms of Activities and Participation "Community, social and civic life", which includes the category "Political life and citizenship", in turn encompassing "enjoying the rights and freedoms associated with citizenship (e.g. [...] protection against unreasonable search and seizure)".[139] This is a general statement, and its final implications pivot on what is understood as "unreasonable". This in turn must be gauged against the backdrop of interventions by WHO in the negotiations of the CRPD, envisaging a place for "involuntary hospitalization", albeit as an exception and surrounded by legal safeguards, when "there is evidence of mental disorder of specified severity as defined by internationally accepted standards; and (b) there is a likelihood of self-harm or harm to others and/or of deterioration in the individual's condition if treatment is not given".[140]

Finally, ICIDH explicitly assumes the need for incarceration based on "behaviour". Under the category "Physical independence handicap", "Critical interval dependence" is included, which entails "need for institutional care in order to provide supervision, such as for behaviour that is socially unacceptable".[141] Such dependence is described as "[r]esidence in an institution by virtue of behavioural maladjustment or the need for restraint".[142] While these statements do not explicitly say that a person can be subjected to such restraint against his or her will, it can be presumed that it is not meant to be left up to the person characterised as affected by "behavioural maladjustment" to determine if "need" is present.

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[138] Hahn, 2000, p. 271.

[139] WHO, 2001, p. 170.

[140] WHO Position Statement on Working Group Draft, 3rd Session, p. 4 (source not paginated). This is stated in relation to Draft Article 11 on Freedom from torture or cruel, inhuman or degrading treatment or punishment.

[141] WHO, 1980, p. 190.

[142] Ibid., p. 197.

7.2.5. Article 15 on Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 15 (1) reiterates the universal guarantee that "no one shall be subjected to torture or cruel, inhuman or degrading treatment or punishment".[143] This includes "in particular, [that] no one shall be subjected without his or her free consent to medical or scientific experimentation".[144] The most controversial issue in the negotiations of Article 15 was the extension of the blanket inclusion of experimentation without consent to *medical intervention* without consent. The Working Group Draft stated that "States Parties […] shall protect persons with disabilities from forced interventions or forced institutionalization aimed at correcting, improving, or alleviating any actual or perceived impairment".[145] This section was later removed, as no consensus could be reached as to whether such interventions are without exception uncalled for which rhymed badly with the prohibition in Article 15 being absolute.[146] While there was no agreement on such interventions, through disregarding withheld consent, automatically amounting to torture or cruel, inhuman or degrading treatment, it remains that medical and other interventions, by virtue of their non-consensual character as well as other features, may amount to a violation of Article 15. In line with the reasoning of the CRPD Committee accounted for above under 7.1.1. and 7.2.3.-7.2.4., the Committee categorically holds that "forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement upon the rights to personal integrity (Article 17), freedom from torture (Article 15), and freedom from violence, exploitation and abuse (Article 16)".[147] Consequently, according to the Committee disregarding withheld consent equals a violation of Article 15.

Article 15 (2) moves from "everyone" to addressing specifically "persons with disabilities" and obliges States to "take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment". To conclude, while the line between valid medical and other interventions and torture or cruel, inhuman or degrading treatment or punishment was not drawn

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[143] This is the only provision in the operative part of the CRPD implicating everyone.

[144] Except for the addition of "or her", Article 15 (1) is a carbon copy of Article 7 of ICCPR.

[145] Working Group Draft, 2004, Draft Article 11 (2) on Freedom from torture or cruel, inhuman or degrading treatment or punishment, pp. 16-17.

[146] See e.g. the record of discussions in Daily Summaries 27-28 January 2005, 5th Session. This disagreement was flagged already in the Working Group Draft in a footnote to Draft Article 11 (2): "Members of the Working Group had differing opinions on whether forced intervention and forced institutionalisation should be dealt with under "Freedom from Torture", or under "Freedom from Violence and Abuse", or under both. Some members also considered that forced medical intervention and forced institutionalization should be permitted in accordance with appropriate legal procedures and safeguards.". Working Group Draft, 2004, p. 17, note 38. IDC adamantly called for the retention of this language in what became Article 15, see e.g. ICD, Information Sheet, Why are Forced Interventions a Form of Torture?, 5th Session, 2005.

[147] CRPD Draft General Comment on Article 12, para. 38.

in the CRPD, subject thus to the question *what* amounts to torture or cruel, inhuman or degrading treatment 15 (2) makes clear that the prevention of torture or cruel, inhuman or degrading treatment must extend equally to the constituency of the CRPD.

The practice of torture symbolises human rights violations and so to say that any of the approaches to disability explored in Part I condones torture (or cruel, inhuman or degrading treatment or punishment) or does not call for the State to protect persons with disabilities from such practices, would be a strong statement. However, the new question posed during the negotiations was to what extent that which has previously been regarded as legitimate treatment by professionals in the medical or other spheres amounted to such practice, either through its nature full stop or through it being imposed disregarding the withheld consent of an individual. Again, the principles expressed by UPIAS and Michael Oliver quoted above in relation to Article 12, and the call for "self-determination" for persons with intellectual disabilities by Harlan Hahn[148] would, applied unconditionally across all categories of persons with disabilities, make unwanted treatment a contender for the serious offences that Article 15 are meant to cover. Particularly, the statement by UPIAS against "enforce[ing] medical and nursing opinions" as they relate to treatment, is in point here.[149]

ICF similarly recognises the value of "autonomy", addressing this explicitly in clinical settings, thus opening up for regarding professional intervention which abuses autonomy as serious indeed.[150] However, based on the intervention by WHO in the negotiations of the CRPD quoted above in relation to Article 14, "treatment" during involuntary hospitalisation, albeit flanked by legal safeguards and the assumption of "capacity", is called for if "there is a likelihood [...] of deterioration in the individual's condition if treatment is not given".[151]

ICIDH contains no principled expression of the importance of individual choice regarding medical or other interventions. With its faith in professionals as decision makers and determinaters of needs, the designation of unwanted interventions as "torture" seems a further step away from ICIDH than from the other three approaches.

7.2.6. Article 16 on Freedom from exploitation, violence and abuse

According to Article 16 (1) States "shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities […] from all forms of exploitation, violence and abuse, including their gender based

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[148] Hahn, 2000, p. 271.

[149] UPIAS, 1974, para. 8.

[150] WHO, 2001, p. 244. See also Ibid., p.170.

[151] WHO Position Statement on Working Group Draft, 3rd Session, p. 4 (source not paginated). This was stated in relation to Draft Article 11 on Freedom from torture or cruel, inhuman or degrading treatment or punishment.

aspects". Article 16 applies "both within and outside the home" and there is thus no context too 'private' for its application. With this explicit recognition of its wide area of application, Article 16 complements the traditional focus on the State as the perpetrator inherent in Article 15.[152] In addition to targeting violations on behalf of private actors (through the explicit reference to "the home") Article 16 also compliments Article 15 by virtue of "exploitation, violence and abuse" not being subjected to the criteria implicating high levels of severity inherent in the latter article. In other words, treatment which does not amount to being "inhuman" or "degrading" may none the less violate Article 16.[153]

Article 16 (2) addresses the prevention of exploitation, violence and abuse. It obliges Sates to "take all appropriate measures to prevent all forms of exploitation, violence and abuse, by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse". State Parties are also to "ensure that protection services are age-, gender- and disability-sensitive".

Article 16 (3) makes the connection between prevention and monitoring. To prevent exploitation, violence and abuse "States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities".

Article 16 (4) deals with recovery from exploitation, violence and abuse. States "shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services". Such processes "shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs".

According to Article 16 (5), following instances of exploitation, violence or abuse, States are to ensure that such instances are "identified, investigated and, where appropriate, prosecuted". To this end, States "shall put in place effective legislation and policies, including women- and child-focused legislation and policies."

To conclude, Article 16 covers prevention, protection, detection, investigation, legal consequences as well as recovery and re-integration services relating to instances of exploitation, violence and abuse of the constituency of the CRPD.

Turning to the approaches to disability explored in Part I and beginning with the Social Model of Disability, UPIAS recognise the potential for abuse of persons who

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[152] See Daily Summaries 28 January 2005, 5th Session, particularly a clarification by the Office of the High Commissioner for Human Rights (OHCHR). The obligations of the State to control the relations between private actors are recognised as a General obligation in Article 4 (1e): "To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;".

[153] See record of intervention by Liechtenstein in Daily Summaries 28 January 2005, 5th Session.

utilise services addressing "personal needs", seeing "a need for a Charter which will focus on basic rights often denied when people are dependent on others for personal needs".[154] UPIAS also emphasise different form of abuse in institutional settings. Such institutions are thus not only a form of abuse in themselves, but also because of the treatment received therein:

> The cruelty, petty humiliation, and physical and mental deprivation suffered in residential institutions, where isolation and segregation have been carried to extremes, lays bare the essentially oppressive relations of this society with its physically impaired members.[155]

UPIAS also recognise the need to take those responsible to task, noting that "[r]esidents in institutions may seek help and national publicity if they are victimised by the authorities".[156].

Both Michael Oliver and Harlan Hahn call for an end to injustices amounting to grave instances of violence and abuse.[157] The particular inclusion of private service providers in Article 16 is a way of addressing a general limitation built into human rights law, namely the predominant focus of State obligations on the relationship between the State and the individual, rather than between private individuals, companies or organisations and the individual.[158] The approaches to disability explored above, albeit their focus is on services provided by the State, does not make any such distinction. Rather, they focus on the recipients of services, irrespective of who provides these services.

ICF includes the "amount of physical and emotional support" provided by, inter alia, "Immediate family", "Extended family", "Personal care providers and personal assistants", "Health professionals" and "Other professionals" as Environmental factors.[159] Consequently, that which is provided by such persons can qualify as a Facilitator or a Barrier, i.e. as helping or hindering the realisation of a specified good. The evaluation here presumably targets the amount of support as well as the quality of such support, but (particularly as that which is being measures is "support") it does not indicate how it anticipates a situation where, rather than concerning the lack of support, that which should "support" amounts to abuse.

Finally, ICIDH does not address instances of abuse as it does not question the authority, intentions or ability of the medical and other service professions.

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[154] UPIAS, 1974, para. 9.

[155] Ibid., para. 7.

[156] Ibid., para. 18.

[157] See above under Article 10 on Right to life.

[158] See Mégret, 2008, pp. 266-267, 271.

[159] WHO, 2001, pp. 187-188.

7.2.7. Article 17 on Protecting the integrity of the person

Article 17, in its entirety, reads:

> Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 17 was conceived largely in order to address non-consensual medical intervention. It is a consequence of the lack of consensus to explicitly equate such intervention with "torture or cruel, inhuman or degrading treatment or punishment" and address it under Article 15.[160] In the end, Article 17 declines to explicitly equate such intervention with a violation of "the integrity of the person". The general controversy surrounding non-consensual intervention led to the much longer draft as it stood before the 8th and last session (which simultaneously obliged States to "protect persons with disabilities from forced interventions or forced institutionalization aimed at correcting, improving or alleviating any actual or perceived impairment (Draft Article 17 (2)) *and* regulated "involuntary treatment of persons with disabilities […] in exceptional circumstances" (Draft Article 17 (4b))) being reduced to the one, general, sentence reproduced above.[161]

Like Article 12, the protection Article 17 affords will hinge on an interpretation of what "equal" respect for integrity entails. As mentioned under Article 12 above, the crux remains to what extent criteria which do not explicitly connect to impairment but which are overrepresented among persons with disabilities are allowed to justify non-consensual intervention.[162] Notwithstanding the outcome of such a situated interpretation of the prohibition of discrimination, it appears beyond doubt that Article 17, like Articles 12 and 14, invalidates the customary practice of automatically treating the constituency of the CRPD, particularly persons with psychosocial and intellectual disabilities, as a case apart in relation to the general rule of requiring consent to medical interventions. In line with the reasoning of the CRPD Committee accounted for above under 7.1.1. and 7.2.3.-7.2.5., the Committee categorically holds that "forced treatment by psychiatric and other health and medical profes-

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[160] See above under 7.2.5. That which became Article 17 on Protecting the integrity of the person (then Draft Article 12 bis) was introduced after the 5th session. See 5th Session Report by the Coordinator, 2005, pp. 14-16, paras. 58-67 and Status of the Text Following the Discussion Held during the Fifth Session of the Ad Hoc Committee [hereinafter 5th Session Status of the Text, 2005], Annex III to 5th Session Ad Hoc Committee Report, 2005, pp. 27-28.

[161] See CRPD Working Text after 7th Session, 2006, pp. 15-16. IDC still argued during the 8th session for the inclusion of Draft 17 (2) in what became Article 15 on Freedom from torture or cruel, inhuman or degrading treatment or punishment and only as a second option, to be kept in what became Article 17 on Protecting the integrity of the person (while deleting all references allowing for involuntary treatment). The end result reflects the third option presented by IDC. See IDC, Correction to Compilation, Article 17 on Protecting the integrity of the person, 8th Session, 2006.

[162] As noted above in note 66, Part II, this concerns how far the prohibition of indirect discrimination reaches. For the coverage of indirect discrimination by Article 5 on Equality and non-discrimination, see below under 7.3.4.

sionals" is a violation of Articles 12 and 17.[163] Taken together with the position of the Committee on the implications of Article 5 on Equality and non-discrimination discussed above under 7.1.1., its position emerges as that health intervention without consent, either explicitly justified by an impairment or which disproportionately affect the constituency of the CRPD equals a violation of Article 17.

Turning to the approaches to disability explored in Part I, the reasoning above under Article 15 applies equally here as Article 17 also primarily concerns medical and other interventions targeting the person, and particularly unwanted such interventions.

7.2.8. Article 18 on Liberty of movement and nationality

Article 18 (1) requires States to "recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their own residence and to a nationality, on an equal basis with others". This includes ensuring, according to 18 (1a) "the right to acquire and change a nationality and [not to be] deprived of their nationality arbitrarily or on the basis of disability" and, according to 18 (1b), not to be deprived "on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement".

States must also ensure, according to 18 (1c), that persons with disabilities are "free to leave any country, including their own" and, according to 18 (1d), that persons with disabilities are not deprived "arbitrarily or on the basis of disability, of the right to enter their own country".

Article 18 (2) situates the question of nationality in relation to children with disabilities and adds the right to a family. It requires that children with disabilities be "registered immediately after birth and [that they] shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents".

To conclude, liberty of movement covers choice of residence, leaving any country, entering one's own country and utilising immigration proceedings. Nationality covers the right to acquire and change nationality, not to be deprived of one's nationality "arbitrarily or on the basis of disability" and not to be deprived of documentation in relation to nationality and identification. To this, Article 18 (2) adds an, albeit qualified, right to know and be cared for by one's parents. In sum, the main focus of Article 18 is the equal recognition of the person with disabilities as a citizen and the equal right to move unrestricted, with ensuing opportunities, inside and outside one's country.

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[163] CRPD Draft General Comment on Article 12, para. 38.

Turning to the approaches to disability explored in Part I, their focus is on the movement, rather than the nationality aspect of Article 18. In addition, their focus is on informal, practical barriers to movement rather than on formal, legal barriers as in prohibitions and denial of documentation which remains the focus of Article 18. This is so as persons with disabilities, particularly physical and sensory, often have been segregated from community life including its residential aspects by tangible attitudinal, communicative and physical barriers rather than by formal legal prohibitions. In an effort to link the former category of barriers with the latter, and thus portray the limited movement of persons with disabilities in known terms of injustice, Harlan Hahn refers to an inaccessible environment as "denial of liberty"[164] and frames it as denying "freedom of movement"[165]. He puts it that "[c]learly, anyone using a wheelchair who is confronted by insurmountable architectural barriers do not enjoy freedom of movement".[166] In the CRPD, the obligation to eliminate not only formal but practical barriers is provided in Article 19 on Living independently and being included in the community (see below) and Article 20 on Personal Mobility (see below under 9.1.10.). The negotiations mirrored this focus on practical rather than formal barriers to movement, and it was not until the 7th session that Article 18 was included in the CRPD to complement Article 20, which had been present since the Working Group.[167]

The provision on children connects to the threats to the lives of children with disabilities recognised by Oliver and Hahn above in relation to Article 10 on Right to life (7.2.1.). A name, being registered and acquiring a nationality is, in addition to being crucial for the entitlement to services, also a life insurance. The right of children to family life is discussed further below in relation to Article 23 on Respect for home and the family (7.2.12.).On the nationality aspect of Article 18, it is notable that ICF calls upon citizenship not only in order to request access to life opportunities by virtue of that citizenship but also covers the acquisition of that citizenship, as in "having legal status as a citizen".[168]

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[164] Hahn, 1987, p. 12 (source not paginated).

[165] Hahn, 1996, p. 55.

[166] Hahn, Harlan, Equality and the Environment: the Interpretation of "Reasonable Accommodation" in the Americans With Disabilities Act [hereinafter Hahn, 1993] Journal of Rehabilitation Administration, Vol. 17, 1993, p. 103.

[167] See Chair's Draft, 7th session, 2006, pp. 24-25, where what became Article 18 on Liberty of movement and nationality is still in brackets to indicate the lack of negotiations on specific language thus far.

[168] This is included as an instance of Activities and Participation part of "Political life and citizenship", in turn part of "Community, social and civic life". ICF, 2001, p. 170.

7.2.9. Article 19 on Living independently and being included in the community

Article 19 stipulates "the equal right of all persons with disabilities to live in the community, with choices equal to others". States "shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community". 19 (a) focuses place of residence; States are to ensure that "[p]ersons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement". Article 19 (b-c) recognise that this requires both access to and responsiveness of the community services used by others and additional services. 19 (b) obliges States to ensure that "[p]ersons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community". 19 (c) obliges States to ensure that "[c]ommunity services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs".

The focus of Article 19 is choice and inclusion and participation in the community, here realised through place and nature of residence and the services upon which this hinges. The anti-thesis of Article 19 is the traditional and still widespread institutionalisation of the constituency of the CRPD. As opposed to earlier drafts of the CRPD, Article 19 does not explicitly mention institutions. Instead it stipulates requirements which amount to the converse of this practice, particularly through the requirement "not [to be] obliged to live in a particular living arrangement".[169] Consequently, forcing a person to live in an arrangement which is isolated from the community and/or entails living together with others on account of impairment is a prima facie violation of Article 15, particularly if the force exerted is through a formal requirement. The question to what extent lacking resources to immediately change a policy and infrastructure of institutionalisation could be a valid excuse by States when the person is in fact deprived of the choice not to live in an institution due to the lack of alternatives provided, is harder to answer categorically and unequivocally. At a minimum the State must show that it actively pursues a change of such policy and infrastructure to provide alternatives living up to the standards set in

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[169] See e.g. Draft Article 15 (2b) on Living independently and being included in the community in the Working Group Draft which obliges the State to take measures to ensure that "persons with disabilities are not obliged to live in an institution or in a particular living arrangement". Working Group Draft, 2004, p. 20. IDC argued as late as the 7th session for the explicit prohibition of institutionalisation of children, by including "[i]n no case shall a child with a disability be institutionalised on the basis of his or her disability". This was justified as follows: "It is imperative to challenge the presumption by both professionals and parents that institutional care is the most appropriate accommodation for children with disabilities.". IDC Amendments to Chair's Draft, 7th Session, p. 40 (source not paginated).

Article 19.[170] As noted by two commentators, Article 19 "brings with it a presumption that independent living will be the default option for disabled people".[171]

The focus of Article 19 is creating opportunities for everyone to live in the community instead of the hitherto automatic segregation of person with disabilities. This is different from the focus of Article 14 on Liberty and security of person, as the latter article targets the intentional deprivation of liberty for a particular person, due to inference of present or future consequences of impairment. In reality, these articles overlap as they both concern the mechanisms of removing persons from community life for reasons connected to perceptions of impairment as well as to questions of resources. Compared to Article 18 on Liberty of movement and nationality, the focus of Article 19 is *living arrangements within the community*, rather than movement between life contexts and on a local, regional, national and international scale.

Turning to the approaches to disability explored in Part I and beginning with the Social Model of Disability, inclusion in the community was at the heart of UPIAS. They called for the provision of services in the community to replace institutions, referring to the latter as "the ultimate human scrap-heaps of this society".[172] It was a

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[170] The relationship to available resources of what became Article 19 was on the table already in the Working Group. A footnote to Draft Article 15 (2b) reads: "Some members of the Working Group, while accepting the principle, thought that States Parties would find it impossible to guarantee this obligation without exception.". Working Group Draft, 2004, p. 20, note 52. Similarly, footnote 53 states the following relating to the provision of services in the community: "Some members of the Working Group considered that it would be difficult for States Parties to ensure the availability of the services described in paragraphs 1(c) [that persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance, necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community] and (d) [community services for the general population are available on an equal basis to persons with disabilities and are responsive to their needs], and in particular the undertaking in paragraph 1(c) to provide personal assistance.". Ibid., note 53. The end result will depend on the characterisation of this article or not as a "social right", which would render is subject to Article 4 (2) on General obligations, stating that "[w]ith regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law". Serbia and Montenegro highlighted the 'mixed' character of what became Article 19 (then Draft Article 15) in this regard, linked to the issue of resources, during the 7th session: "The rights in this article are primarily economic and social, and therefore subject to progressive realization. This is complicated by the centrality of freedom of choice in the article, which has more immediate implementation implications. Countries in transition may have difficulty guaranteeing the right to freedom of choice in the context of personal assistance.". In response, the Chair stated that "most of the elements of Article 19 are economic, social and cultural rights. The measures needed to incorporate such elements will need to be both appropriate and progressively implemented". Daily Summaries 20 January 2006, 7th Session.

[171] Clements, Luke and Parker, Camilla, The UN Convention on the Rights of Persons with Disabilities: A New Right to Independent Living?, European Human Rights Law Review, Vol. 4, 2008, p. 523.

[172] UPIAS, 1974, para. 6. See also Ibid., para. 10: "The Union is opposed to the building of any further segregated institutions by the State or by voluntary organisations. We believe that providing adequate services to people in their own homes is a much better use of resources.".

central aim of UPIAS "to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society".[173] Like Article 19, UPIAS call for "real choice", expressed as "a situation where as physically impaired people we all have the means to choose where and how we wish to live".[174] UPIAS note as well that as long as the focus remains on segregated facilities, the resources for realising participation in the community will remain tied up:

> While any of these institutions are maintained at a huge cost, it is inconceivable that we will all receive in addition the full resources needed to provide us with a genuine opportunity to live as we choose. This point applies not just to residential homes, hospital units, hostels, villages and settlements, but also to other kinds of segregated facilities.[175]

Inclusion in the community is similarly central to Michael Oliver, as evidenced in his adoption of the UPIAS definition of Disability, equating Disability as it does with exclusion from "the mainstream of social activities".[176] He notes that State welfare (in the case of the UK) has taken away "the citizenship rights of disabled people":

> Examples of this include the provision of segregated residential facilities […] which deny some disabled people to live where they choose, not necessarily maliciously but because to live in such an establishment means that individuals are regarded as being adequately housed; consequently there is not statutory duty on the housing authority to house them.[177]

Harlan Hahn similarly focuses exclusion, emphasising the problems facing persons with disabilities as "*segregation* and inequality"[178] and "*segregation* and discrimination"[179]. He particularly notes how this extends to "everyday activities and public or residential structures within their [disabled peoples'] own communities".[180]

The focus of ICF on inclusion in the community flows from the categorisation of valuable life opportunities as Participation, connoting as it does "involvement".[181] Participation includes Domains such as "Community, social and civic life" which comprises "social life outside the family, in community, social and civic areas of life"[182] as well as "Domestic life" which covers, inter alia, "acquiring a place to live"[183]. As an

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[173] Ibid., initial paragraph on Aims. UPIAS notes however, that all may not agree: "The Union will try to assist anyone who seeks to move out - or stay out - of an institution. But we fully respect the feelings of individuals who regard institutional life as their best solution at the present time. We understand also that some disabled people will disagree with our views on segregation, and we hope that they will organise to put forward their arguments too.". Ibid., para. 10.

[174] Ibid., para. 11.

[175] Ibid.

[176] Oliver, 1981, p. 28.

[177] Oliver, 1996, p. 52.

[178] Hahn, 1996, p. 43. Emphasis added.

[179] Ibid., p. 54. Emphasis added.

[180] Ibid., p. 55.

[181] WHO, 2001, p. 15, note 14.

[182] Ibid., p. 168.

[183] Ibid., p. 153.

Environmental factor, the Domain "Services, systems and policies" includes "General social support services, systems and policies" which are explained as "[s]ervices, systems and policies aimed at providing support to those requiring assistance in areas such as shopping, housework, transport, self-care and care of others, in order to function more fully in society".[184]Another Environmental factor is the Domain "Support and relationships" which is explained as "people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities".[185] From this it can be concluded that ICF envisages life as integrated in the community, made possible through accessible services.

Finally, ICIDH (particularly through the inclusion of the Handicap category) sets its aim as the inclusion in mainstream life, addressing life for its constituency as "moving as it does, between home and work".[186] Simultaneously it envisages institutional arrangements stemming from the "need" of the person: "Physical independence handicap" includes "need for residential care in order to be looked after", "need for institutional care in order to provide supervision, such as for behaviour that is socially unacceptable" and "need for institutional care in order to provide restraint of behaviour".[187]

7.2.10. Article 21 on Freedom of expression and opinion, and access to information

According to the chapeau of Article 21 "States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice". The chapeau refers back to the definition of communication in Article 2, according to which "[c]ommunication" is defined broadly and inclusively as "includ[ing] languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology".

According to 21 (a) which reads as the heart of Article 21, the obligations flowing from this article include "[p]roviding information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost". 21 (b) similarly concerns official dealings, requiring States to "[a]ccept […] and facilitat[e] the use of sign languages, Braille, augmentative and alternative communications, and all other

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[184] Ibid., p. 202.
[185] Ibid., p. 187.
[186] WHO, 1980, p. 25.
[187] Ibid., p. 190.

accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions". 21 (e) exceeds this obligation of acceptance and facilitation in relation to sign languages by requiring States to "[r]ecogniz[e] and promot[e] the use of sign languages".

Article 21 (c-d) concern the accessibility of information provided by private actors to the public, including information supplied by Internet providers and the media. 21 (c) requires States to "[u]rg[e] private entities that provide services to the general public, including through the internet, to provide information and services in accessible and useable formats for persons with disabilities". 21 (d) obliges States to "[e]ncourag[e] the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities".

In sum, Article 21 is about making information available to everyone and making sure that everyone can participate in different social contexts involving communication. This is to be achieved by opening up social interaction through the use of accessible means, modes and formats of communication. As recognised in Article 21 this requires change in both the public and the private sphere, and key aspects of such change are choice, cost and timeliness.

Turning to the approaches to disability explored in Part I, like Article 21, they focus on overcoming practical rather than formal barriers. Their main target is the provision of accessible alternatives to the information and communication already flowing but denied persons with disabilities, rather than generally ensuring that the State does not actively restrict the flow of information and communication. Beginning with the Social Model of Disability, albeit UPIAS focuses on physical rather than information and communicative barriers, analogies are easily made to the accessible communicative and information environment demanded by Article 21. Indeed, UPIAS mentions "people who are blind, or deaf, or cannot speak" as examples of others facing exclusion.[188] In addition, Article 21 is key to being in control of one's own affairs, such as for example receiving personal information directly rather than through family or friends, which is key to UPIAS. Michael Oliver, in discussing the widening of the constituency of the Social Model of Disability, refers to Victor Finkelstein in concluding that the Social Model of Disability "can also take in sensory impairments" and gives examples of communicative barriers.[189]

Harlan Hahn similarly includes "persons with sensory [...] disability"[190] under the Minority Group Model of Disability and notes that "[c]learly, [...] anyone with a vision or hearing impairment who must rely exclusively on printed or oral modes of communication cannot be said to have complete freedom of speech".[191]

ICF includes "Communication" as a Domain of Activities and Participation and includes here the use of languages and modes of communication such as sign-lan-

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[188] UPIAS, 1975, p. 15.

[189] Oliver, 1981, p. 30.

[190] Hahn, 1987, p. 9 (source not paginated).

[191] Hahn, 1993, p. 103.

guage and Braille.[192] In addition, the Domain of Activities and Participation titled "Community, social and civic life" in turn includes the category "Political life and citizenship" which covers "the rights of [inter alia] freedom of speech".[193] The role of the environment in relation to communication is recognised under Environmental factors as the Domain "Products and technology" which in turn includes the category "Products and technology for communication", covering "[e]quipment, products and technologies used by people in activities of sending and receiving information, including those adapted or specially designed, located in, on or near the person using them".[194] In addition, the Domain "Services, systems and policies" includes the category "Communication services, systems and policies", which in turn includes "[s]ervices, systems and policies for the transmission and exchange of information"[195] as well as the category "Media services, systems and policies", which in turn includes "[s]ervices, systems and policies for the provision of mass communication through radio, television, newspapers and internet"[196].

Finally, in ICIDH, one of the categories of Handicap is "Orientation handicap" which is defined as "the individual's ability to orient himself in relation to his surroundings".[197] However, what is measured is the ability of the person relating to "seeing, listening, touching, speaking"[198] and not as in Article 21 the modalities of the surroundings in enabling expression, communication and accessing information.

7.2.11. Article 22 on Respect for privacy

According to Article 22 (1) "[n]o person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interferences with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation". In addition, "[p]ersons with disabilities have the right to the protection of the law against such interference or attacks".

A major concern when drafting Article 22 was the exposed situation of persons currently living in institutions.[199] Similar to Article 19 on Living independently and being included in the community, Article 22 does not mention institutions. However, to make sure that the guarantees of Article 22 (1) none the less are applied

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[192] WHO, 2001, p. 134.
[193] Ibid., p. 170.
[194] Ibid., p. 175.
[195] Ibid., p. 196.
[196] Ibid., p. 199.
[197] WHO, 1980, p. 185.
[198] Ibid.
[199] See e.g. Daily Summaries 8-9 January 2004, Working Group Session.

in existing institutional settings, the provision is explicitly phrased as being applicable "regardless of place of residence or living arrangement".[200]

Article 22 (2) safeguards the privacy of information concerning the person by obliging States to "protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others". To conclude, in addition to explicitly extending respect for privacy to persons with disabilities Article 22 is shaped to target circumstances particularly relevant to persons with disabilities, as in institutionalisation (albeit implicitly only) and the privacy of records containing professional measurements and evaluations concerning the person which can lead to disadvantage if inappropriately shared.

Turning to the approaches to disability explored in Part I and beginning with the Social Model of Disability, UPIAS notes the potential for violations of "privacy" if "degree of disability" (quoting a proposal from the Disability Alliance) is to be the basis for allocation of benefits:

> The scene facing every physically impaired person, then, is of an army of "experts" sitting on panels which are set up all over the country. These "experts", armed with the latest definitions and tests for measuring, will prod and probe into the intimate details of our lives. They will bear down on us with batteries of questions, and wielding their tape measures will attempt to tie down the last remaining vestige of our privacy and dignity as human beings. To calculate the "degree of disability" they will be forced to snoop and spy.[201]

Michael Oliver brings up that such consideration also play out when provision are decided based on means as "[t]he imposition of some assessment procedures deny some disabled people the right to privacy in that they may have to reveal details of all their financial affairs in order simply to be supplied with an aid to daily living".[202] Oliver also addresses the privacy deficit in residential living arrangements.[203]

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[200] Section 1 of Draft Article 14 on Respect for privacy, the home and the family in the Working Group Draft read: "Persons with disabilities, *including those living in institutions,* shall not be subjected to arbitrary or unlawful interference with their privacy, and shall have the right to the protection of the law against such interference.". Working Group Draft, 2004, p. 18. Emphasis added. This was removed due to concerns that it would take the emphasis of the fact that this entitlement was to apply equally in all living arrangements (see the discussion of the proposal by the EU which ended up the basis for the final text, recorded in Daily Summaries 2 February 2005, 5th Session) and that the recognition of institutions was tantamount to their acceptance. IDC made the latter point during the 4th session: "Although the Caucus appreciates the motivation for singling out people living in institutions in 14(1), doing so necessarily implies the existence of institutions in the future. It is preferable to use wording that ensures application of the article to all PWD [persons with disabilities], regardless of the individual's circumstances.". Daily Summaries 27 August 2004, 4th Session. Draft Article 14 was later split during the 5th session into what became Article 22 on Respect for privacy and Article 23 on Respect for home and the family. See Daily Summaries 2 February 2005, 5th Session and Draft Article 14 and Draft Article 14 bis in 5th Session Status of the Text, 2005, pp. 29-30.

[201] UPIAS, 1975, pp. 17-18.

[202] Oliver, 1996, p. 52.

[203] Oliver, 1983, p. 95.

Harlan Hahn brings up issues regarding the privacy of health information, noting that this actualises “the right to privacy”[204] and that the abuse of this right through the unwanted disclosure of health information is likely to lead to other forms of abuse, including lack of access to services based on assumptions about connections between health states and quality of life.[205]

ICF, through its Annex on Ethical Guidelines for the Use of ICF, also relates to 22 (2). It calls for that “the information coded using ICF should be viewed as personal information and subject to recognized rules of confidentiality appropriate for the manner in which the data will be used”.[206]

To conclude, the right to privacy has many dimensions and some of these have accentuated relevance for persons with disabilities, such as assessment procedures in order to qualify for different forms of assistance and the confidentiality of records addressing “health and rehabilitation”. The latter aspect of protection is expressly recognised in Article 22 (2) and protection in relation to the former aspect will hinge upon the extent to which such procedures are regarded as “arbitrary or unlawful” (22 (1)).

7.2.12. Article 23 on Respect for home and the family

According to Article 23 (1) States “shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others”. 23 (1a) concerns marriage and calls for measures to ensure that “[t]he right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized”. 23 (1b) concerns childbearing and calls for measures to ensure that “[t]he rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and [that] the means necessary to enable them to exercise these rights are provided”. 23 (1c) targets the widespread practice of sterilisation targeting segments of the constituency of the CRPD by calling for measures to ensure that “[p]ersons with disabilities, including children, retain their fertility on an equal basis with others”. The reference to children is aimed at counteracting the lacuna created by the limited recognition of the legal capacity of children; now a choice made by a parent on behalf of a child (alone or together with medical professionals) must hold up to the scrutiny of 23 (1c).[207]

Article 23 (2) concerns child-rearing. States “shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trust-

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[204] Hahn, 2002a, p. 4.

[205] See Ibid., pp. 4-12.

[206] WHO, 2001, p. 244.

[207] See further below under 12.1.4.

eeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interest of the child shall be paramount". In order to exercise the responsibilities of child-rearing, States "shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities".

Article 23 (3) similarly concerns child-rearing but focuses on the relationship between the child with disabilities and his or her family. It obliges States to "ensure that children with disabilities have equal rights with respect to family life". To this end, and "to prevent concealment, abandonment, neglect and segregation of children with disabilities", States Parties undertake to provide "early and comprehensive information, services and support to children with disabilities and their families".

Article 23 (4) contains safeguards against the forcible separation by the State of children and parents based on impairment. Accordingly, States "shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interest of the child". In addition to these safeguards regarding legislation and judicial review, 23 (4) explicitly states that "[i]n no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents". As discussed in numerous places above, this means that impairment cannot per se amount to ground for separation. However, the question remains to what extent general criteria which overlap disproportionately with impairment are permissible, in other words, what amounts to separation "on the basis of a disability".[208]

Article 23 (5) emphasises the importance of growing up in a family setting when the primary aim of remaining in one's immediate family, expressed through 25 (4-5), has failed. Accordingly, States "shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting".

To conclude, Article 23 is unequivocal on the role of adults with disabilities as spouses and parents and emphasises the role of the State in enabling families to keep and to cater to the requirements of their children with disabilities. This is to be done through the provision of information to change perceptions and attitudes, as well as through assistance in carrying out parenting responsibilities. The potential value of family life is emphasised all the while its current shortcomings ("concealment, abandonment, neglect and segregation") are recognised with an explicitness otherwise avoided in the CRPD. Although Article 23 does not mention the institutionalisation of children, the emphasis on "a family setting" in 23 (5) and the express condemnation of "segregation" in 23 (3) establishes the unacceptability of this currently widespread practice.

Turning to the approaches to disability explored in Part I, marriage, relationships and family life (including parenthood for persons with disabilities and the access of

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[208] See above under 7.1.1., 7.2.3.-7.2.5. and 7.2.7. and below under 7.3.4.

the child with disabilities to his or her family) are not strong themes within the Social Model of Disability or the Minority Group Model of Disability. Having said that, it remains that these approaches are firmly against segregation and institutionalisation, which represents the ultimate negation of these aspects of life.[209]

ICF includes "Domestic life" as a Domain under Activities and Participation which includes the category "Assisting others" where children are explicitly mentioned.[210]. Furthermore, Activities and Participation include the Domain "Interpersonal interactions and relationships", in turn containing the category "Family relationships", which is explained as "[c]reating and maintaining kinship relationships, such as with members of the nuclear family, extended family, foster and adopted family and step-relationships, more distant relationships such as second cousins, or legal guardians".[211] The Domain "Interpersonal interactions and relationships" also contains the category "Intimate relationships" which is explained as "[c]reating and maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners".[212] Finally, the category "General social support services, systems and policies" among Environmental factors in the Domain "Services, systems and policies" includes such services, systems and policies "aimed at providing support to those requiring assistance in areas such as [...] care of others, in order to function more fully in society".[213]

Finally, ICIDH mentions "discharging the responsibilities customarily expected of a parent bringing up young children" under "Occupational handicap". [214] Here, ICIDH indirectly takes the effect of the environment into account when assigning to a particular category, as "Adjusted occupation" entails "having to make special arrangements to allow [...] looking after children (e.g., by compensatory role adaptation by spouse [or] by some extra support from social net-work)".[215] Contrary to ICF, such assistance is not categorised and measured *per se*, instead it qualifies the individual (or rather his or her 'ability') for a different categorisation. In addition, "Behaviour disabilities" include the category "Parental role disability" which includes restrictions in "undertaking and performance of child care tasks".[216] In relation to marriage, the category "Restricted participation" under "Social integration handicap" includes "individuals who do not participate in the full range of customary social activities, such as those with impairments or disabilities that interfere with opportunities for marriage".[217] Consequently, marriage is recognised as a valuable

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[209] Oliver addressed marriage in Oliver, 1983, pp. 76-79 and deplores the restrictions of the family life of children consequent upon a focus on rehabilitation in Oliver, 1996, p. 107. Hahn refers in general terms to "social interactions with families, neighbours and friends". Hahn, 2002, p. 177.

[210] WHO, 2001, pp. 157-158.

[211] Ibid., p. 162.

[212] Ibid., p. 163.

[213] Ibid., p. 202.

[214] WHO, 1980, p. 196.

[215] Ibid.

[216] Ibid., p. 151.

[217] Ibid., p. 199.

life opportunity, but problems in this regard are put down to the Impairment or Disability. Relating to children, under “Social integration handicap”, the category “Socially isolated” is included which contains, inter alia, “children in an orphanage or otherwise abandoned” whose “capacity for social relationship is indeterminable because of their isolated situation”. Notably, this situation is explicitly attributed to “lack of social support in the home or community”, i.e. to the environment.[218]

7.2.13. Article 24 on Education

Article 24 (1) starts by declaring that States “recognize the right of persons with disabilities to education”. Towards the end of “realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning”. According to 24 (1a), such education is to be directed towards “[t]he full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity”.[219] According to 24 (1b), such education is to be directed towards “[t]he development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential”.[220] In addition, according to 24 (1c) such education is to be directed towards “[e]nabling persons with disabilities to participate effectively in a free society”.

Article 24 (2) elaborates aspects of this right further. 24 (2a) targets the core of the principal current problem, that is, segregation. Accordingly, States shall ensure that “[p]ersons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability”. 24 (2b) addresses the availability of primary and secondary education in the community by obliging States to ensure that “[p]ersons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live”. 24 (2c) emphasises the need for individual solutions by obliging States to ensure that “[r]easonable accommodation of the individual’s requirements is provided”.[221] Article 24 (2d-e) continue in the same vein. 24 (2d) obliges States to ensure that “[p]ersons with disabilities receive the support required, within the general education system, to facili-

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[218] Ibid., p. 200.

[219] The reference to “human diversity” is a new addition compared to ICESCR Article 13 and CRC Article 29. On the question from China on the meaning of this, recorded as the expression of “confusion as to whether “human diversity” referred to cultural diversity or biodiversity”, the Chair is recorded as clarifying that ““human diversity” refers to the variety of shapes, sizes, abilities and disabilities found in the human population”. Daily Summaries 24 January 2006, 7th Session.

[220] The reference to “mental and physical abilities” originates from CRC Article 29 (1a).

[221] Compare the definition of “[r]easonable accommodation” in Article 2 on Definitions, reproduced below under 7.3.4.

tate their effective education". 24 (2e) further elaborates such support by obliging States to ensure that "[e]ffective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion".

Article 24 (3) concerns particular aspects of education, namely life and social development skills. States "shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community". States shall take "appropriate measures" to this end, which includes, according to 24 (3a) "[f]acilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring". According to 24 (3b), such measures include "[f]acilitating the learning of sign language and the promotion of the linguistic identity of the deaf community". Finally, 24 (3c) addresses the learning environment from the view-point of the communication needs of persons with sensory disabilities by stating that obligations include "[e]nsuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development".

The general rule and presumption of, and indeed the change sought after by Article 24 is education in the mainstream setting with the provision of the necessary support and accommodations. Here, 24 (3c) carves out a tightly circumscribed exception for the named groups. The final phrasing of this paragraph was the result of much tweaking and remains so indirectly phrased that you would not know at a first glance what is sought after. In effect, the function of the phrasing "environments which maximize academic and social development" (without the equivalent of the reference in 24 (2e) to "consistent with the goal of full inclusion") is to open up for the education of the groups of students mentioned together with students with similar impairments. Regulation to this effect was ardently called for by representatives from WBU, World Federation of the Deaf (WFD) and World Federation of the Deafblind (WFDB) with reference to the particular communication requirements of these groups.[222]

The main aim of the negotiators in relation to education was always to end the widespread segregation of the constituency of the CRPD. However, earlier versions of Article 24 explicitly opened up for "special and alternative" settings as an option extending outside the groups now mentioned in 24 (3c).[223] As the negotiations

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[222] See e.g. written submission for the 6th session by World Federation of the Deaf (WFD), WBU and World Federation of the Deafblind (WFDB), Article 17, Statement on Inclusive Education for Persons Who are Deaf, Blind and Deafblind: The Rationale for Choice in Education, 6th Session, 2 August 2005.

[223] See Draft Article 17 (3) of the Working Group Draft:
"3. States Parties shall ensure that where the general education system does not adequately meet the needs of persons with disabilities special and alternative forms of learning [footnote] should be made available. Any such special and alternative forms of learning should: [footnote]

proceeded, the desire for a clear-cut obligation on behalf of the State to provide mainstream education led to the focus on inclusion in 24 (1-2) and the tightly circumscribed exception in 24 (3c) of the final text of the CRPD.[224] While the possibility for alternative educational solutions outside of the tightly circumscribed group identified in 24 (3c) can be interpreted as flowing from 24 (2e), the overwhelming presumption remains education in inclusive settings.[225]

Article 24 (4) concerns the employment and training of professionals and staff in the educational system. Accordingly, States "shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education". This training shall cover "disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities".

Article 24 (5) explicitly mentions levels of education primarily targeting adults. States "shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and life long learning without discrimi-

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(a) Reflect the same standards and objectives provided in the general education system;

(b) Be provided in such a manner as to allow children with disabilities to participate in the general education system to the maximum extent possible; [footnote]

(c) Allow a free and informed choice between general and special systems;

(d) In no way limit the duty of States Parties to continue to strive to meet the needs of students with disabilities in the general education system.".

The controversy surrounding mainstream or separate education is visible from a footnote attached to Draft Article 17 (3): "[…] Different approaches were also identified with respect to setting out the relationship between the provision of specialist education services and the general education system. Some members considered that education of children with disabilities in the general education system should be the rule, and the provision of specialist education services the exception. Others thought that specialist education services should be provided not only where the general education system was inadequate, but should rather be made available at all times without a presumption that one approach was more desirable than the other. Some members of the Working Group, for example, highlighted the need for deaf and blind children to be allowed to be educated in their own groups. If the latter approach were to be taken, the Working Group considered that there should still be an explicit obligation on the State to make the general education system accessible to students with disabilities, without limiting the individual's ability to choose either the general system or the specialist services.". Working Group Draft, 2004, pp. 22-23.

[224] Some wanted to retain the explicit recognition of an open-ended claim to alternative education in the Working Group Draft, see e.g. the submission for the 7th session by Jackson, Richard S., on behalf of The National Society for Children and Adults with Learning Disabilities and their Families, (RESCARE), Letter dated 5 January 2006, 7th Session. Others argued against even a circumscribed right to alternative settings: "Article 17 should fully reflect the social model of disability, focusing government obligations on removing the barriers to full participation in education by persons with disabilities. Education of some learners in separate settings because of their disabilities or impairments reflects and perpetuates a view of disability premised on the medical and charity models of disability.". Centre for Studies on Inclusive Education (CSIE), Ending Segregation – Inclusive Education for All Children [hereinafter CSIE, Paper on Inclusive Education, 5th Session], 5th Session, 2005, p. 1.

[225] For a thorough account of the drafting history of Article 24 and its implications in this regard, see Arnardóttir, Oddný Mjöll, The Right to Inclusive Education for Children with Disabilities – Innovations in the CRPD, in Eide, Asbjørn et al. (Eds.), Making Peoples Heard: Essays on Human Rights in Honour of Gudmundur Alfredsson, Brill, The Netherlands, 2011, pp. 208-227.

nation and on an equal basis with others". As in relation to the levels of education covered in 24 (2) States "shall ensure that reasonable accommodation is provided to persons with disabilities".

To conclude, the focus of Article 24 is on inclusion, requiring as it does "an inclusive education system". To this end, the requirements of each individual must be catered for within this system, including through reasonable accommodation and other support measures. Notwithstanding the openings for segregated education in Article 24, each dimension of segregated or alternative settings or modes of education (which place themselves somewhere between 'complete segregation' and 'complete inclusion') must be justified against the standard of "academic and social development". Such settings or modes particularly beg the question if they target groups other than those explicitly mentioned and/or are against the choice of the individual in question and/or (if applicable) his or her parents or likewise.

Turning to the approaches to disability explored in Part I and beginning with UPIAS, the main theme of Article 24, inclusion, resonates with their core message. Indeed, UPIAS note that "a real opportunity of equal participation in normal educational [...] activities" necessitates ending the spending on "vastly expensive special schools, colleges and day-centres".[226] Michael Oliver similarly concludes that in "the struggle of disabled people for inclusion [...] special, segregated education has no role to play".[227]

Against the backdrop of the exemption explicitly made for persons with sensory disabilities in Article 24 of the CRPD, it should be noted that UPIAS address only persons with physical disabilities and that this remains the core focus of Michael Oliver as well. The same must be noted regarding Harlan Hahn, who expresses a similar general view on segregated education. He deplores that "[m]ost disabled children in America have been assigned to "special" or separate schools".[228] Furthermore, Hahn notes that "[a]lthough the "minority group model" clearly supports the integration of schools", meaningful integration requires a change of attitude towards disabled children. [229]

Turning to ICF, "Education" is one of the "Major life areas" covered as Activities and Participation.[230] In addition, the Domain "Products and technology" under Environmental factors in turn contains the category "Products and technology for education" which is explained as "[e]quipment, products, processes, methods and technology used for acquisition of knowledge, expertise or skills, including those adapted or specially designed".[231] Similarly, the Domain "Services, systems and policies" in turn contains the category "Education and training services, systems and policies" which is explained as "[s]ervices, systems and policies for the acquisition,

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[226] UPIAS, 1974, para. 11.

[227] Oliver, 1996, pp. 93-94.

[228] Hahn, 1985, p. 94.

[229] Hahn, 1987, p. 16 (source not paginated).

[230] WHO, 2001, p. 164.

[231] Ibid., p. 175.

maintenance and improvement of knowledge, expertise and vocational or artistic skills".[232] ICF addresses education without any reference to 'alternative' or 'segregated' education.

Turning to ICIDH, it contains references to mainstream as well as to "special" education. The category "Curtailed occupation" under "Occupational handicap" includes "children able to attend normal school but who suffer from disabilities that restrict participation in all the activities of the school".[233] In addition, the category "Restricted occupation" under "Occupational handicap" includes "disabilities that preclude a child from attending a normal school (e.g., the need to attend a special establishment for disabled children, where such exists)".[234] Finally, the category "Confined occupation" under "Occupational handicap" includes "disabilities that require the child to be resident in an institution for purposes of education (where such exists), or to be educated at home (where this is not customary)".[235] In all cases, these situations are portrayed as predetermined by the individual child and not the environment.

7.2.14. Article 27 on Work and employment

Article 27 (1) opens by declaring that States "recognize the right of persons with disabilities to work, on an equal basis with others". This includes "the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities". States are obliged to "safeguard and promote the realization of the right to work […] by taking appropriate steps, including through legislation". This obligation is explicitly extended to "those who acquire a disability during the course of employment".

Article 27 (1a-k) elaborate further the steps to be taken to achieve opportunities in the open labour market. 27 (1a) obliges States to take steps to "[p]rohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions". 27 (1b) somewhat overlaps with 27 (1a) through stipulating that such steps shall "[p]rotect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances". 27 (1c) addresses the organisation of workers by requiring that measures to be taken by States include steps to "[e]nsure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others". 27 (1d) covers technical and voca-

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[232] Ibid., p. 204.

[233] WHO, 1980, p. 195.

[234] Ibid., p. 197.

[235] Ibid.

tional guidance through requiring steps to "[e]nable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training". 27 (1e) covers the creation of employment opportunities by requiring steps to "[p]romote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment". 27 (1f) covers self employment through requiring steps to "[p]romote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business". 27 (1g) concerns the State as an employer by requiring steps to "[e]mploy persons with disabilities in the public sector". 27 (1h) concerns employment in the private sphere and requires the State to take steps to "[p]romote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures".[236] 27 (1i) concerns the need for the workplace to adapt to the individual by requiring steps to "[e]nsure that reasonable accommodation is provided to persons with disabilities in the workplace".[237] 27 (1j) focuses on work experience through requiring the State to take steps to "[p]romote the acquisition by persons with disabilities of work experience in the open labour market". Ending Article 27 (1), 27 (1k) addresses retaining work or returning to work by requiring steps to "[p]romote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities".

Finally, Article 27 (2) addresses forced labour through requiring States to "ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour".

Like Article 24 on Education, the aim of Article 27 is inclusion. The current largely segregated state of affairs is not mentioned and instead the goal is emphasised by calling for "a labour market and work environment that is open, inclusive and accessible to persons with disabilities". While everyone in the negotiations agreed with this general focus, some argued that since part of the constituency of the CRPD are currently employed outside the open labour market, explicit regulation of these settings is necessary to counter the currently widespread abuse there.[238] Some also argued that the importance of regulation was not only due to the fact that such settings de facto exist, but that they are a necessary part of the future as well in relation to "persons with disabilities who may be unable to work in the open labour market".[239] The arguments was that not all persons, even after the elimination of prejudice and

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[236] See further under 7.3.4. below on affirmative action.

[237] See further under 7.3.4. below where the definition of "[r]easonable accommodation" from Article 2 on Definitions is reproduced.

[238] See e.g. Israel Position Paper for the 7th Ad Hoc Committee - First week [hereinafter Israel Position Paper, 7th Session], 7th Session, 12 January 2006, and International Labour Organization (ILO), Chair's Text, ILO Technical Advisory Note [hereinafter ILO Technical Advisory Note on Chair's Text, 7th Session], 7th Session, 2006, pp. 3-6 (source not paginated). See also proposals by Israel and Namibia for the 3rd session, Compilation of Proposals before the 4th Session, 2004, pp. 61-62.

[239] ILO Technical Advisory Note on Chair's Text, 7th Session, p. 13 (source not paginated).

the provision of accommodation, will function in the open labour market or at least will need alternative employment as a transitory mechanism towards employment in the open labour market.[240] Opponents of explicitly regulating the conditions for and of alternative employment took the position that such forms of employment are undesirable and are to be phased out, and their role taken over by the required change of the open labour market. In addition, regulating alternative employment would be tantamount to accepting segregated settings.[241]

In the end, the well received argument that regulations must reach current segregated settings was appeased by the addition of 27 (1a) during the 7th session, stating that discrimination on the basis of disability is to be prohibited "with regard to all matters concerning *all* forms of employment".[242] The upshot is that any segregated setting qualifying as "employment" must live up to these requirements. Furthermore, while Article 27 does not explicitly outlaw segregated employment settings, it provides the constituency with "the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities". The focus of Article 27 is on creating opportunities to work in the open labour marker, i.e. to be neither forced nor 'herded' into a segregated employment sector. Hence, the designation of anyone to a segregated setting begs the question, and particularly so if it is against the preferences of that person. In sum, through the prominence of choice and inclusion in Article 27 as well as in the remainder of the CRPD it can be concluded that segregated employment opportunities as the only alternative for an individual, particularly one who wishes otherwise, is highly questionable.[243] Furthermore, in 27 (2), the worst variations of 'employment' are expressly outlawed.

Turning now to the approaches to disability explored in Part I of this book and beginning with UPIAS, it is clear that they see mainstream employment as the key to change. According to UPIAS, "[a]ll the other situations from which physically impaired people are excluded are linked, in the final analysis, with the basic exclusion

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[240] See numerous submission by ILO, e.g. Ibid., pp. 3-6, 13 (source not paginated).

[241] See e.g. the position of IDC in their proposal for the 6th session: "The IDC has rejected any mention of sheltered employment or any language suggesting that such employment fulfills the right to work of people with disabilities. In many places, "sheltered employment" means workplaces characterized by segregation and economic exploitation, where ordinary labor laws and rights do not apply. Such measures represent a limitation rather than a protection of our right to work and to gain a living by work which we freely choose.". IDC Information Sheet on Article 22 Right to work, 6th Session, 2005, p. 2 (source not paginated). See also recorded positions negative to the inclusion of references to alternative forms of employment by e.g. New Zealand (Daily Summaries 9 August 2005, 6th Session) and the EU (Daily Summaries 26 January 2006, 7th Session). For a thorough account and analysis of the negotiations of Article 27 on Work and employment in relation to "adapted work settings" see Ferraina, Sabrina, Analysis of the Legal Meaning of Article 27 of the UN CRPD: Key Challenges for Adapted Work Settings, European Association of Service Providers for Persons with Disabilities (EASPD), Brussels, 2012.

[242] Emphasis added. This text is based on a proposal by IDC for the 7th session. IDC Amendments to Chair's Draft, 7th Session, p. 56 (source not paginated).

[243] Compare e.g. Preamble (n) and Article 3 (a) on General principles.

from employment".[244] They also note that, in order for this to become reality, other aspects of life must be addressed:

> [P]hysically impaired school children are characteristically excluded from normal education preparatory to work, we are unable to achieve the same flexibility in using transport and finding suitable housing so as to live conveniently to our possible employment, and so on.[245]

UPIAS recognised the existence of segregated work and notes that "[p]eople in sheltered workshops or centres may ask our support in their struggles to improve their appalling rates of pay".[246] Achieving mainstream employment is likewise central to Michael Oliver.[247]

Like the Social Model of Disability, Harlan Hahn repeatedly problematises the unemployment rates for persons with disabilities, as well as the confinement of persons with disabilities to segregated employment and the condition therein. He deplores "the exploitation and indignity imposed on disabled persons who receive far less than the minimum wage in so called 'sheltered workshops'" and furthermore questions whether these can function as a road towards integrated employment.[248] Hahn is also explicitly positive to employment quotas.[249]

Turning to ICF, "Work and employment" is one of the "Major life areas" among "Activities and Participation".[250] In addition, the Domain "Products and technology" under Environmental factors contains the category "Products and technology for employment" which is explained as "[e]quipment, products and technology used for employment to facilitate work activities".[251] Also, the Domain "Services, systems and policies" contains the category "Labour and employment services, systems and policies" which is explained as "[s]ervices, systems and policies related to finding suitable work for persons who are unemployed or looking for different work, or to support individuals already employed who are seeking promotion".[252] ICF addresses employment without any reference to 'segregated' or 'alternative' employment.

Turning to ICIDH, it contains references to mainstream as well as to "sheltered" employment. "Occupational handicap" includes the category "Adjusted occupation" which includes "inability to follow customary occupation, but the individual is able to follow modified or alternative full-time occupation (including modifications to customary occupation because of disability, e.g., alterations at work place or provisions of special assistance or aids)".[253] In addition, the category "Restricted occupa-

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[244] UPIAS, 1975, p. 16.
[245] Ibid., p. 14.
[246] UPIAS, 1974, para. 18.
[247] See e.g. Oliver, 1996, p. 64.
[248] Hahn, 2001, p. 75.
[249] Hahn, 1987, p. 16 (source not paginated).
[250] WHO, 2001, pp. 165-166.
[251] Ibid., p. 176.
[252] Ibid., p. 205.
[253] WHO, 1980, p. 196.

tion" includes being "able to gain employment only under special circumstances (e.g., in a sheltered workshop)".[254] Finally, "Economic self-sufficiency handicap" includes the category "Economically inactive", which includes "individuals without family support who are unable to undertake economic activity by virtue of limited competence (such as that resulting from mental retardation)".[255] Notably, the determinants of the restrictions above are derived from both the environment and the individual.

7.2.15. Article 28 on Adequate standard of living and social protection

Article 28 (1) covers standard of living. It opens by declaring that States "recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions". States are obliged to "take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability".

Article 28 (2) covers social protection. It opens by declaring that States "recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability". Mirroring the previous section, States "shall take appropriate steps to safeguard and promote the realization of this right". 28 (2a-e) specify the ends towards which measures are to be taken. 28 (2a) requires measures to "ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable service, devices and other assistance for disability-related needs". 28 (2b-c) focuses poverty. 28 (2b) requires measures to "ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes". 28 (2c) requires measures to "ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care". 28 (2d) addresses housing and requires measures to "ensure access by persons with disabilities to public housing programmes". Finally, 28 (2e) addresses retirement through requiring measures to "ensure equal access by persons with disabilities to retirement benefits and programmes".

To conclude, Article 28 demands that persons with disabilities have access to the general safety nets providing for core aspects of existence: means for subsistence, food, water, clothing and housing. It also requires not only that existing programmes are extended to the constituency of the CRPD but also that programmes and services address "disability-related" needs.

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[254] Ibid., p. 197.

[255] Ibid., p. 204.

Turning to the approaches to disability explored in Part I of this book and beginning with UPIAS, they call for financial and other assistance by the State through assuring that "[o]f course the Union supports and struggles for increased help for physically impaired people, there can be no doubt about our impoverishment and the need for urgent change".[256] However, and herein lies the emphasis, this is not an alternative to the opportunity to earn ones living through employment:

> Financial and other help is placed here in relation to the achievement of independence and integration into ordinary employment. This is the fundamental principle by which schemes for meeting the financial and other needs of disabled people can be judged. This means that for people of working age financial and other forms of help must above all be geared to the retention or achievement of integrated employment.[257]

Michael Oliver similarly emphasises the problem of assistance which "effectively discourages many of those who struggle for autonomy and financial independence".[258]

Harlan Hahn echoes the same theme, deploring schemes which "compensate them [people with disabilities] with transfer payments for their inability to fulfil these requirement [the physical and behavioural standards established by the non-disabled]" instead of altering the environment.[259]

Turning to ICF, "Economic life" is one of the "Major life areas" among Activities and Participation.[260] This includes "Economic self-sufficiency" which is explained as "[h]aving command over economic resources, from private or public sources, in order to ensure economic security for present and future needs".[261] Environmental factors includes the Domain "Services, systems and policies" which in turn includes the category "Social security services, systems and policies". [262] The latter category is explained as "[s]ervices, systems and policies aimed at providing income support to people who, because of age, poverty, unemployment, health condition or disability, require public assistance that is funded either by general tax revenues or contributory schemes".[263]

Finally, ICIDH covers "Economic self-sufficiency handicap", which is explained as "the individual's [in]ability to sustain customary socioeconomic activity and independence".[264] Such self-sufficiency includes "economic self-sufficiency sustained by virtue of any compensation or standard disability, invalidity, or retirement pension that the individual receives or to which he may be entitled".[265]

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[256] UPIAS, 1975, p. 15.
[257] Ibid.
[258] Oliver, 1996, pp. 64-65.
[259] Hahn, 1996, p. 56.
[260] WHO, 2001, p. 166.
[261] Ibid., p. 167.
[262] Ibid., p. 201.
[263] Ibid.
[264] WHO, 1980, p. 202.
[265] Ibid.

To conclude, while all approaches emphasise the fundamental need for subsistence, particularly the Social Model of Disability and the Minority Group Model of Disability emphasise that social protection must not take the place of or otherwise interfere with employment opportunities.

7.2.16. Article 29 on Participation in political and public life

The chapeau of Article 29 starts out by obliging States to "guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others". In 29 (a-b) these undertakings are elaborated further. 29 (a) obliges States to "[e]nsure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected". Article 29 (ai-aiii) elaborate further the undertakings towards enabling participation in elections as a voter or a candidate. According to 29 (ai) such undertakings include "[e]nsuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use". 29 (aii) extends its coverage to holding office, stipulating the undertaking of "[p]rotecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate". Finally, 29 (aiii) addresses assisted voting through stipulating the undertaking of "[g]uaranteeing the expression of the free will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice".

Article 29 (b) requires States to "[p]romote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs". Article 29 (bi-bii) elaborate further these undertakings in relation to organisations, associations and political parties. According to 29 (bi), States undertake to encourage "[p]articipation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties". 29 (bii) emphasises the undertaking to encourage the "[f]orming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels".

To sum up, Article 29 covers three dimensions of political and public participation: to vote, to be elected and to hold office, and to participate in civil society. Regarding civil society, the opportunity to be part of organisations of persons with disabilities is emphasised in particular.

Turning to the approaches to disability explored in Part I and beginning with UPIAS, they emphasise in particular the aspect of politics covered in 29 (bii), through calling for the collective organisation of disabled people in a "great movement to raise our consciousness of our social identity".[266] Such organisation will in turn influence the general political process.[267] Michael Oliver similarly emphasises the organisation of disabled people as key. He celebrates the "collective self-confidence of disabled people to engage in their own political activities and no longer to be reliant on traditional forms of political articulation through the party system or single issue pressure groups".[268]

Harlan Hahn has increasingly emphasised the role of the Minority Group Model of Disability in the political process, recognising that this model "can be employed to promote political mobilisation that might eventually contribute to the growth of a disability constituency that could supplement the quest for civil rights with the exercise of significant political influence in the democratic process".[269] In order to exert such influence, he calls for permanent representation on local councils in order to ensure political influence.[270] In addition to this instrumental value of political organisation, Hahn (much like Michael Oliver)[271] emphasises the value for the person of political organisation, in the sense that it is conducive to "achieving a positive sense of personal and political identity".[272] Hahn recognises these two goals as mutually reinforcing.[273]

Turning to ICF, the Domain "Community, social and civic life" included among Activities and Participation contains the category "Political life and citizenship" which is explained as "[e]ngaging in the social, political and governmental life of a citizen, having legal status as a citizen and enjoying the rights, protections, privileges and duties associated with that role, such as the right to vote and run for political office, [and] to form political associations".[274] Environmental factors contains the Domain "Services, systems and policies which in turn contains the category "Political services, systems and policies".[275] This category is explained as "related to voting, elections and governance of countries, regions and communities, as well as international organizations".[276]

Finally, ICIDH does not touch upon the life opportunities addressed in Article 29 on Participation in political and public life.

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[266] UPIAS, 1975, p. 16.
[267] Ibid., p. 4.
[268] Oliver, 1996, p. 152.
[269] Hahn, 2001, p. 74.
[270] Ibid., p. 78.
[271] See e.g. Oliver, 1996, p. 89.
[272] Hahn, 1996, p. 55.
[273] See e.g. Hahn, 2002, p. 182 and Hahn, 1985, p. 100.
[274] WHO, 2001, p. 170.
[275] Ibid., p. 206.
[276] Ibid.

To conclude, all approaches save ICIDH recognise the importance of political life and the Social Model of Disability and the Minority Group Model of Disability emphasise in particular the importance of the collective organisation of their constituencies.

7.2.17. Article 30 on Participation in cultural life, recreation, leisure and sport

Article 30 (1) opens by declaring that States "recognize the right of persons with disabilities to take part on an equal basis with others in cultural life". States "shall take all appropriate measures" to ensure that persons with disabilities enjoy the life opportunities covered in 30 (1a-c). According to 30 (1a), such measures shall ensure enjoyment of "access to cultural materials in accessible formats". According to 30 (1b) such measures shall ensure enjoyment of "access to television programmes, films, theatre and other cultural activities, in accessible formats". Finally, according to 30 (1c) such measures shall ensure the enjoyment of "access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance".

In addition to taking part in the cultural life created by others, Article 30 (2) requires States to "take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society".

Article 30 (3) deals with intellectual property law as a potential barrier to accessibility. It requires States to "take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials".

Complementing access to and participation in 'mainstream' culture, 30 (4) acknowledges that persons with disabilities have a "specific cultural and linguistic identity" which shall be supported. It does so through requiring that "[p]ersons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture".

Article 30 (5) addresses recreation, leisure and sport. It stipulates its goal as "enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities" and obliges States to "take appropriate measures" to this end. 30 (5a) addresses mainstream sports and requires measures to "encourage and promote participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels". 30 (5b) addresses impairment specific sport and recreation through requiring measures to "ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources". 30 (5c) concerns accessible venues and requires measures to "ensure that persons with disabilities have access to sporting, recreational and tourism venues". 30 (5d) emphasises the needs of children by requiring measures to "ensure that children with disabilities have equal access with other children to participate in play, recreation and leisure and sporting activities, including those activities in the school system". Finally, 30 (5e) targets organisers of activities through requiring measures to "ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities".

To conclude, the dual theme of Article 30 is access to 'mainstream' activities as well as the opportunity to develop and take part in cultural activities related to ones identity as part of the constituency of the CRPD and in sporting activities which are particular to impairments covered by the CRPD.

Turning to the approaches to disability explored in Part I and beginning with UPIAS, their focus is on the access of disabled people to "a real opportunity of equal participation in normal […] leisure activities" which in their view will not become a reality as long as "separate holiday camps and hotels" remain.[277] Michael Oliver supplements the call for access to activities in the mainstream with the celebration of "the development of a disability culture and the public affirmation of this through the disability arts movement".[278] This celebration of a disability culture is echoed by Harlan Hahn who calls for "the discovery of what many of us call 'a disability culture'".[279] Consequently, Oliver and Hahn embrace the dual theme of Article 30.

Turning to ICF, the Domain "Community, social and civic life" included among Activities and Participation contains the category "Recreation and leisure" which is explained as "[e]ngaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programmes of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure".[280] Under Environmental factors, as part of the Domain "Services, sytems and policies", the category "Associational and organizational services, systems and policies"[281] is included, covering such services, systems and policies regarding "associations and organizations providing recreation and leisure, sporting, cultural, religious and mutual aid services".[282] The Domain "Products and technology" includes the category "Products and technology for culture, recreation and sport" which is explained as "[e]quipment, products and technology used for the conduct and

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[277] UPIAS, 1974, para. 11.

[278] Oliver, 1996, p. 152.

[279] Hahn, 2001, p. 60. See also Hahn, 1987, p.14 (source not paginated).

[280] WHO, 2001, p. 168.

[281] Ibid., p. 198.

[282] Ibid., p. 199.

enhancement of cultural, recreational and sporting activities, including those adapted or specially designed".[283] ICF thus explicitly covers the main categories of activities mentioned in Article 30, but makes no mention of any dimensions of culture, sports or leisure specific to the constituency of the CRPD.

Finally, ICIDH includes "play or recreation" under the category "Occupational handicap".[284] Such Handicap includes the category "Intermittently unoccupied" which is explained as "intermittent inability to follow customary occupation or leisure-time activities, e.g., because of interference by conditions such as epilepsy, migraine, or allergy, or because of occasional falls (with or without injury) in the elderly".[285] Notably, the reason for lacking occupation is found solely in the individual.

7.2.18. The coverage of composite life opportunities in the CRPD in light of ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

From the above, it emerges that when comparing the life opportunities recognised as valuable in the CRPD, as well as the threats to these, to the approaches to disability explored in Part I of this book, little principled discrepancy emerge. All approaches as well as the CRPD affirm the value of composite life opportunities such as education and employment for everyone, as well as recognise restrictions of such composite life opportunities as central problems.

Only a few features of the CRPD indicate that the range of composite life opportunities explicitly recognised therein is narrower than that explicitly recognised by one or more of the approaches explored in Part I or less than those promoted by the critique of these approaches included there. In the following I will bring out three such features: religious life, domestic life and focusing on 'normal' life.

Beginning with religious life, ICF explicitly recognises "Religion and spirituality" as a component of "Community, social and civic life". It defines the former as "[e]ngaging in religious or spiritual activities, organizations or practices for self-fulfilment, finding meaning, religious or spiritual value and establishing connection with a divine power, such as is involved in attending a church, temple, mosque or synagogue, praying or chanting for a religious purpose, and spiritual contemplation".[286] Under Environmental factors, the Domain "Products and technology" includes "Products and technology for the practice of religion and spirituality" which is explained as "[p]roducts and technology, unique or mass-produced, that are given or take on a symbolic meaning in the context of the practice of religion or spirituality, including those adapted or specially designed".[287]

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[283] Ibid., p. 177.

[284] WHO, 1980, p. 195.

[285] Ibid.

[286] WHO, 2001, p. 169.

[287] Ibid., p. 177.

Contrary to ICF, the CRPD does not explicitly refer to religion. Freedom of religion was discussed in the negotiation as part of the traditional human rights cluster of freedom of thought, conscience and religion.[288] These rights were discussed in relation to Article 30 on Participation in cultural life, recreation, leisure and sport as well as in relation to Article 21 on Freedom of expression and opinion, and access to information. Proposals were submitted throughout the negotiations and particularly a proposal by Kenya on the inclusion of religion into what became Article 30 was discussed and received support during the 3rd session of the Ad Hoc Committee.[289] The lack of explicit attention to this issue seems to stem from the apprehension that it is sufficiently protected in ICCPR and that no particular dimensions relating to disability merited the inclusion in the CRPD, as well as from fear of diluting standards (as cautioned by Ireland in the 3rd session as a response to the named proposal by Kenya).[290] While the above does not mean that the CRPD cannot be interpreted as covering this area of life, the fact remains that it lacks explicit recognition.[291] Similarly, the approaches to disability explored in Part I are clearly non-exhaustive in their accounts of valuable composite life opportunities.

Another potential discrepancy in coverage between ICF (as well as ICIDH) and the CRPD, again to the detriment of the latter, is attention paid to domestic life. As noted above under 3.7.2. the Social Model of Disability was implicated, with feminist key signature, for inducing a policy focus which encourages, or at least does not transgress, the division between public and private life to the detriment of the latter. Such criticism seems to stick both to the original UPIAS accounts as well as to later accounts of the Social Model of Disability by Michael Oliver, in view of their relative silence on domestic life and the pre-eminence they accord employment outside the home. Such criticism would likewise seem to stick to the Minority Group Model of Disability with its similar focus on employment outside the home, but not to ICIDH and ICF, due to their broad coverage explicitly including areas such as caring and domestic life. As mentioned above in relation to Article 23 on Respect for home

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[288] Compare ICCPR Article 18, CRC Article 14 and ICERD Article 5 (dvii).

[289] Daily Summaries 3 June 2004, 3rd Session. These issues were not included in any of the drafts of the CRPD and the Chair stated after the 6th session that the "general feeling" was not to include a reference to "participation in religious life" in what were to become Article 30 (Draft Article 24). 6th session Report by the Chairman, 2005, p. 23, para. 134. IDC proposed the inclusion of "freedom of thought, belief and conscience" (explicitly noting that this was intended to cover "religious beliefs") into what were to become Article 21 as late as the 8th session. IDC Amendments to CRPD Working Text, 8th Session, p. 34.

[290] Daily Summaries 3 June 2004, 3rd Session.

[291] Religion is explicitly recognised as a prohibited ground for discrimination in Preamble (p). This indicates that the obligations to "guarantee to persons with disabilities equal and effective legal protection against discrimination on *all grounds*" in Article 5 (2) on Equality and non-discrimination indeed extends to discrimination of the constituency of the CRPD based on religion (emphasis added). The coverage here is however different as it prohibits disadvantage based on religion in relation to the areas of life covered by the CRPD, rather than extend those areas of life to cover religious practice. However, as Article 1 sets the area of protection of the CRPD as "all human rights and fundamental freedoms", this subsumes religious practice, as well as issues of thought and conscience.

and the family, ICF includes as Activities and Participation the Domain "Domestic life", which includes "acquiring a place to live, food, clothing and other necessities, household cleaning and repairing, caring for personal and other household objects, and assisting others".[292] Such "others" include, inter alia, "children or members of the household who are sick" and "an elderly".[293] ICIDH, in turn, includes "the [in]ability to run a household in the accepted manner" under "Occupational handicap".[294]

This criticism accounted for above under 3.7.2. was forwarded from the perspective of women with disabilities (as women traditionally spend more time and energy in domestic dimensions of life than men) and as reflecting a general lack of attention to the circumstances of women. Notwithstanding this, its importance was noted in relation to both men and women. This criticism arguable sticks to the CRPD as well. In Article 23 of the CRPD on Respect for home and the family the issue of childbearing as well as child-rearing (including through adoption) is addressed, and assistance in the performance of such responsibilities is required. However, other domestic work such as taking care of a home or assisting other family members is not explicitly addressed in Article 23, nor is it envisaged by Article 27 on Work and employment. The upshot is that domestic activity, apart from childrearing, is largely invisible in the CRPD.

Yet another strand of critique launched at the Social Model of Disability, which seems applicable to all the other approaches as well as to the CRPD, is the assumption of the value of 'normal' life. This critique amounted to questioning an uncritical acceptance of life in the mainstream as valuable, including questioning the value of e.g. employment and family life. As noted above under 3.7.1.6. 'normal life' has thus been questioned as a possible curse rather than a blessing. Instead of rallying against the exclusion from mainstream life, the value of composite life opportunities such as being a parent or a spouse or employment is questioned and persons with disabilities are seen as fortunate for not so easily being drawn into the 'tyranny' of normal life. Another aspect of the focus on accessing 'normal' life opportunities is that the acceptance of societal norms on 'the good life' serves to strengthen these norms, producing those who by choice or otherwise do not enjoy such life opportunities as 'different' and thus as begging the question. One particular aspect of this mentioned was the habitually strong focus on employment.[295]

Turning to the approaches to disability explored in Part I and beginning with UPIAS, they do not explicitly address the rationale for their choice of composite life opportunities (the restrictions of which are defined as Disability). Instead the documents analysed emerge as, in essence, a call for the opportunities already accorded others to be extended to the constituency of UPIAS. The aims of UPIAS are expressed as "participating more fully in *ordinary* society"[296], "a real opportunity of

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[292] WHO, 2001, p. 153.
[293] Ibid., p. 158.
[294] WHO, 1980, p. 195.
[295] See above under 3.7.1.4.
[296] UPIAS, 1974, para. 3. Emphasis added.

equal participation in *normal* educational, work and leisure activities"[297] and, in the definition of Disability, as "participation in the *mainstream* of social activities"[298]. Furthermore, the ability of *all* to participate in gainful employment is emphasised.[299]

Michael Oliver questions the idea of "normality", but it is not obvious how far this critique extends from denouncing "normality" in relation to Impairment onto denouncing the composite life opportunities that make up mainstream life. Oliver questions the view of disabled people as wanting to achieve "normality" in the sense of "the normal life of the community" but follows on with examples which seem to rather address Impairment:[300]

> [I]ncreasingly the disability movement throughout the world is rejecting approaches based upon the restoration of normality and insisting on approaches based upon the celebration of difference. From rejections of the 'cure', through critiques of supposedly therapeutic interventions such as conductive education, cochlea implants and the like, and onto attempts to build a culture of disability based upon pride, the idea of normality is increasingly coming under attack.[301]

In criticising 'the theory of normalization'[302] Oliver targets the designation of certain "social roles" as those to be aspired as too limited, as it does not envisage a society in which "all roles are valued".[303] The thrust however seems to be his perception of an inevitable link between "normal" roles and "normal" people, as in "making individuals normal".[304] In other words, the core problem appears as that "normalization is part of a discourse which is predicated on the normal/abnormal distinction", and not the assumption that people want lives in the mainstream.[305] To conclude, as Oliver, like UPIAS, also criticises lack of access to mainstream life, it is not entirely clear what the implications of this critique of 'normality' are.[306]

Moving on to the Minority Group Model of Disability, the emphasis by Harlan Hahn on "'a disability culture'"[307] does not, against the background of his calling for access to "common social, economic and political activities"[308], amount to a call for

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[297] Ibid., para. 11. Emphasis added.

[298] UPIAS, 1975, p. 14.

[299] Ibid., p. 15.

[300] Oliver, 1996a, p. 44.

[301] Ibid.

[302] For a brief account of this theory and further references see Nirje, Bengt, How I Came to Formulate the Normalization Principle, in Flynn, Robert J. and Lemay, Raymond A., (Eds.) A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact, University of Ottawa Press, Ottawa, 1999.

[303] Oliver, 1999, p. 172.

[304] Ibid., p. 170.

[305] Ibid., p. 167.

[306] According to Oliver, the UPIAS definition of Disability "can accommodate the development of a politics of difference" as it does not refer to "the normal life of the community" but instead to "the mainstream of social activities". Oliver, 1996a, p. 44. He contrasts it with the DPI definition of disability which refers to "the normal life of the community", reproduced in Ibid., p. 41.

[307] Hahn, 2001, p. 60 and Hahn, 1987, p.14 (source not paginated).

[308] Hahn, 1985, p. 94.

an alternative life style denouncing the value of composite life opportunities in the mainstream of life.

Turning to ICF, the standard against which restrictions of Participation emerge, is "the population norm, which represents the experience of people without the specific health condition".[309] In other words, the standard for valuable composite life opportunities flows from the "norm", i.e. life as it plays out in the mainstream.

Moving on to ICIDH, the rationale presented for the choice of the particular categories constituting Handicap is that they represent "survival roles"[310] and that they have cross-cultural relevance.[311] The manual notes that Handicap is "a dangerously subjective realm"[312] and acknowledges that what is a Handicap is determined by "existing societal values" which are in turn influenced by "the institutional arrangements of society".[313]

> Any direct attempt to measure values is fraught with difficulties. However, one can identify certain fundamental accomplishments that are related to the existence and survival of man as a social being and are expected of the individual in virtually every culture. An individual with reduced competence in any of these dimensions of existence is, *ipso facto*, disadvantaged in relation to his peers. The degree of disadvantage attached to reduced competence may vary appreciably in diverse cultures, but some adverse valuation is almost universal. [314]

However, while it is explicitly recognised that the choice of life opportunities included in the Handicap component is value based, this potential concern is diffused by the assertion that "[t]he only value assumed in this analysis is that existence and survival are necessary and good".[315] As Handicap is defined as limited fulfilment of "a role that is normal", it follows that the standard for valuable composite life opportunities flows from the "norm", i.e. life as it plays out in the mainstream.[316]

To conclude, before moving on to the CRPD, the baseline of all of the approaches explored in Part I of this book is that the composite life opportunities important to others are likewise to their constituencies. The common experience of exclusion and segregation has shaped the central concern as getting access to a 'normal' life as it plays out in a particular national and cultural context. This is a reflection of that tell tale for the common constituency of these approaches is not having access to those aspects around which people habitually build their lives: family, social life, education, employment, leisure activities, spirituality, and so on. While Harlan Hahn and in particular Michael Oliver recognise a value in ways of life specific to disabled per-

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[309] WHO, 2001, pp. 15-16.
[310] WHO, 1980, p. 39.
[311] Ibid., p. 38.
[312] Ibid., p. 42.
[313] Ibid., p. 29.
[314] Ibid., p. 38.
[315] Ibid., p. 39.
[316] Ibid., p. 183.

sons, it is unclear to what extent this questioning reaches the point espoused by the "affirmative model" of disability presented above under 3.7.1.6.

Moving on to the CRPD its negotiators, like the framers of the approaches to disability explored in Part I in relation to their constituencies, were primarily occupied with the discordance between the lives of the constituency of the CRPD and the lives of others. The negotiations of the CRPD proceeded from the conviction that all life opportunities potentially relevant and valuable to other persons are likewise to persons with disabilities. Consequently, ICESCR, ICCPR, CEDAW and CRC in particular were scrutinised in order for the CRPD not to 'miss' any life opportunities. The negotiators thus envisaged an ideal closely resembling an idea of 'normal' life, rather than alternative ideals.[317] As noted just above, most of the titles of the articles in the CRPD mirror those of earlier human rights conventions. The ones that do not instead represent ways to access 'normal' life rather than embrace alternative lifestyles. Consequently, the CRPD focuses on opening the existing mainstream life world to its constituency. However, the call for recognition of 'a disability culture' by Harlan Hahn and Michael Oliver is heeded by Article 30 (4) on Participation in cultural life, recreation, leisure and sport in the sense that it requires "recognition and support of their [persons with disabilities] specific cultural and linguistic identity, including sign languages and deaf culture".[318] While the notion of the constituency of the CRPD having any particular "culture" different from national ones was opposed by some States,[319] other actors, notably NGO's, recognised the existence of a particular culture among Deaf persons as well as among the rest of the constituency of the CRPD[320]. Another move away from the mainstream in Article 30 is the recognition of "disability-specific sporting and recreational activities".[321] Finally, in relation to the creation of norms by emphasising the ability to do and be things, the danger of emphasising employment was indirectly recognised in the negotiations through cautions that as the entire constituency of the CRPD will not be able to or chose to work, such emphasis might serve to designate them as of less "dignity and worth".[322] However, the overwhelming focus was on securing the right to mainstream work for

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[317] While most references to this goal were phrased as 'normal' life, or to live 'like others', some are recorded as explicitly referring to "the principle of normalization", such as Chile during the 7th session. Daily Summaries 20 January 2006, 7th Session. See also a reference by Japan to "the principle of "normalization."" in a proposal on "Objectives of the Convention". Compilation of Proposals before the Working Group, 2004, p. 22.

[318] Note also Article 24 (3b) on Education obliging States to facilitate "the learning of sign language and the promotion of the linguistic identity of the deaf community".

[319] The reason for this apprehension was concerns that this somehow threatened or diminished the importance of national culture. See record of statements by in particular Yemen in Daily Summaries 24 and 27 January 2006, 7th Session.

[320] See e.g. record of statements by New Zealand, WFD and The All Russian Society of the Deaf. Daily Summaries 27 January 2006, 7th Session.

[321] Article 30 (5b).

[322] Written submission by World Network of Users and Survivors of Psychiatry (WNUSP): "Some people with psychosocial disabilities are unable to work for short or long periods of time. They should not face prejudice or discrimination on account of not being able to be economically productive. Society should recognize the inherent worth and dignity of each human being, which

the constituency of the CRPD by ensuring access to "a labour market that is open, inclusive and accessible to persons with disabilities" and to this end emphasise the capacity of persons with disabilities in relation to employment.[323]

In sum, the emphasis of the CRPD remains to open up mainstream 'normal' life for its constituency. There is no questioning of the value of such composite life opportunities per se. However, there remains a more circumscribed recognition of alternative if not life so "culture" in Article 30, existing by virtue of membership in a particular community: the constituency of the CRPD. However, the general vision throughout the negotiations, as well as of the provisions produced, remains the opportunity to be a part of the same life contexts as everyone else, with everyone else, as expressed in Preamble (m): "that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of *belonging*".[324]

The following section will draw out generic features about how such mainstream life is to be enjoyed by the constituency of the CRPD.

7.3. Generic aspects of life opportunities

At its most general, the life opportunities forwarded as valuable in the CRPD are subsumed under the common roof of "rights", as in "Convention on the *Rights* of Persons with Disabilities".[325] This then decomposes into the particular 'areas' or 'aspects' of life discussed in the previous section. Somewhere in between comes Article 3 on General principles, which draws out a number of dimensions which are seen as adding value to any such life areas or aspects, be it education, employment, family life or cultural life. These principles are the "compass" of the CRPD and are there to inform the interpretation of each and every right it covers.[326]

The aim of this section is to further nuance the picture of what life opportunities the CRPD recognises as valuable by drawing on Article 3 on General principles, distilling as it does central information about the way each area or aspect of life explored in the previous sections of this chapter is to be enjoyed. Article 3 reads as follows:

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does not depend on economic values.". WNUSP, Position Paper for the 3rd Meeting of the Ad Hoc Committee [hereinafter WNUSP Position Paper, 3rd Session], 3rd Session, 2004, p. 7.

[323] Article 27 (1). See also Article 8 (2aiii) which obliges States to "promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market".

[324] Emphasis added.

[325] Emphasis added.

[326] Gerard Quinn calls Article 3 the core of the "moral compass" that the CRPD provides. Quinn, Gerard, The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability, Jacobus tenBroek Disability Law Symposium, April 17, 2009, Texas Journal on Civil Liberties & Civil Rights, Vol. 15, No. 1, p. 41.

The principles of the present Convention shall be:
(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
(b) Non-discrimination;
(c) Full and effective participation and inclusion in society;
(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
(e) Equality of opportunity;
(f) Accessibility;
(g) Equality between men and women;
(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

In the following I will explore the principles proclaimed in paragraphs (a-f) from the point of view of what they add to the entitlements in the CRPD covering particular aspects or areas of life.[327] This will in turn be posited against the use of these principles by the approaches to disability explored in Part I.

7.3.1. Respect for inherent dignity

The opening principle in Article 3, "[r]espect for inherent dignity" is mirrored in Article 1 on Purpose, indicating its centrality to the interpretation of the rights in the CRPD. Dignity is an age old concept in human rights law, visible in the opening paragraphs of the Universal Declaration of Human Rights (UDHR)[328], ICCPR and ICESCR, noting as they do that "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world".

While references to this principle are included in a number of provisions in the CRPD, there was little concerted discussion in the negotiations informative to what it actually entails.[329] One discernible theme however was that dignity is something which, while it must be respected by others, is not dependant on that respect. This led to the reference to "[d]ignity" as a General principle in the Working Group Draft being changed to "[r]espect for inherent dignity" in the final version of Article 3 (a).[330] Similarly, this notion led to the reference to dignity being eliminated from the title of the CRPD (the preliminary title was "Draft comprehensive and integral international convention on the protection and promotion of the rights and *dignity*

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[327] Principles (g) and (h) will be explored below under 10.3.

[328] Universal Declaration of Human Rights (UDHR). Adopted by the UN General Assembly 10 December 1948. UN Doc: A/RES/3/217/A (III).

[329] Preamble (a, h and y), Article 1 on Purpose, Article 3 (a) on General principles, Article 8 (1a) on Awareness-raising, Article 16 (4) on Freedom from exploitation, violence and abuse, Article 24 (1a) on Education and Article 25 (d) on Health.

[330] Working Group Draft, 2004, Draft Article 2 on General principles, p. 9. See in particular Daily Summaries 27 and 30 January 2006, 7th Session.

of persons with disabilities")[331] and instead being included in Article 1 on Purpose, phrased as "respect for their [persons with disabilities] inherent dignity".[332]

What does it mean then, to enjoy a right such as education, freedom from violence and abuse, or culture with "[r]espect for inherent dignity"? Turning to the interpretative context of Article 3, one can detect from Preamble (h) that dignity is closely linked to non-discrimination, as well as relates to a sense of the "worth" of the person, recognising as (h) does that "discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person". The core of the connections made in (h) is that comparative disadvantage is habitually linked to perceptions of the lesser value or import of the person due to the characteristic in question, here impairment, and that this is a violation of dignity. To some extent, any violation of a right compromises dignity as the person has not received the treatment due as a 'human', as a subject of 'human rights'. Hence, the emphasis on dignity in Articles 1 and 3 as "inherent", as well as its repeated mentioning during the negotiations, chiefly reflect the widespread abuse of human rights en masse against the constituency of the CRPD. However, violations involving lacking autonomy, choice or independence, use of force or lacking physical and mental integrity have a particularly close connection with the concept of dignity.[333] In sum, it would seem that the negation of anything which is seen as central to 'being human', and particularly when this rest on a negative valuation of the person affected, amounts to lacking "[r]espect for inherent dignity".

As noted above under 7.1.1., while dignity requires the valuation of each *person,* the question if this includes the valuation of *impairment per se* has to be distilled from

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[331] Working Group Draft, 2004, p. 7. Emphasis added.

[332] During the 7th session, the working title changed to "International Convention on the Rights of Persons with Disabilities: working text". CRPD Working Text after 7th Session, 2006, p. 6. The original title was inserted into what became Preamble (y): "*Convinced* that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries;". Emphasis in original. It is notable that the principled changes made to what became Articles 1 and 3 (through the insertion of "respect" and "inherent") were overlooked here. During the 8th session the Committee settled on the final title: "Convention on the Rights of Persons with Disabilities".

[333] Compare Article 25 (d) obliging States to "[r]equir[e] health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, *dignity*, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care". Emphasis added. Compare also the concepts the reference to dignity is coupled with in Article 3 (a): "[I]ndividual autonomy including the freedom to make one's own choices, and independence of persons;". The connection between dignity, autonomy and force was explicitly made in the negotiations, such as here by IDC in relation to forced intervention: "A Way Forward Respecting Inherent Dignity [.] Forced interventions to correct, improve or alleviate any actual or perceived impairment have no place in a society that respects the inherent dignity and worth of every human being.". IDC Working Group 1 on Legal Capacity, Integrity and Related Issues, Forced Interventions [hereinafter IDC Working Group on Legal Capacity, Integrity and Related Issues, 8th Session], 8th Session, 2006.

the sum total of the attention paid to impairment in the CRPD. Corresponding to the conclusions drawn in that section, the entitlements to prevention, minimisation and elimination of impairment in Articles 25 on Health and 26 on Habilitation and rehabilitation outweigh the declaratory statements on the value of impairment in Preamble (m). Hence, against the background of Articles 25 and 26, efforts to prevent, minimise or eliminate impairment are not *per se* envisaged by the CRPD as violating dignity. Having said that, dignity does carry a sense of not being portrayed in a negative light, potentially implicating not only the person as such but also his or her impairment. Consequently, even as a contextual interpretation yields that entitlements to prevention, minimisation and elimination of impairment is not as such a violation of dignity, dignity remains relevant to the portrayal of, attitudes to and responses to impairment.[334]

Comparing to the approaches to disability explored in Part I, none of these have a focus on dignity as a 'label' of a particular aspect of the enjoyment of life opportunities.[335] Note that this conclusion only covers the use of dignity as a *label*, as by forwarding their own approach to what their constituencies should be granted they make their own assertion of what is due a 'human' and thus, if one were to choose to label it so, what 'dignity' is. Indeed, all the following principles could be seen as constitutive to 'dignity', which illustrates the elusive borders of this concept.

7.3.2. Autonomy and choice

Individual autonomy was a central theme during the negotiations and ended up explicitly mentioned in four articles.[336] In addition to Article 3, its value is generally recognised in Preamble (n), which is similarly worded:

> *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.[337]

The core addition to any life opportunity by the principle of autonomy is the added value that *personal choice* brings, namely the exercise of agency in one's own life. It targets the widespread prejudice in relation to the constituency of the CRPD about inability to 'know one's own good'. It rebuts paternalistic tendencies to accord the power to make decisions, big or small to other persons, be they family or medical,

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[334] See further below under 12.2.2.

[335] This does not mean that the concept is not applied at all, for example UPIAS note that assessment procedures can be intrusive and thus violate "privacy and dignity as human beings". UPIAS, 1975, p. 18. Likewise Harlan Hahn posits the lack of recognition of the "dignity and worth as human beings" as the reason for the inequality of disabled persons. Hahn, 1985, p. 93.

[336] The term "self-determination" was espoused especially by IDC but was rejected due to its established meaning in international law. See e.g. Daily Summaries 30 January 2006, 7th Session.

[337] Emphasis in original. References to autonomy are also made in Article 16 (4) on Freedom from exploitation, violence and abuse and Article 25 (d) on Health.

social and increasingly, legal professionals. The recognition of autonomy in Article 3 (d) and Preamble (n) complements the collectively focused provisions on the involvement of organisations of persons with disabilities in implementing the CRPD. They thus complement the constant call by ICD during the negotiations as in "nothing about us without us"[338] with its individualised equivalent, 'nothing about me without me'.

As discussed above under 7.1.1., 7.2.3.-7.2.5. and 7.2.7., several articles in the CRPD amount to situated regulations of autonomy and choice. Article 12 on Equal recognition before the law addresses the power to make choices with practical and legal consequences generally, Article 14 on Liberty and security of person addresses this power in the particular context of not being deprived of one's physical freedom and Article 15 on Freedom from torture or cruel, inhuman or degrading treatment or punishment, Article 17 on protecting the integrity of the person, Article 25 (f) on Health and Article 26 (b) on Habilitation and rehabilitation address the power to make decisions regarding medical and other interventions. Among these, Article 12 is thus the overarching provision relating to autonomy and choice, while the other articles address particular context where the denial of autonomy and choice is seen as creating the gravest consequences.

It has been asserted that Article 12 has the potential to be either a clearing house or a bottleneck for the entire potential of the CRPD in the sense that if the enjoyment of a life opportunity is not by choice, it cannot be of value.[339] Provisions in the CRPD explicitly emphasising choice illustrate its centrality in rendering the life opportunity in question valuable, indeed as translating it from a violation of human rights to the fulfilment of human rights. A telling example is the fact that Article 25 (d) as well as Article 26 (b) situate the will of the person as deciding if a form of intervention amounts to a legitimate fulfilment of the 'good' recognised in these articles *or* an instance of human rights abuse, with lacking attention to such will opening the door to Articles 15 and 17.

Irrespective of the importance accorded autonomy in the negotiations as well as in the CRPD, as discussed above under 7.1.1., 7.2.3.-7.2.5. and 7.2.7., the question of the outer limits of autonomy and choice were subject to much controversy in the negotiations. This lingering disagreement formatively shaped particularly Articles 12, 14 and 17, leaving several loose ends to interpretation. Notwithstanding the value thus accorded autonomy and choice in the CRPD, States were not ready to give up the power to choose for, incarcerate and medically intervene with persons who are perceived as unable to exercise choice in their own best interest. Consequently, the reach of these articles are limited to undue connections with impairment and while this would seem to outlaw restrictions directly referring to impairments it is not clear to what extent they reach neutrally phrased criteria which overlap with im-

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[338] See e.g. IDC Amendments to CRPD Working Text, 8th Session, p. 1. See further below under 9.1.7.

[339] See e.g. Minkowitz, 2007 and Dhanda, 2007.

pairment.[340] However, irrespective of the lack of consensus on the 'frontier' between individual choice and State over-drive required by the CRPD in each context, 3 (a) still establishes choice and autonomy as a guiding light in the enjoyment of all the right in the CRPD. In addition, it is notable that the CRPD Committee has taken the categorical position that to have one's expressed will overridden with reference to the perceived or actual decision-making abilities of an individual is a violation of the CRPD.[341]

Turning to the approaches to disability explored in Part I and starting with UPIAS, making one's own decisions and taking control of one's own life is at their core.[342] As mentioned above in relation to the particular provisions actualising issues of autonomy and choice, the assertions of autonomy made by UPIAS in relation to persons with physical disabilities would if uncompromisingly applied across the board of different impairments render illegitimate substituted decision-making, the crunch question relating to autonomy and choice. The approach of Michael Oliver echoes this sentiment, as does the position of the Minority Group Model of Disability through Harlan Hahn.[343] Hahn and Oliver furthermore use the concept of autonomy to refer to practical, rather than merely formal restrictions. Oliver deplores the lack of "autonomy"[344] in residential care and Hahn refers to the "denial of the right to choose" and restrictions of "autonomy" caused by an inaccessible attitudinal and built environment[345].

Like these approaches, ICF explicitly recognises the value of control over one's own life. Activities and Participation include the Domain "Community, social and civic life" which in turn includes the category "Human rights".[346] The latter category explicitly includes "the right to self-determination or autonomy; and the right to control over one's destiny".[347] As discussed in relation to Article 12 on Equal recognition before the law and Article 14 on Liberty and security of person, these general statements are qualified by the fact that WHO assumes a role for substituted decision-making, albeit as an exception and surrounded by legal safeguards.[348]

Finally, moving on to ICIDH, the issue of decision-making does not receive any explicit attention in the ICIDH scheme or manual and it is silent on the role of the individual recipient of services in the taking of such decisions.

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[340] See above under 7.1.1., 7.2.3.-7.2.5. and 7.2.7. and below under 7.3.4.

[341] CRPD Draft General Comment on Article 12, para. 12.

[342] See UPIAS, 1975, e.g. pp. 8, 18 and UPIAS, 1974, e.g. paras. 8, 14.

[343] Hahn, 2000, p. 271.

[344] Oliver, 2004, p. 28.

[345] Hahn, 1987, p. 10 (source not paginated).

[346] WHO, 2001, p. 170.

[347] Ibid.

[348] See above under 7.2.3. and 7.2.4.

7.3.3. Independence

The idea of "independence of persons" is linked to 'choosing for oneself' but carries an additional connotation, namely to be able to, with or without assistance, execute ones will trough public and private 'living' without undue dependence on others, particularly family members.[349] The aspect of maximising the potential to do as much as possible without assistance is emphasised in Article 26 (1) on Habilitation and rehabilitation and in Article 20 on Personal mobility, setting as they do "maximum independence" and "the greatest possible independence" as their respective goals. The foci of these articles are increasing the level or mode of functioning of the person, providing enabling aids and equipment, and in the case of Article 20 providing services amounting to mobility. These articles are complemented by Article 9 on Accessibility positing "to live independently" as the goal of the changes to the environment it demands. Through Article 3, as well as the above articles, the demand for independence recognises a value added to all the life opportunities protected in the CRPD, be it housing, education, cultural participation or any other, by 'doing things for oneself'.

An aspect of independence particularly emphasised in the negotiations was independence towards family. Through a changed environment and the assistance of the State the person should be able to do and be as much as possible without depending on those to whom he or she is close, notably family. This aspect, as opposed to the ideal to 'do as much as possible instead of having it done for you', was not uncontested as an inherent value in the enjoyment of all the rights in the CRPD. This controversy played out in particular in connection with Article 19 on Living independently and being included in the community. Here, the value of family life generally was asserted, as was the non-universal character of the practice to leave ones family as one grows up.[350] This issue landed as recognition that the constituency of the CRPD should have the same opportunities to independence from family as others, but that the choices made in this regard are likely to differ around the world.[351] The other aspect of Article 19, "being included in the community", illustrates that any form of "living independently" still must be a part of the community.

Additional reservations to the emphasis on independence in Article 19 stemmed from a concern that independence could be used as a *prerequisite* for entitlements to live in the community, rather than as a demand. As put by Israel, the concern regarded that Article 19 must make clear "the principle that the right to live in the

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[349] See also Preamble (n) which is worded similarly to Article 3 (a).

[350] A footnote to Draft Article 15 on Living independently and being included in the community pays witness to this controversy: "Some members of the Working Group expressed the concern that the words "living independently" in the title and the chapeau of this draft article did not reflect the cultural norm in many countries, and that the words might suggest that persons with disabilities should be separated from their families. The Ad Hoc Committee may wish to consider an alternative formulation.". Working Group Draft, 2004, p. 20, note 51. See also Daily Summaries 19-20 January 2006, 7th Session.

[351] See recorded statement by the Chair in Daily Summaries 20 January 2006, 7th Session.

community and to take part in all its activities and/or contribute to society belongs to every person and derives from the right to equality, regardless of the level of physical or psychosocial independence".[352] In the final version of Article 19 the only reference to independence is in its title and the article as such focuses on inclusion in the community, thus pre-empting the interpretation feared by Israel.

To conclude, the independence sought by Article 3 operates on two levels. Firstly, to maximise what one can do *without* dependence on others through interventions targeting the environment as well as the individual and through the provision of aids and equipment. Secondly, to maximise what one can do *through* the assistance of others (with the control over such assistance resting with the person).[353]

Turning to the approaches to disability explored in Part I of this book, it can initially be noted that they are all concerned with enlarging the opportunities of their constituencies to do or be things, and preferably by oneself. As will be discussed in the next two chapters, they however find the factors instrumental to independence in different places. The Social Model of Disability and the Minority Group Model of Disability emphasise changes in the larger environment and, to some extent, in the provision of services, aids and equipment, ICIDH focuses on increasing the levels and modes of functioning of the individual's body and mind and, to some extent, the provision of services, aids, equipment, and ICF focuses on all of the above.

Beginning with UPIAS, independence is their explicit aim, expressed as "the maximum possible independence in daily living activities".[354] Michael Oliver echoes this sentiment and emphasises the role of the environment in enabling independence, as well as the importance of resources and power balances in creating *real* independence:

> [Under the UK Home Care or Home Support service], disabled people should receive personal support to maintain an appropriate degree of control, independence and autonomy for users in their own homes. In practice, staff provide a service to help disabled users go to bed at the end of the day, yet they have to fit in with when staff are available to provide such support. As a consequence, the service does not meet users' needs, but they dare not complain for fear of damaging important relationships.[355]

Hahn similarly emphasises the importance of the environment in creating independence, as well as the role of a defective environment in creating the need for services:

> In surroundings that have been designed with little regard for their needs, people with disabilities obviously require many types of services. But corresponding or equivalent

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[352] Proposal by Israel, 4th Session, 2004. See also Israel Position Paper, 7th Session: "We also propose to delete the word "independently" both from the caption and the text of Article 19 as this term is capable of being misinterpreted as applying primarily to those persons with disabilities who are capable of living in the community independently without support and assistance.". See also the subsequent discussion in Daily Summaries 19-20 January 2006, 7th Session.

[353] Compare the coupling of independence with autonomy and choice in Article 3 (a).

[354] UPIAS, 1974, initial paragraph on Aims.

[355] Oliver, 2004, p. 28.

> emphasis also should be focused on efforts that would grant them independence rather than perpetuating their dependency.[356]

As mentioned above ICIDH as well has independence at its core (compare the Handicap category "Physical independence handicap"[357]) but traces its source to the individual's level and mode of functioning of the body and mind and the provision of services, aids and equipment. ICF however, while it includes the aspects of carrying out a task independently (compare the Activities and Participation category "Undertaking a single task independently" which is explained as "managing and executing a task on one's own and without the assistance of others")[358] in addition sets its sights on the environment in a larger sense.

7.3.4. Non-discrimination and equality of opportunity

Principles (b) Non-discrimination and (e) Equality of opportunity, in addition to being devoted a separate Article (Article 5 on Equality and non-discrimination) are the most repeated in the CRPD out of the principles in Article 3. Out of all the thirty-three substantive provisions of the CRPD, all but eight provisions (Articles 8, 11, 16, 20, 26 and 31-33) use the language of equality and/or non-discrimination to express the entitlements and obligations they create. The Preamble uses the notion of equality and/or non-discrimination thirteen times[359] and Article 1 on Purpose uses it not only to define the purpose of the CRPD but in the very depiction of the protected constituency, "[p]ersons with disabilities".[360]

From this it can be concluded that the concepts of "[e]quality of opportunity" and "[n]on-discrimination" in Article 3 are envisaged as adding a central dimension to the life opportunities protected under the CRPD. The smallest common denominator of this dimension is that of comparison. It appends a relative element to each guarantee of enjoyment, hinging this element onto the standards set for or enjoyed by others. It adds to the idea that the enjoyment of a life opportunity should not fall below a particular minimum standard the *additional* idea that neither should it be unduly discrepant from the enjoyment of that life opportunity by others. Pertinent questions concern the coverage and strength of these principles, to what situations they apply and how much 'levelling' they demand. In other words, what kind or equality or non-discrimination does the CRPD require?

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[356] Hahn, 1987, pp. 7-8 (source not paginated).

[357] WHO, 1980, p. 188.

[358] WHO, 2001, p. 129.

[359] Preamble (a-b) ((b) uses the expression "distinction"), (c-f), (h), (k), (p), (r) and (x).

[360] Compare Oddný Mjöll Arnardóttir referring to equality as the "[l]eitmotif" of the CRPD. Arnardóttir, Oddný Mjöll, A Future of Multidimensional Disadvantage Equality [hereinafter Arnardóttir, 2009], in Arnardóttir, Oddný Mjöll and Quinn, Gerard (Eds.) The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, Martinus Nijhoff Publishers, Leiden, 2009, p. 42.

Article 5 on Equality and non-discrimination sets the area of application of these two principles and makes it clear that State authorities have to adhere to these, including not only the judiciary but the legislator as well. Article 5 (1) stipulates that "all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law". To be equal before the law requires an even-handed application of the law. It obliges the judiciary and other authorities to honour those distinctions foreseen by the law and to not make any distinctions which are not foreseen by the law. The entitlement to the equal protection of the law extends to the rationale for, the contents of and the effects of the law. It creates obligations for the legislator to use legislation as a tool in a way that does not amount to undue disadvantage for a person covered by the CRPD.[361] In addition to all laws being open to scrutiny from the perspective of their potential discriminatory content and impact as well as the obligation to legislate so that they benefit all equally, Article 5 (2) of the CRPD establishes obligations for the State to use the law to *protect* against discrimination. States are to "prohibit all discrimination on the basis of disability" as well as "guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds".[362] The reference to "all grounds" means that persons with disabilities must be protected not only from discrimination on the basis of disability but on other grounds as well.[363] Paragraph (p) indicate which grounds are included by expressing concern about "the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status". It follows from the reference to "other status" that this list is non-exhaustive.

Delving further into these principles, the quest for the meaning of "non-discrimination" holds most promise as its mirror image, "[d]iscrimination on the basis of disability" is defined in Article 2 on Definitions:

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[361] Article 5 (1-2) is almost a carbon copy of Article 26 of ICCPR. Compared to Article 26 of ICCPR, the aspect of equal protection of the law is fortified in Article 5 (1) of the CRPD by the inclusion of the express entitlement to equality "under" the law and to the equal "benefit" of the law.

[362] The obligation to prohibit "discrimination on the basis of disability" in Article 5 (2) potentially opens a window to extend protection against such discrimination outside the constituency defined in Article 1 ("[p]ersons with disabilities"). The main question under discussion during the negotiations regarding this aspect of the reach of the protection in Article 5 (2) was the potential inclusion of 'discrimination by association'. This would mean that not only persons with disabilities, but also persons without disabilities who are disadvantaged on the basis of someone else's impairment are protected. See e.g. proposals of text to this effect by Australia during the 3rd session. Compilation of Proposals before the 4th Session, 2004, p. 18. The inclusion of text to this effect met with some opposition. During the 4th session Canada is recorded as stating that "[i]t opposes the proposal of Australia to reference "or by association with a person with a disability" in 7(2)(b) as it may detract from the ultimate focus of the convention which is PWD [persons with disabilities] and not families or support persons". Daily Summaries 25 August 2004, 4th Session. The inclusion of text to this effect was proposed by IDC as late as the 7th session. See Daily Summaries, 31 January 2006, 7th Session.

[363] See further below under 10.3.

> "Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation[.]

The second sentence explicitly includes denial of reasonable accommodation as one of the "forms" of discrimination prohibited by the CRPD. "Reasonable accommodation" is also defined in Article 2:

> "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms[.]

The gist of this concept is that it creates a right for an individual to demand alterations to the social context, be it the built environment, modes of communication or any other standard for conducting life. While it is heavily qualified (measures asked for must be "necessary" and not impose "a disproportionate or undue burden" on behalf of the provider (be it the State or a private actor)) it amounts to a principled recognition of the right to adjustments, to differential treatment, as part and parcel of the prohibition of discrimination.

While the reference to "*all* forms of discrimination" in Article 2 gives no indication as to *which* such "forms" are included, its purpose was to send an inclusive message.[364] The intention was that no situation would fall outside the concept of discrimination in CRPD by generic reference to it constituting a certain 'form' of discrimination. The primary form of discrimination in mind was "indirect" discrimination, which was indeed explicitly covered in the Working Group Draft as well as in following drafts up until the 8th session.[365] The lack of consensus to expressly include this concept in the definition of discrimination was not based on unwillingness to include particular situations thought to fall under this label. Rather, the reason was the perception of a lack of clarity as to the exact meaning of "indirect" and "direct" discrimination and the delineation between these. In this context it was argued that the reference to "purpose *or effect*" in the definition of discrimination in what ended up Article 2 on Definitions, as well as the reference to "*all* forms of discrimination" there, sufficiently covered what(ever) was intended by "indirect discrimination".[366]

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[364] Emphasis added.

[365] Draft Article 7 (2b) on Equality and non-discrimination, Working Group Draft, 2004, p. 13. In the text of the CRPD as it stood after the 7th session, the reference to "direct and indirect discrimination" is in brackets, indicating lack of consensus on its future inclusion. Draft Article 2 on Definitions, CRPD Working Text after 7th Session, 2006, p. 8.

[366] Emphasis added. See e.g. a footnote to Draft Article 7 (2b) on Equality and non-discrimination in the Working Group Draft: "Some members of the Working Group considered that the Convention should have a specific reference to both direct and indirect discrimination. Other members

Different definitions of "indirect discrimination" were proposed while the reference to it was still in the draft of the CRPD. For example, the core of the concept was phrased by the EU as "an apparently neutral provision, criterion or practice [placing] a person having a disability at a particular disadvantage compared with other persons".[367] The above description catches the common gist of different proposals, namely the neutrality of a provision in combination with ensuing disadvantage on account of diversity.[368]

The principle of non-discrimination thus includes an explicit prohibition of "denial of reasonable accommodation" as well as an implicit prohibition of not only 'direct' but 'indirect' discrimination. This means that the meaning of non-discrimination as a general principle is indeed broad. Through the concept of reasonable accommodation we know that it requires advantageous differential treatment based on the particular circumstances of an individual, i.e. it is not limited to a demand to extend to the constituency of the CRPD measures or accommodations fitted to and taken in relation to others. Instead the demands that can be made on the basis of non-discrimination in relation to each right extend to accommodation of diversity. In addition, through the recognition of indirect discrimination, disadvantage which is not explicitly legitimised through reference to impairment still potentially contravenes the prohibition of discrimination, if it exclusively or disproportionately impacts on persons with disabilities.[369]

Moving from "non-discrimination" to "equality", Article 3 (e) characterises the equality it requires as "[e]quality of opportunity".[370] Equality of opportunity is not defined in the CRPD. Over and above the comparative dimension of equality noted above, it does not have an 'ordinary meaning', rather it is one of the most elusive concepts there is. It is here qualified by the term "opportunities", which is a qualification often used in contrast to 'results'. The gist is that the former sets a lower standard

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considered that the distinction between the two forms of discrimination was not sufficiently clear. They considered that both a reference to "all forms of discrimination" in paragraph 1, and the reference to the "effect" of discrimination in paragraph 2(a), would cover the concept of indirect discrimination.". Working Group Draft, 2004, p. 13, note 24.

[367] Proposal by the EU during the 3rd session. Compilation of Proposals before the 4th Session, 2004, p. 20.

[368] Compare e.g. proposal by ILO during the 3rd Session, 2004, on Draft Article 3 on Definitions (later to become Article 2 on Definitions). Compare also contribution by a coalition of Australian organisations for the 7th session on Draft Article 2 on Definitions. AFDO, PWDA and NACLC, Report of the National Consultation Project on the Chair's Text of the Proposed Comprehensive and Integral International Convention on the Rights and Dignity of Persons with Disabilities [hereinafter PWDA et al. Report on National Consultations, 7th Session], 7th Session, November 2005, p. 11.

[369] As mentioned above under 7.1.1. the prohibition of indirect discrimination is not absolute and such overlap remains subject to further consideration of, inter alia, whether 'objective and reasonable justification' of measures exist (which in turn emanate from conclusions about some person with disabilities as relevantly different from others). See note 66, Part II.

[370] The only other term used to qualify equality in CRPD is the term "de facto equality", which is only used in a specific context: to portray the goal of "[s]pecific measures" in article 5 (4).

than the latter; an "opportunity" is seen as entailing less than a "result".[371] In the larger debate about the meaning of equality, commentators have however criticised the dichotomy between 'equality of opportunity' and 'equality of results', holding that it is misguided:

> The interesting question is not in the choice between equality of opportunity and equality of result. It is how much equality of opportunity we want. To what extent do we want the levelling entailed by the proposition – which I am taking as definitional of equality of opportunity – that fortunes should not depend on arbitrary circumstances?[372]

Human rights in general, including those forwarded in the CRPD are clusters of entitlements or obligations presented under an 'umbrella concept', a heading such as life, education, employment or accessibility. A right thusly asserted does not mean that all entitlements and obligations which can be seen as conducive to conceptions of life, education or employment are included. Consequently, rather than the umbrella concept defining the ambit of the right, it is the cluster of obligations and entitlements which set the formers outer markers. These obligations and entitlements can be characterised as outlawing certain obstacles either by requiring the removal of existing hindering factors or by requiring the creation of additional conducive factors. The impact of equality and non-discrimination in the different areas of life protected in the CRPD thus depends on *which* obstacles are to be removed and *which* conducive factors are to be provided, how these are to be removed respectively provided and by whom and when; a quantitative rather than a qualitative distinction. This is arguably a scale and the crucial questions are these, and not if the life opportunity to be produced is 'an opportunity' or 'a result'.

Turning to the context of Article 3 (e), as described above in relation to non-discrimination, the standard set by Article 5 of the CRPD is demanding in the sense that it requires action and advantageous differential treatment as well as focuses on actual outcomes in terms of enjoyment of life opportunities. In addition, Article 5 (4) notes that "specific measures […] to accelerate or achieve de facto equality of persons with disabilities" are not discriminatory as long as they are "necessary" to achieve this end. Additional provisions echo this, for example Article 27 (1h) on Work and employment explicitly suggest the use of "affirmative action programmes".

Turning to the preparatory works to confirm the demanding standard set by requiring "[e]quality of opportunity", the lack of a definition of this concept was perceived

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[371] See e.g. Quinn, 2009, p. 257 and Quinn, Gerard and Degener, Theresia, The Moral Authority for Change: Human Rights Values and the Worldwide Process of Disability Reform, in Quinn and Degener with Bruce at al., 2002, pp. 11-12.

[372] Strauss, David A., The Illusory Distinction between Equality of Opportunity and Equality of Results, in Devins, Neal and Douglas, Davison. M. (Eds.) Redefining Equality, Oxford University Press, New York, 1998, p. 56.

as problematic by some[373] and a number of definitions were suggested, particularly for the session of the Working Group. According to a proposal by India, ""equality of opportunity" means the condition in which society treats each individual with a disability as a person equal in dignity and rights and removes any restrictions or limitations by appropriate means, adjustments and allocations, and by affirmative action, reasonable accommodation or "special measures" and provides enabling environments to ensure de facto equality between persons with and without disability".[374] Mexico used the term "equality of rights and opportunities", noting that "[i]n order to guarantee equality of rights and opportunities for persons with disabilities, States Parties shall promote, among others, positive or compensatory measures".[375] The outcome of an African Regional Consultative Conference (ARCC) called for "the principle of the equalisation of opportunities for persons with disabilities" which it noted "will ensure the benefits of substantive equality in their daily lives". It further stated that "[i]n essence, substantive equality requires that persons with disabilities are able to access economic, human and social rights".[376] Chile defined "[e]quality of [o]pportunities" before the 4th session as "[t]hose measures, actions or exemptions, as appropriate, which tend to place persons with disabilities in a position to be able to enjoy and fully exercise their human rights and fundamental freedoms".[377] Corresponding to the contextual analysis of 3 (e) above, these depictions indicate equality of opportunity as demanding in the sense that it requires action and advantageous differential treatment as well as focuses on actual outcomes in terms of enjoyment of life opportunities. The upshot is that based on the notion of "equality of opportunity" indicated by negotiating States, a dichotomy between 'equality of opportunity' and 'equality of result', in line with the quote by David Strauss above appears uninformative as to what kind of equality the CRPD requires.[378]

Perhaps the demanding understanding of equality displayed in the negotiation statements above, as well as the choice of "[e]quality of opportunity" as the term chosen to depict the equality required by the CRPD is partly due to a heritage from the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (StR), which carries a connection between the concept 'equality of opportunity' and 'whatever it takes':

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[373] See e.g. Chile problematising the lack of such a definition during the 7th session. Daily Summaries 30 January 2006, 7th Session.

[374] Proposal by India, Compilation of Proposals before the Working Group, 2004, p. 44.

[375] Proposal by Mexico, Compilation of Proposals before the Working Group, 2004, p. 76.

[376] African Regional Consultative Conference (ARCC), 1-6 May 2003, in Compilation of Proposals before the Working Group [hereinafter ARCC, Compilation of Proposals before the Working Group, 2004], 2004, p. 39.

[377] Proposal by Chile, 4th Session, 2004.

[378] The use of the concepts "equality of opportunity" and "equality of results" sometimes overlapped in the negotiations. For example, according to the record of the 7th session, when Chile described its understanding of "equality of opportunity" as "a constantly changing process" sometimes including "both non-discrimination and affirmative action measures", El Salvador seconded the position of Chile, referring to it as "equality of results". Daily Summaries 30 January 2006, 7th Session.

> The term "equalization of opportunities" means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities. […] The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation.[379]

Further supporting negotiating States understanding of "[e]quality of opportunity" in Article 3 as a demanding one is the connections made between "equality of opportunity" and "substantive equality" in the negotiations. In addition to the explicit connections made by the ARCC in the statement just above, States referred to "substantive equality" as the normative background against which calls for particular measures were launched.[380] At face value "[e]quality of opportunity" does not reach the standard of 'substantive equality' which is commonly rather associated with the concept 'equality of result', again through connoting 'outcomes', rather than 'possibilities'.[381] However, the intention with choosing to express the equality required by the CRPD as "[e]quality of opportunity" does not seem to be expressly based on it being less demanding than its corollaries "equality of result" or "substantive equality".[382] While the more demanding nature of the concept "substantive equality"

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[379] Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Adopted by the UN General Assembly 20 December 1993. UN doc: A/RES/48/96, Introduction, paras. 24-25. A link between the CRPD and the StR is created through Preamble (f): "*Recognizing* the importance of the principles and policy guidelines contained in the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in influencing the promotion, formulation and evaluation of the policies, plans, programmes and actions at the national, regional and international levels to further equalize opportunities for persons with disabilities,". Emphasis in original.

[380] See e.g. record of statements by Canada in Daily Summaries 1 June 2004, 3rd Session and 9 August 2005, 6th Session.

[381] Canada called for the addition of "substantive equality" as a general principle, to complement "equality of opportunity" in Draft Article 2 (e) on General Principles. Daily Summaries 24 August 2004, 4th Session.

[382] It is of interest here that current practice by the older treaty monitoring bodies is to bridge any conceptual gap between such valours of equality. The practice of the Committee on the Elimination of Discrimination against Women [hereinafter CEDAW Committee] calls upon "equality of results" and "substantive equality" as the requirement of CEDAW, while the instrument uses only the terms "equality of opportunity and treatment" and "de facto equality" (the latter term is used only in Article 4 (1) in relation to "temporary special measures"). This expansive take on the interpretation of equality was made in the context of "temporary special measures" (i.e. measures which amount to advantageous differential treatment the compatibility with equality and non-discrimination of which is determined through group membership, rather than through individual circumstances): "In the Committee's view, a purely formal legal or programmatic approach is not sufficient to achieve women's de facto equality with men, which the Committee interprets as substantive equality. In addition, the Convention requires that women be given an equal start and that they be empowered by an enabling environment to achieve equality of results. […] Equality of results is the logical corollary of de facto or substantive equality. These results may be quantitative and/or qualitative in nature; that is, women enjoying their rights in various fields in fairly equal numbers with men, enjoying the same income levels, equality in decision-

was noted in the negotiations, a contextual interpretation of Article 3 (e) yields that "[e]quality of opportunity" embodies the features attributed "substantive equality" there. Thus, when Canada during the 4th session, proposed that ""substantive equality" should be added after "equality of opportunity" because equality of opportunity should not be interpreted as sameness of treatment", the demand for "reasonable accommodation" in the final version of Article 5 (3) and the note of the prima facie neccessity of "specific measures" in 5 (4) with reference to "equality" effectively preempt such an interpretation.

The fact that both "[e]quality of opportunity" and "[n]on-discrimination" are included in Article 3 begs the question what, if any, the difference between these two standards is. Is there a difference between realising "[e]quality of opportunity" and "[n]on-discrimination" in e.g. education, family life, cultural or political participation or freedom from violence and abuse? It is often asserted that equality is the goal and non-discrimination is the way to get there, a view expressed during the negotiations as well.[383] In the text of the CRPD, the obvious difference in use between the term of equality and the term non-discrimination is in Article 5 (3) and 5 (4). The requirement for advantageous differential treatment on an individual basis ("reasonable accommodation") in 5 (3) is made in the name of *both* non-discrimination and equality:

> In order to promote *equality* and eliminate *discrimination,* States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.[384]

In comparison, the permissibility of differential treatment on a group basis ("specific measures" in 5 (4)) is made in the name of equality only ("to accelerate or achieve de facto equality"). Indeed, the measures called for in 5 (4) are depicted as prima facie suspicious from the viewpoint of non-discrimination, as the statement that these are permissible is phrased as that such measures "shall not be considered discrimination":

> Specific measures which are necessary to *accelerate or achieve de facto equality* of persons with disabilities shall *not be considered discrimination* under the terms of the present Convention.[385]

However, as concluded above both standards require active measures as well as differential treatment. The remaining dividing line thus seems to be that while both non-discrimination and equality apply to the enjoyment of rights by *an individual*

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making and political influence, and women enjoying freedom from violence.". Committee on the Elimination of Discrimination against Women General Recommendation No. 25 on Article 4, Paragraph 1, of the Convention on the Elimination of All Forms of Discrimination against Women, on Temporary Special Measures [hereinafter CEDAW General Recommendation 25] 2004, UN doc: A/59/38, paras. 8-9.

[383] See e.g. Australia in Daily Summaries 25 May 2004, 3rd Session, and Mexico in Daily Summaries 24 January 2005, 5th Session.

[384] Emphasis added.

[385] Emphasis added.

and require both advantageous differential treatment as well as active measures, *only equality applies to the enjoyment of rights measured on a group basis*.[386] In other words, such measures cannot be demanded or justified based on non-discrimination, but only with reference to equality.[387]

Another indication that these concepts are to some degree complementary is that many places in the CRPD hold references to both these concepts. In addition to the General principles in Article 3 affirming both "[n]on-discrimination" (b) and "[e]quality of opportunity" (e) and Article 5(4) requiring reasonable accommodation in the name of both equality and non-discrimination, provisions covering particular areas of life take the same approach. Article 24 on Education and Article 29 on Participation in political and public life reiterate this dual focus by requiring enjoyment "without discrimination *and* on the basis of equal opportunity" (24 (1)) and "without discrimination *and* on an equal basis with others" (24 (5) and 29 (b)).[388] This explicit inclusion of terminology derivative of both terms ("[e]quality" *and* "discrimination") signals that the conceptual pairs equality-inequality and discrimination-non-discrimination are *not* interchangeable in the CRPD. However, the particular rationale for and consequence of using the two concepts together is not detectable from the instrument as such or the negotiations, nor is the rationale for choosing one or the other in those provisions that refer only to one of these con-

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[386] While these measures were in earlier instruments explicitly characterised by their temporary character (see CEDAW Article 4 (1) and ICERD Articles1 (4) and 2 (2)), the customary reference to this effect was intentionally left out of CRPD 5 (4) in order not to exclude measures of a permanent character. For an account of such reasoning, see e.g. the proposal from the Facilitator of what became Article 5 on Equality and non-discrimination. Facilitators Proposed Modifications on Draft Article 7- Equality and non-discrimination, 5th session, 31 January 2005.

[387] It is interesting to note here that this particular feature has been intentionally down played by the CEDAW Committee and the Committee on the Elimination of Racial Discrimination. Although CEDAW and ICERD display the same structure as Article 5 (by portraying these measures as simultaneously called for to achieve equality and as an exception to non-discrimination) both Committees have collapsed this distinction. See CEDAW General Recommendation 25, para. 18: "The Committee views the application of these measures [measures taken under Article 4 (1)] not as an exception to the norm of non-discrimination, but rather as an emphasis that temporary special measures are part of a necessary strategy by States parties directed towards the achievement of de facto or substantive equality of women with men in the enjoyment of their human rights and fundamental freedoms.". See also Committee on the Elimination of Racial Discrimination General Recommendation No. 32 on the Meaning and Scope of Special Measures in the International Convention on the Elimination of Racial Discrimination, 2009, UN doc: CERD/C/GC/32, para. 20: "By employing the phrase '**shall not be deemed racial discrimination**', Article 1, paragraph 4 of the Convention makes it clear that special measures taken by States parties under the terms of the Convention do not constitute discrimination, a clarification reinforced by the *travaux préparatoires* of the Convention which record the drafting change from 'should not be deemed racial discrimination' to 'shall not be deemed racial discrimination'. Accordingly, special measures are not an exception to the principle of non-discrimination but are integral to its meaning and essential to the Convention project of eliminating racial discrimination and advancing human dignity and effective equality.". Emphasis in original.

[388] Emphasis added.

cepts. Finally, to complicate matters further the definition of "[d]iscrimination" in Article 2 uses "on an *equal* basis with others" to depict its comparative feature.[389]

The upshot is that while the mere inclusion of both terms indicates some degree of complementary function, the only discernible difference is the one indicated above, namely that the permissibility of advantageous different treatment on a group rather than an individual basis is called for only in the name of equality and indeed is prima facie suspicious against the standard of non-discrimination. Furthermore, irrespective of a particular provision referring to "on an equal basis with others" or "without discrimination", as general principles these apply to every provision. Thus any discrepancy between these in terms of what they require will arguably not affect the standard set in relation to the enjoyment of a particular life opportunity. In relation to the provisions that use both concepts any such possible discrepancy is similarly a mute point. To illustrate, irrespective of if the obligation "to promote equality" creates demands that exceed those created by the obligation "to eliminate discrimination" in relation to reasonable accommodation in 5 (3), both must be adhered to. The only discernible difference thus remains that while a situations that amounts to equality of opportunity for the constituency of the CRPD is not discriminatory for someone else (indicating the compatibility of these principles), the text of 5 (4) indicates that measures amounting to differential treatment which target a group, rather than are decided on an individual basis, can only be called for and justified in the name of equality.

To sum up, the principles of equality of opportunity and non-discrimination may differ in their power to sustain particular demands made in relation to the life opportunities covered by the CRPD, but since they as general principles do their work simultaneously this will not affect the central outcome, namely what can be demanded through the General principles articulated in Article 3. These essentially comparative standards determine what is due the constituency of the CRPD against the baseline of what is granted other rights holders in human rights law and by comparing the constituency of the CRPD to others. They add a relative guarantee to each minimum standard in the CRPD, thus demanding that if the level of enjoyment of the constituency of the CRPD goes below the enjoyment by others, then levelling is required. Together, they make far-reaching demands by setting the life opportunities protected for and/or available to those not covered by the CRPD as a benchmark and making demands which cannot be discarded with reference to a State not having created the current state of affairs by active measures or to the State treating everyone 'the same'. Rather, these measures extend to changing State passivity into conducive action, including action which treats a person covered by the CRPD differently compared to others, if this is necessary to level out access to life opportunities.

Turning to the approaches to disability explored in Part I of this book, it is fundamental to note what they all share with the principles of equality and non-discrimination, namely that they set the standard for what is claimed against the baseline of

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[389] Emphasis added.

what is accorded others. Like these principles, this does not necessarily mean that everyone should be accorded the same life opportunity, or accorded that life opportunity in the same way as another. However, the central comparative feature remains, even if steadily ascending in abstraction from identical treatment of everyone towards general expressions such the principles protected in Article 3, or even 'rights'.

All approaches, save ICIDH[390] use the concepts of equality and discrimination to depict their aims and their concerns. Beginning with UPIAS, they call for "a real opportunity of equal participation in normal educational, work and leisure activities"[391] and refer generically to the "discrimination against physically impaired people"[392]. Michael Oliver draws attention to "unequal treatment and unequal outcomes between disabled and non-disabled people", making the general point that "[d]iscrimination does not exist in the prejudiced attitudes of individuals but in the institutionalised practices of society".[393]

The manual of ICF recognises "protection against discrimination" as a dimension of Activities and Participation and more specifically a dimension of the category "Political life and citizenship".[394] In addition, the manual forwards ICF as a tool to "promote equal opportunities for all people, and support the fight against discrimination based on disability".[395]

As elaborated in Chapter 5, the use and the conceptualisation of the equality and non-discrimination theme is central to the Minority Group Model of Disability. The account there refers to two different such conceptions that Harlan Hahn finds promising: "equality of results" and "equal shares".[396] The latter, which is preferred, entails a levelling of material resources while the former seems to focus more on access to valuable life opportunities, conceptualised in relation to education as "participation in a democratic society"[397]. These details allow for a comparison to the CRPD which would seem to correspond the best to the conceptualisation of equality of results by Hahn, focusing as it does on access to particular life opportunities rather than the redistribution of resources per se. Opportunities and resourced remain of course related, but differ as metrics used to measure when an acceptable outcome has been achieved. Even though the CRPD forwards "[e]quality of opportunity" rather than

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[390] The manual of ICIDH only contains one reference in passing to discrimination in relation to Handicap; as a characterisation of its genesis. According to the ICIDH manual "[t]he essence of an adverse valuation by society is discrimination by other people, but the concept is, nevertheless, essentially neutral as regards its origins". This is noted in relation to that Handicap can arise irrespective of if "deviation is [...] the product of his [the person implicated by Handicap] own choice". Consequently, this does not read as a problematisation of "discrimination", but rather as using the term, without valuation, as signifying the 'perceptions' of others. WHO, 1980, p. 29.

[391] UPIAS, 1974. para. 11.

[392] UPIAS, 1975, p. 16.

[393] Oliver, 1990, p. 76.

[394] WHO, 2001, p. 170.

[395] Ibid., Annex 8 Future Directions for ICF, p. 250.

[396] Hahn, 2001, p. 66. Here Hahn quotes himself in Hahn, 1997, p. 326.

[397] Hahn, 2001, p. 66, quoting Hahn, 1997, p. 326.

‘equality of results’ as its goal, as discussed above these concepts are not necessarily qualitatively different.

Additional similarities between the concepts of equality and non-discrimination in the CRPD and in the Minority Group Model of Disability is that they both require advantageous differential treatment by adaptation of the environment to the individual as a requirement of non-discrimination (“reasonable accommodation” in Article 5 (3) on Equality and non-discrimination in the CRPD and “Equal Environmental Adaptation”[398] in the Minority Group Model of Disability). The comparative standard set by the latter concept, measuring how much resources are spent on whom, aptly illustrates the invisible privileges systematically bestowed upon person without disabilities.[399] In comparison with the definition of “[r]easonable accommodation” in Article 2 of the CRPD, the latter satisfies itself by expressing its goal in general terms (“the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”) and does not go into how much resources are to be spent on whom as a metric for what is “equal”.

Finally, the CRPD and the Minority Group Model of Disability converge in that they are both positive to group-based measures such as the “specific measures” acknowledged in Article 5 (4).[400]

Moving away from the principles of equality and non-discrimination, it should be noted that the expansive features of these principles as they are understood in the CRPD (differential advantageous treatment and active measures) are encapsulated in the particular provisions of the CRPD as a part of those ‘rights’. Similarly, as noted above in relation to dignity, the fact that an approach to disability does not rely upon a particular concept does not mean that it cannot carry its content, but under a different label. A case in point is the categorical reference by the Social Model of Disability to “oppression” as a label encapsulating the injustices against disabled people.[401]

7.3.5. Participation and inclusion in the community and accessibility

Principle (c) of Article 3 is “[f]ull and effective participation and inclusion in society”, reflecting active and passive segregation and exclusion as the hallmark of the restriction of life opportunities for the constituency of the CRPD. These principles are closely connected to principle (f) “[a]ccessibility” as the former depend upon the latter, opening up as accessibility does the attitudinal, communicative and physical

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[398] Hahn, 1996, p. 47. See also Hahn, 2001, p. 67 and Hahn, 1993.

[399] Ibid.

[400] In addition to the general provision in Article 5, Article 27 (1h) on Work and employment in the CRPD calls for “affirmative action” in relation to employment. For the endorsement of such measures by Hahn, see e.g. Hahn, 2002, pp. 183-184 regarding political life and Hahn, 1987, p. 16 regarding employment (source not paginated).

[401] See e.g. UPIAS, 1975, p. 14 and Oliver, 1983, p. 23.

life world for everyone.[402] While every demanded change will be subject to an analysis of the precise entitlements and obligations flowing from the particular provision of the CRPD where it is stipulated, the point of departure remains participation, inclusion and accessibility.[403] These principles are reflected in the text of a number of provisions. Article 9 is titled "Accessibility" and both Article 29 (Participation in political and public life) and Article 30 (Participation in cultural life, recreation, leisure and sport) use "[p]articipation" to depict the main theme in the enjoyment of their respective areas of life.

Among all the areas of life protected in the CRPD the emphasis on participation and inclusion is strongest in Article 19 on Living independently and being included in the community. Indeed, the designation of the constituency of the CRPD to institutions segregated from the rest of society illustrates the potential added value by participation and inclusion to any life opportunity, segregated institutions being a travesty of the good of 'housing'. Other life opportunities where inclusion is emphasised are Article 24 on Education and Article 27 on Work and employment, similarly reflecting areas of life where segregation has been and remains pervasive. Finally, Preamble (m) emphasises the emotional value of participation and inclusion through noting that the "full participation by persons with disabilities will result in their enhanced sense of belonging", thus emphasising the added value to any person in the enjoyment of any right gained through a sense of meaningful belonging.

Like 3 (c), many provisions in the CRPD include references to both participation and inclusion, begging the questions what the added value of using both concepts are.[404] In what way is the participation in a particular area of life different from the inclusion in that area? From the common use of these terms, "participation" arguably focuses *the action* of the individual while "inclusion" focuses *the context* where one is to participate. Along these lines it can be argued that through the reference to "participation" the active role of the individual carries a value in itself, but that "inclusion" is required irrespective of the level of activity by the individual. In addition, "participation" also carries a connotation of consultation, i.e. to be a part of decision-making processes concerning different life opportunities on an individual as well as a collective level.[405] "[I]nclusion", in turn, puts the *environment* directly in the spotlight, emphasising the importance of it being receptive of each individual.

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[402] See also Preamble (v) and Article 9 on Accessibility.

[403] See also Preamble (k) and (y).

[404] Provisions referring to terms derivative of both participation and inclusion are Article 19 on Living independently and being included in the community, Article 24 on Education and Article 26 on Habilitation and rehabilitation. Provisions referring only to terms derivative of participation are Preamble (e), (k), (m) and (y), Article 1 on Purpose, Article 9 on Accessibility, Article 29 on Participation in political and public life, Article 30 on Participation in cultural life, recreation, leisure and sport, Article 33 on National implementation and monitoring and Article 34 on the Committee on the Rights of Persons with Disabilities. Provisions referring only to terms derivative of inclusion are Article 27 on Work and employment and Article 32 on International cooperation.

[405] This dimension did figure in the deliberations on Article 3 (c). See e.g. recorded statement by DPI during the 4th session, Daily Summaries 24 August 2004, 4th Session.

The focus on the environment is carried further in principle (f) "[a]ccessibility". While notions of participation and inclusion were a part already of the Working Group Draft, "[a]ccessibility" was added as a General principle later in the process.[406] The meaning of "[a]ccessibility" is fleshed out in Article 9 on Accessibility which has its main focus on, but is not limited to, altering the physical environment, transport, information and communication. It can thus be seen as a key mechanism to achieve participation and inclusion. In sum, accessibility ensures the 'fit' between the systems and contexts of each life opportunity and the requirements of the constituency of the CRPD and is as such a prerequisite for the enjoyment of life opportunities. Through the simultaneous emphasis on participation and inclusion, it is underscored that such accessible environments are to mainstream life and not parallel frameworks for life.

Turning to the approaches to disability explored in Part I of this book, the focus on inclusion, participation and accessibility resonate with nearly all these approaches, the caveat being the limited role of accessibility in ICIDH. While the life opportunities covered by the Handicap concept does include composite life opportunities which amount to participation and inclusion in society, the accessibility of the environment is not implicated as an operative factor in relation to these. In addition, ICIDH if not promotes so assumes segregated facilities such as "residential care"[407], "special education"[408] and "a sheltered workshop"[409].

The Social Model of Disability has the message of principles (c) and (f) at its core, defining Disability as restricted participation "in the mainstream of social activities".[410] Particularly, the eradication of residential institutions as well as other segregated facilities is central to the message of UPIAS.[411] The role of access is similarly present in their definition of Disability, implicating as it does "contemporary social organisation" as its genesis.[412]

The Minority Group Model of Disability similarly has participation and inclusion in society at its core, calling for "full inclusion in social, economic and political structures"[413] and underscoring the urgency to "change the environment instead of the individual", i.e. accessibility, as a crucial aspect of and mechanism towards this

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[406] Draft Article 2 (c) on General principles in the Working Group Draft, 2004, p. 9. In the compilation of proposals for change after the 3rd session proposals from both Thailand and South Africa to include accessibility as a principle in Draft Article 3 are noted. Compilation of Proposals before the 4th Session, 2004, p. 11. It was included in the Chair's Draft provided as the basis for negotiations in the 7th session. Chair's Draft, 7th Session, 2005, p. 18. In connection with this, the Chair notes that including accessibility as a general principle had "received a good level of support". Letter from the Chair to the Ad Hoc Committee, dated 7 October 2005, 7th Session, p. 4, para. 22.

[407] WHO, 1980, p. 190.

[408] Ibid., p. 53.

[409] Ibid., p. 197.

[410] UPIAS, 1975, p. 14. Michael Oliver likewise subscribes to this definition, see e.g. Oliver, 1981, p. 28.

[411] See above under Article 19 on Living independently and being included in the community, Article 24 on Education and Article 27 on Work and employment.

[412] UPIAS, 1975, p. 14 and Oliver, 1981, p. 28.

[413] Hahn, 2002, p. 184.

end.[414] Harlan Hahn emphasises that physical barriers are as effective means of segregation as are formal, expressly intentional policies:

> Disabled citizens have confronted barriers in architecture, transportation, and public accommodations which have excluded them from common social, economic and political activities even more effectively than the segregationist policies of racist governments.[415]

Like UPIAS and Oliver, Hahn deplores segregated facilities such as "“special" or separate schools"[416] or "‘sheltered workshops’"[417].

ICF similarly has a focus on participation and inclusion (compare the designation of composite life opportunities as Participation) as well as accessibility (compare the Domains of determinants of Functioning/Disability labelled Environmental factors). The ICF manual furthermore emphasises that "ICF information should be used towards the development of social policy and political change that seeks to enhance and support the participation of individuals".[418] Relating to ICF, WHO also describes its "basic core values" as "equity, inclusion and the aim of all to achieve a life where each person can exploit his or her opportunities to the fullest possible degree".[419] Against this background, albeit ICF does not qualify its life opportunities and facilities in terms of 'mainstream' or 'separate', mainstream can safely be assumed to be its baseline.

7.3.6. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

Article 3 (d) stipulates "[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity" as one of the principles to guide the interpretation of the rights in the CRPD. This provision was hailed in the negotiations as crucial. To illustrate, IDC was paraphrased during the 7th session as stating that 3 (d) is "one of the most forward-looking parts of the convention that [is] essential to communicating a paradigm shift in how society views PWD [persons with disabilities]".[420]

The implications of this provision for the interpretation of the life opportunities covered in the CRPD have been discussed already above under 7.1.1., as it implicates the valuation of impairment. As noted there, at a minimum, 3 (d) requires that each person be respected and accepted and calls for accommodation, i.e. that society must

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[414] Hahn, 1996, p. 45.
[415] Hahn, 1985, p. 94.
[416] Ibid.
[417] Hahn, 2001, p. 75.
[418] WHO, 2001, Annex 6 Ethical Guidelines for the Use of ICF, p. 245.
[419] WHO, 2002, p. 5.
[420] Recorded statement by IDC, Daily Summaries 30 January 2006, 7th Session.

be constructed based on the needs of *all*. It carries a particular emphasis on attitudinal barriers through the reference to "acceptance".[421] 3 (d) contains a core message of the CRPD, namely that human beings are equally different from each other and consequently all policy must depart not from a narrow construction of normality but from the needs of everyone. This base line entails that difference in terms of levels and modes of functioning of the body and mind cannot be 'milked' as legitimate excuses for restricted access to life opportunities. The following submission from the Asia Pacific Forum about (what became) 3 (d) to the 3rd session of the Ad Hoc Committee captures this point:

> This principle is based on, and states quite effectively, the concept that disability is a universal feature of the human condition and that legislation, social policies and environments should accordingly reflect the full range of diversity of abilities that exist in society. [422]

On the question of valuation of impairment per se, Article 3 (d) does amount to a general claim of being respected and accepted 'as one is', which would seem to invite a questioning of negative assumptions about impairment per se and not just about the person. This is so as impairment embodies the aspect of "diversity" of the constituency of the CRPD in question here. However, based on the entitlements provided by Article 25 on Health and Article 26 on Habilitation and rehabilitation to the prevention, minimisation and elimination of impairment, as well as on the preparatory works of Article 3 (d), it cannot be read as generally and principally condemning a negative valuation of impairment (as opposed to condemning a negative valuation of the person with the impairment).

Turning to the approaches to disability explored in Part I, they all depart from the position that persons sporting the diversity targeted by the CRPD should be approached by others as an accepted part of humanity and that this difference be respected. As discussed above under 7.1.1. such respect and acceptance can be interpreted to mean different things however, as it can attach to the person or to the impairment as such with differing consequences. Attaching it to the person is uncontroversial and all approaches to disability explored in Part I resonate with the message that all persons should be positively valued by virtue of their humanity. As a consequence (with the caveat of ICIDH and its missing focus on the environment), these approaches all hold that social organisation should take diversity of levels and modes of functioning of the body and mind into account in order not to create disadvantage. In addition to this, as discussed above under 7.1.3., Michael Oliver and Harlan Hahn would emphasise that the "respect" and "acceptance" enshrined in 3 (d) is not sufficient if construed as 'despite', or even 'irrespective of' impairment, instead

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[421] Article 3 (d) amounts to a principled recognition of the message in Article 8 on Awareness-raising, namely the centrality of general attitudes to the realisation of the enjoyment of life opportunities by the constituency of the CRPD.

[422] Submission for the 3rd session by the Asia Pacific Forum of National Human Rights Institutions (APF) to the Ad Hoc Committee, 3rd Session, May 2004, p. 22, para. 53.

it should be ‘because of’ impairment. Hahn expresses this by referring to “pride” [423] as the relevant standard the remainder of society should mirror and Oliver calls for that “difference not be merely tolerated and accepted but that it is positively valued and celebrated”[424]. ICIDH, conversely, is explicit on that impairment is negative. ICF, while being less explicit, draw on a categorical view of impairment as something prima facie meriting prevention, minimisation and elimination, i.e. as negative.

To conclude, the principles above do not show up notable discrepancies between the CRPD and the approaches to disability explored in Part I (save the lacking focus on accessibility and autonomy and choice in the case of ICIDH). At this early stage of interpreting the CRPD, these principles largely remain abstract constructions and the question ‘how far’ they will reach is unchartered territory. This makes detailed comparison difficult, a case in point being 3 (d) just explored.

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[423] See e.g. Hahn, 2001, p. 74 and Hahn, 2001a, p. 41.

[424] Oliver, 1990, p. 89.

8. Causality of restricted life opportunities according to the CRPD compared to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

Compared to the approaches to disability explored in Part I, human rights law in general displays much less of a focus, including much less explicit language, on the *causes* of the problems it aims to solve. In contrast, the named approaches to disability all *define* the problems they target through how these are caused. Human rights law calls for solutions based on ideas of what persons should be able to do or be, i.e. what the 'good life' is. It departs from the position that the social context, primarily the State, should respond to individuals (by taking certain actions as well as omitting others) so as to enable them to enjoy certain life opportunities conceptualised as 'human rights'. The text of the law thus consists mainly of descriptions of such life opportunities or their restrictions and measures to be taken towards change, i.e. solutions.

In all probability, the negotiations through which human rights law is created shuns the allocation of blame connected to issues of causality. Such law is after all created by States, who remain its designated perpetrators. Some potential controversy and friction between negotiating States is thus skirted by focusing on what things should be like and how to get there, rather than on the root cause of any undesired state of affairs, or even on the current state of affairs full stop. The former strategy also allows for parity among States in the sense that they are all equal in as much as that they have the same goal. The latter strategy would put the spotlight on current lack of enjoyment, which of course differs dramatically among States.

In addition, as law, human rights conventions do not have the same need as approaches to disability to use causality to *justify* the solutions asked for. While implementation of human rights law admittedly is much more of a negotiation process than advocates would like to admit, such negotiations relate more to how much and when and less to *why* prescribed solutions should be implemented. As regards the latter aspect, human rights law first and foremost relies on its status as binding law. Consequently, human rights conventions are constructed primarily through descriptions of desirable or undesirable states of affairs and required conduct in relation to these, rather than through expressions of causality.

In doctrine, particular life opportunities are sometimes picked out by commentators as instrumental to the realisation of other rights.[425] For example, lack of education is often construed as a cause of lacking enjoyment of other rights.[426] However, while rights covering different life opportunities are undoubtedly interrelated and interdependent, the instruments per se construe lacking implementation of provisions such as the right to education as a violation *in itself* and not by virtue of it being a cause of other violations.[427]

The closest human rights law prior to the CRPD gets to identifying the root causes of human rights violations are the provisions in CEDAW and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)[428] on changing "idea/s" which lead to violations. Article 5 (a) in CEDAW requires the modification of "the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women" and Articles 4 and 7 of ICERD respectively require measures towards the elimination of "all propaganda and all organizations which are based on ideas or theories of superiority of one race or group of persons of one colour or ethnic origin" and "prejudices which lead to racial discrimination". The inclusion of these provisions posits ideas of superiority and inferiority (and in the case of CEDAW "stereotyped roles") as generally instrumental

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[425] Each commentator typically notes his or her own field of interest as the starting point in a causal chain of denial of human rights en masse.

[426] See e.g. Wilson, Duncan, Human Rights: Promoting Gender Equality in and through Education, Paper Commissioned for the Education for All Global Monitoring Report 2003/4, The Leap to Equality, 2003, p. 17.

[427] Compare Preamble (c): "*Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination.". Emphasis in original.

[428] International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Adopted 21 December 1965. Entered into force 4 January 1969. 660 UNTS 195.

to the human rights violations they prohibit, which in turn are conceptualised as “discrimination”.[429]

Notwithstanding the scarce focus on causality in human rights law generally compared to the approaches to disability explored in Part I, the CRPD does offer guidance as to how it envisages the casual relations of the problems it addresses. CRPD generically depicts these problems as “violations of […] human rights”[430], “discrimination”[431] and “disability”[432]. The first concept does not easily lend itself to a definition (due to its level of abstraction it either becomes a restatement or an enumeration) and is not defined in the CRPD. Like in CEDAW and ICERD, “[d]iscrimination” is indeed defined but contains no reference to its genesis.[433] However, unlike these two instruments the CRPD contains a concept flanking that of discrimination, “disability”, and this concept is indeed depicted in terms of causality. As illustrated by the approaches to disability in Part I this is symptomatic of the genesis of this definition as disability discourse rather than human rights law. The closest the CRPD thus gets to establishing the causality of the restrictions it prohibits is in its depiction of “disability” in Preamble (e) and its depiction of “[p]ersons of with disabilities” in Article 1 on Purpose. The “environmental and attitudinal barriers” identified as instrumental to “disability” in Preamble (e) are elaborated further particularly in Article 8 on Awareness-raising and Article 9 on Accessibility.

References to the causality of impairment featured in the negotiations but were not included in the final text.

In the following, these expressions of causality in the CRPD are explored against the backdrop of the approaches to disability presented in Part I. The causality of restrictions of composite life opportunities (8.1.) and of impairment (8.2.) are addressed in turn. Within 8.1., causality as built into the depiction of “disability”/“[p]ersons with disabilities” (8.1.1.) is separated from causality in the CRPD at large (8.1.2.). The comparison with the approaches to disability explored in Part I of this book will be done in under 8.1.2. and 8.2.

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[429] While the definitions of discrimination in these instruments do not themselves contain any causal references to ideas, this causal relationship between ideas and discrimination is explicit in ICERD Article 7 and implicit in CEDAW. In the latter case, this relationship is inferable through the inclusion of Article 5 viewed against the object and purpose of CEDAW as the elimination of discrimination.

[430] Preamble (k).

[431] Article 5 on Equality and non-discrimination and Article 2 on Definitions.

[432] Preamble (e) and Article 1 on Purpose (depicting “[p]ersons with disabilities”).

[433] See above under 7.3.4.

8.1. Causality of restricted composite life opportunities

8.1.1. Causality as a feature of disability/persons with disabilities in the CRPD

According to Preamble (e) "disability *results* from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".[434] According to Article 1 on Purpose "[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments *which* in interaction with various barriers *may hinder* their full and effective participation in society on an equal basis with others".[435] Article 1 on Purpose describes "[p]ersons with disabilities" (the persons affected by the envisaged problem), rather than "disability" (the envisaged problem). However, as these are two sides of the same coin (the 'who's' are depicted directly through the 'what') both provisions have bearing on the meaning of "disability".[436] Causality is a central feature of both these provisions. Preamble (e) is worded as explicitly opening with what "disability *results from*"[437] and both provisions define the casual relationship of "disability"/"disabilities" before getting to its manifestation, as in restricted "full and effective participation in society on an equal basis with others".

At the outset one can conclude that the two categories of factors which have to be present in order for "disability"/"disabilities" (as a form of restricted participation) to ensue are "impairments" (specified in Article 1 as "physical, mental, intellectual or sensory impairments") and "barriers" ("specified in Preamble (e) as "attitudinal and environmental barriers"). Both provisions point towards the "*interaction"* as the 'hub' between "impairments" and "barriers"; the point where such "disability"/"disabilities" arise/s.

Readings of the causality of "disability" in the CRPD is likely to remain centre stage in the larger disability discourse, due to the emphasis put on defining disability and to the practice of depicting such definitions primarily through causality. As

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[434] Emphasis added.

[435] Emphasis added.

[436] The answer to the question *who* is covered by the CRPD (who are "[p]ersons with disabilities"?) thus logically overlaps with the answer to the question *what* connects this group (what is "disability"?), as it is through the phenomenon that the group is depicted. This relationship was discussed throughout the negotiations. The Coordinator of the Working Group is recorded as asking Venezuela (who proposed that those negative to defining "disability" could well be positive to defining "persons with disabilities") if it was "possible to define PWD [persons with disabilities] without defining disability". Venezuela is recorded as answering that it is "easier" to define the former than the latter. Subsequently, Ireland is recorded as noting that "defining PWD was not different than defining disability because it just adds "persons with."". Daily Summaries 16 January 2004, Working Group Session. During the 7th session Yemen is recorded as similarly noting that "if a definition of "disability" is decided upon, it will logically lead to a clear definition of "persons with disabilities."". Daily Summaries 31 January 2006, 7th Session.

[437] Emphasis added.

noted above, the comparison between the CRPD and the approaches to disability explored in Part I is placed below under 8.1.2.

8.1.2. Causality in the CRPD at large

The concept used to depict restricted life opportunities in Preamble (e) and Article 1 on Purpose is thus “disability”/“disabilities”, which in the CRPD at large is flanked by two other such expressions, namely “violations of […] human rights”[438] and “discrimination”[439]. Together, these represent the negative mirror image of what the CRPD requires. As mentioned above, the two latter concepts are not depicted by way of causality, which instead has to be inferred from the CRPD at large. As noted above, Article 1 and Preamble (e) present two categories of potential causes of restrictions to the composite life opportunities they name “disability”/“disabilities”, namely “barriers” and “impairments”. Among these, the CRPD at large has an overwhelming focus on the former category: “barriers”. The provisions creating entitlements to particular composite life opportunities in the CRPD such as education, employment and political participation stipulate solutions which target such barriers as the variable to change and thus assume impairments as the constant. As mentioned in the introduction to this chapter, human right law uses the language of solutions more often than that of causes. However, when something is depicted as being *instrumental towards* the enjoyment of composite life opportunities, it appears reasonable to assume that this amounts to recognition of *lack of that something* as instrumental to *lacking* enjoyment of composite life opportunities.

“[B]arriers” are further specified in Preamble (e) as “attitudinal and environmental” and the structure of the CRPD at large mirrors this categorisation. Two provisions in the CRPD explicitly address these in turn, namely Article 8 on Awareness-raising and Article 9 on Accessibility.

8.1.2.1. Attitudinal barriers

Beginning with Article 8, it is the sister provision to CEDAW’s Article 5 and ICERD’s Articles 4 and 7 mentioned above. The mission of Article 8 is to change how others perceive the constituency of the CRPD, in other words ‘what people think’ of persons with disabilities. Article 8 obliges States to take “immediate, effective and appropriate measures”, including within the educational system and in relation to the media and including public awareness campaigns and awareness-training programmes. The mission according to Article 8 (1 a-c) is “[t]o raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities, [t]o combat stereotypes, prejudices and harmful practices relating to persons with disabilities,

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[438] Preamble (k).

[439] Article 5 on Equality and non-discrimination and Article 2 on Definitions.

including those based on sex and age, in all areas of life, [and to] promote awareness of the capabilities and contributions of persons with disabilities". Awareness-raising is thus to target all of society, and the family receives a particular mention.

Among the measures to this end further regulated in Article 8 (2), public awareness-raising campaigns are subject to the most detailed regulation. According to 8 (2a) such campaigns are to "nurture receptiveness to the rights of persons with disabilities" and to "promote positive perceptions and greater social awareness towards persons with disabilities". This includes promoting the "recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market". The goal of awareness-raising measures in the educational system is expressed in 8 (2b) as "[f]ostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities". In relation to the media, the obligation according to 8 (2c) is to "[e]ncourag[e] all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention". 8 (2d) obliges Sates to "[p]romot[e] awareness training programmes regarding persons with disabilities and the rights of persons with disabilities". Two main themes are discernible in the mission of Article 8, namely to raise awareness and receptiveness of the *rights* of persons with disabilities and to promote *positive perceptions* of persons with disabilities through highlighting "capabilities and contributions", the mirror image of which is to "combat stereotypes [and] prejudices". Compared to ICERD and CEDAW, Article 8 does not refer to ideas of inferiority and superiority as its target, but like CEDAW and ICERD respectively the CRPD identifies "stereotypes" and "prejudices" among the attitudes that States should combat.[440]

Outside the depiction of "disability"/"[p]ersons with disabilities" in Preamble (e) and Article 1 on Purpose, similarly to CEDAW the instrumental relationship between ideas and attitudes and the problems which the CRPD aims to solve, "discrimination" [441] and "violations of […] human rights" [442] is not explicitly recognised. Article 8 stops at requiring measures towards changed attitudes; it does not spell out the ills caused by current attitudes nor the good towards which changed attitudes are envisaged as instrumental. However, this relationship between ideas and attitudes and the problems the CRPD aims to solve is implicitly inferable through the inclusion of Article 8 viewed against the purpose of the CRPD as expressed notably in Article 1 ("to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".)[443] As in the instrument, this connection was largely

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[440] While only CEDAW refers to "stereotyped roles" both CEDAW and ICERD refer to "prejudices". Article 4 of ICERD contains the gravest expression of such attitudes: "racial hatred".

[441] Article 5 on Equality and non-discrimination and Article 2 on Definitions.

[442] Preamble (k).

[443] The connection to discrimination is through the addition of "equal" to "full" in Article 1. For the relationship between "equality" and "non-discrimination" see above under 7.3.4. Speaking also for this link is the explicit causal role attributed to barriers in Preamble (e) and Article 1 in relation to "disability"/"disabilities"; assuming that "violations of [...] human rights" and "discrimination"

taken for granted in the negotiations. Sometimes it was however explicitly expressed, such as when Venezuela proposed the following language to the Working Group, calling for States to combat "stereotypes, social and cultural patterns, customary practices and any other type of practices *which lead to* segregation or discrimination or which prevent persons with disabilities from exercising their rights".[444] The centrality of attitudes was recognised throughout the negotiations, to the point where it was asserted as an obstacle of an importance exceeding that of resource constraints. During the 7th session the High Commissioner on Human Rights noted that "it is often attitudes, rather than resource constraints, that create the strongest barriers to the enjoyment of civil and political rights and of economic, social and cultural rights by persons with disabilities".[445]

Article 8 singles out particular levels of society such as the family (1a) as well as certain systems for transmission of learning, namely public awareness programmes (2a), the education system (2b), the media (2c) and awareness-training programmes (2d), as particularly central to its mission. The depiction of who it targets is wide, expressed as "society" (1a) and "all children" (2b). The main target of awareness-raising discussed in the negotiations was society at large, arguably understood as everyone but the constituency of the CRPD. However, some attention was also paid to the need to address directly the effect of surrounding attitudes (as well as environmental barriers) on the self-regard of the constituency of the CRPD, addressed in the negotiations as "internalized oppression"[446] or "negative self-image"[447]. For example, this question was brought up during the 5th session through a proposal by Namibia to ensure that information aiming at awareness-raising should be "accessible" to the constituency of the CRPD for the purpose of counteracting "negative self-image".[448] The reference to the accessibility of awareness-raising did not make it into the final version of the CRPD.

Another dimension of the largely dualistic point of departure of the negotiations (that it is exclusively persons who do not form part of the constituency of the CRPD who need to learn to respect the dignity and rights and recognise the abilities and

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largely overlap with "disability"/"disabilities". For a discussion on potential limitations regarding the latter two terms see further below under 10.1.6. and 12.1.3.

[444] Proposal by Venezuela, Compilation of Proposals before the Working Group, 2004, p. 77. Emphasis added.

[445] Statement by Arbour, Louise, UN High Commissioner for Human Rights, to the General Assembly Ad Hoc Committee, 7th Session, 27 January 2006.

[446] Recorded statement by the British Council of Organisations of Disabled People, on behalf of IDC, Daily Summaries 2 February 2006, 7th Session.

[447] Recorded statement by Namibia, Daily Summaries 3 February 2005, 5th Session.

[448] Ibid. The proposal by Namibia concerned Draft Article 14 on Respect for privacy, home and the family and resulted in the inclusion of a requirement of the accessibility of awareness-raising in this article after the 5th session. See 5th Session Report by the Coordinator, 2005, pp. 23-24, paras. 124-125. When references to awareness-raising were consolidated in Article 8 on Awareness-raising the reference to accessibility was not included. Related proposals were made by others, such as a recorded proposal by China during the 4th session asking for the inclusion of language to the effect of "[e]ncouraging and assisting PWD [persons with disabilities] to have self-esteem" in what were to become Article 8. Daily Summaries 25 August 2004, 4th Session.

contributions of those who are covered by the CRPD) is that no attention was given to the need to raise awareness among one part of the constituency about its other parts. However, as the object of awareness-raising presumably is to cover persons with *all* impairments recognised by the CRPD and the subject targeted is as large as "society", it can be presumed that the line between object and subject (those about whom awareness is to be raised and those whose awareness is to be raised) is not so clear cut. This is so as persons with impairments other than the one(s) brought out by a certain awareness-raising measures may be among those harbouring such attitudes as Article 8 targets. As brought out by the proposal by Namibia above this has implications for the accessibility requirements of such measures.

Other provisions where the importance of attitudes and ideas shines through are Article 23 on Respect for home and the family and Article 25 on Health. When 23 (3) calls for "early and comprehensive information" to the families of children with disabilities with a view to realising the right to family life, including the prevention of "concealment, abandonment, neglect and segregation of children with disabilities" it implicitly recognises negative attitudes and ideas as instrumental to such forms of abuse.[449] The importance attached to the attitudes of family is further evident in the explicit mention of family as the target for awareness-raising in Article 8 (1a). These provisions reflect a reality succinctly described by the British Council of Organisation of Disabled People during the 6th session:

> There is a history of "disableism" around the world, which impacts on the lives of disabled children. A majority of their parents do not have experience of living with an impairment and find it difficult to adjust to the negativity that is still out there in society in everything we do – on television, in the cinema, in comic books and playgrounds, in the way that nondisabled peers react because they have not been taught any other way.[450]

Similarly, when Article 25 (d) calls for "raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care", it recognises not only the clinical proficiency but the *attitudes and ideas* of the health profession as instrumental to violations of the CRPD.[451]

Turning to the approaches to disability explored in Part I and beginning with UPIAS, they explicitly recognise the importance of attitudes noting "a positive shift in the attitudes of some able-bodied people as they have responded to our presence amongst them [which] show[s] that general attitudes can be changed for the

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[449] The existence of such practices were noted in the negotiation in relation to the need for awareness-raising, such as the record from the 3rd session of Trinidad and Tobago stating that "[s]ome families hide their children with disabilities out of shame". Daily Summaries 25 May 2004, 3rd Session.

[450] Record of Statement by the British Council of Organisations of Disabled People, Daily Summaries 2 August 2005, 6th Session.

[451] See further below under 9.1.6. and 12.1.4.

better”.[452] UPIAS relate such “prejudiced attitudes” to the existence of “segregated institutions”:

> It is also true that the kind of prejudiced attitudes we all experience -other people being asked if we take sugar in our tea is the usual example -are related to the continued unnecessary existence of sheltered institutions. [...] Physically impaired people will never be fully accepted in ordinary society while segregated institutions continue to exist, if only because their unnecessary survival today reinforces out of date attitudes and prejudices.[453]

In relation to the issue of self-perception raised by Namibia in the negotiations UPIAS note the effects of the attitudes of others on an individual by giving the example that professionals in segregated settings “*convince* them [disabled people] that they cannot realistically expect to participate fully in society and earn a good living”.[454]

Michael Oliver similarly recognises the role of attitudes in the creation of Disability, but emphasises that the core focus should be on what society actually does, on the tangible result of attitudes rather than on the attitudes themselves, as “[d]iscrimination does not exist in the prejudiced attitudes of individuals but in the institutionalised practices of society”.[455] In addition, Oliver points out that disabled people are not immune to the attitudes of others, particularly as Disability is often experienced in isolation from others affected:

> Precisely because disability in all parts of the world is an isolating experience, most disabled people only experience their disabilities in individual terms. Thus, they may internalise the ideology of personal tragedy, they may come to see themselves as a burden and feel that their problems are their own fault.[456]

From this follows the value of organising collectively emphasised by the Social Model of Disability.[457]

Harlan Hahn directs his main focus towards attitudes, asserting that “[a]ttitudes restrict opportunities even more blatantly than physical barriers”.[458] Hahn uses attitudes to illustrate that such barriers are not “accidental or coincidental”.[459] He calls attention to the severity and prevalence of negative attitudes (that “[a]nimus toward disabled people seems to be an endemic and deep-seated characteristic of most cultures of the world”) as a way of emphasising the invidiousness of actual, tangible bar-

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[452] UPIAS, 1974, paras. 3-4.
[453] Ibid., para 13.
[454] Ibid., para. 7. Emphasis added.
[455] Oliver, 1990, p. 76.
[456] Ibid., p. 122.
[457] See e.g. UPIAS, 1975, p. 16 and Oliver, 1996, p. 152.
[458] Hahn, 1987, p. 6 (source not paginated). See also Hahn, 2002, p. 171 and Hahn, 1999, p. 7.
[459] Hahn, 1985, p. 95.

riers.[460] In contrast to Article 8, the Minority Group Model of Disability emphasises the intensity of the current *negative* attitudes of others towards its constituency, and calls for a deeper investigation into these.[461] Article 8, in comparison, moves quickly to calls for the development of *positive* attitudes: to "foster respect for the rights and dignity of persons with disabilities" (1a), to "promote awareness of the capabilities and contributions of persons with disabilities" (1c) and to promote "positive perceptions and greater social awareness towards persons with disabilities" (2aii). While Article 8 (1b) does call for the State to "combat stereotypes, prejudice and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life", it does not linger on these and omits the references to the instrumental role of ideas of superiority and inferiority which are explicitly recognised in ICERD and CEDAW.[462] The preference for "positive language" was explicitly voiced in the negotiations, and in relation to Article 8 in particular.[463] While Article 8 thus explicitly acknowledges problematic current attitudes, it does not touch upon possible reasons for or characteristics of these and instead moves quickly to the kind of attitudes it calls for. Thus, while the focus on attitudes and the detailed provisions in Article 8 resonate with the Minority Group Model of Disability, the lack of explicit recognition of invidious ends served by current attitudes, particularly as these are recognised in relation to ethnicity and sex, does not correspond well with this approach.

Like the Social Model of Disability, the Minority Group Model of Disability recognises the instrumental damage done by the attitudes of others:

> Embedding the minority-group model of disability into American political and cultural thought has sweeping implications for people with disabilities, especially for young children whose self-concepts have not yet been mutilated by experiences of stigmatization. First, the awareness that their problems, including some degree of their incapacities, are created by defects of their social environment rather than of themselves relieves them from the enormous burden of psychological distress imposed by guilt and shame. Second, raising their consciousness in this regard is vital to promoting disabled people's sense of personal and political identity and empowerment.[464]

Turning to ICF, Environmental factors includes the Domain "Attitudes" which covers "attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs".[465] It is recognised that "[t]hese attitudes influence individual behaviour and social life at all levels, from interpersonal relationships and community associations to political, economic and legal structures".[466] The category "Attitudes" does not address the attitude of a person

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[460] Hahn, 2002, p. 183. See also Ibid., p. 180.

[461] See Hahn, 2001, p. 70-71, Hahn, 1985, p. 103 and Hahn, 1999, pp. 8-9.

[462] See above under 8.

[463] See e.g. record of statement by the Holy See in Daily Summaries 16 January 2006, 7th Session.

[464] Hahn, 2000, p. 272.

[465] WHO, 2001, p. 190.

[466] Ibid.

towards him- or herself, instead "[t]he attitudes classified are those external to the person whose situation is being described".[467] Presumably, the attitude of a person towards him- or herself would fall under Personal factors, which are recognised by ICF but not part of the classification. To some extent such Personal factors seem to overlap with Body functions. For example, the Domain "Mental functions" includes the category ”Global mental functions" which in turns includes the category "Temperament and personality functions".[468] This category includes "Confidence" which is described as "[m]ental functions that produce a personal disposition that is self-assured, bold and assertive, as contrasted to being timid, insecure and self-effacing".[469]

Finally, ICIDH recognises the causal relationship between attitudes and restricted composite life opportunities as in Handicap, but on a different level. While it is attitudes as in *expectations* which create the fact that it is perceived as a problem when someone no longer carries out an expected role, attitudes are not categorically recognised as something which *hinders* someone from actually carrying out that expected role. Having said that, in effect, the latter role of attitudes in relation to Handicap is indirectly recognised in the manual through the example of a person "who has recovered from an acute psychotic episode but who bears the stigma of being a "mental patient"".[470] Here, the problem in question is not attitudes in the sense of ideas about what a person should be able to do, but attitudes which hinder him or her from actually doing it. This aspect is however not built into the general depiction of the causality of Handicap in ICIDH, which categorically points to Impairment and Disability.[471] On the issue of self-regard, ICIDH recognises the importance of this and its effect upon the enjoyment of composite life opportunities. However, it puts problems in this regard down to the existence of Impairment or Disability, noting as the manual does that "self-perception – the sense of identity – is assaulted by changes in the body and its functional performance".[472] Further along the same line, as part of "Social integration handicap", "Inhibited participation" is described as including the following situation:

> [I]individuals in whom the presence of an impairment or disability gives rise to non-specific disadvantage that may inhibit but not prevent participation in the full range of customary social activities (includes embarrassment, shyness, and other defects of self-image *due to* disfigurement or other impairments and disabilities).[473]

Again, the genesis of disadvantage is features of the individual and not the attitudes of others.

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[467] Ibid.

[468] Ibid., p. 50.

[469] Ibid., p. 51.

[470] WHO, 1980, p. 31.

[471] See e.g. Ibid., p. 30.

[472] Ibid., p. 24.

[473] Ibid., p. 199. Emphasis added.

8.1.2.2. Environmental barriers

The second category of barriers recognised as instrumental to "disability" in Preamble (e) is "environmental" barriers. Like attitudinal barriers these are dedicated a provision, Article 9 on Accessibility. According to Article 9 (1) its overarching aim is "[t]o enable persons with disabilities to live independently and participate fully in all aspects of life". The essence of this article is to open up the entire existing and potential life world to everyone. According to 9 (1), States "shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban or rural areas". The two main areas covered in Article 9 are the physical environment and transportation on the one side and information and communication on the other. The former category includes "[b]uildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces". The latter category includes "[i]nformation, communications and other services, including electronic services and emergency services".[474]

Article 9 (2) further develops the obligations of States to make the world accessible, calling for "appropriate measures" to be taken to this end. 9 (2a) requires measures which "[d]evelop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public". 9 (2b) concerns the private sphere. It requires States to adopt measures to "[e]nsure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities". 9 (2c) concerns the competence of providers of services and facilities, as well as of users. It requires measures which "[p]rovide training for stakeholders on accessibility issues facing persons with disabilities". 9 (2d) concerns signage for orientation and requires measures which "[p]rovide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms". 9 (2e) concerns live assistance and intermediaries and requires measures which "[p]rovide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public". 9 (2f) functions as a swallow all provision in relation to information through requiring measures which "[p]romote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information". 9 (2g) concerns e.g. the Internet and requires measures which "[p]romote access for persons with disabilities to new information and communications technologies and systems, including the Internet". Finally, 9 (2h) emphasises the link between early attention

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[474] According to Article 2 on Definitions, ""[c]ommunication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology".

to accessibility questions and the cost of accessibility, through obliging States to take measures which "[p]romote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost".

The centrality of the problem of lacking accessibility is visible from that, in addition to Article 9, accessibility guarantees and measures are part of many of the provisions protecting particular life opportunities in the CRPD, identifying the physical, transport and communicative and information environment as a central target for solutions to restricted composite life opportunities. As mentioned above under 7.3.5., accessibility is one of the General principles in Article 3 and Preamble (v) underscores "the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication". The concept of accessibility is also included in the definition of "[c]ommunication" in Article 2 on Definitions. Article 4 (1h) on General obligations calls for "accessible information" about "mobility aids, devises and assistive technologies". Article 21 (a-d) on Freedom of expression and opinion, and access to information emphasises accessibility in relation to official information provided to the public, communication in official interactions, information and services from private entities and the services of the mass media. Article 27 (1) on Work and employment calls for the labour market and work environment to be accessible. Article 29 (ai) on Participation in political and public life calls for accessible procedures, facilities and materials in relation to voting. Article 30 on Participation in cultural life, recreation, leisure and sport calls for accessibility in relation to all the areas of life it covers, extending to venues as well as activities and materials. Article 31 (3) on Statistics and data collection calls for the accessibility of statistics produced. Finally, Article 32 (1a) on International cooperation calls for the accessibility of international cooperation.

Turning to the approaches to disability explored in Part I of this book, putting the problems affecting their constituencies down to an inaccessible physical, transportation, communicative and information environment echoes all these save ICIDH.

Beginning with UPIAS, their definition of disability implicates "contemporary social organisation" as the genesis of restricted composite life opportunities.[475] As their focus is limited to people with physical disabilities they focus on aspects of the environment such as "flights of steps, inadequate public and personal transport [and] unsuitable housing".[476] Michael Oliver also sets the built environment as his primary focus, and draws attention to additional areas mentioned in Article 9 by addressing the restricted composite life opportunities of persons with sensory disabilities due to inaccessible communication.[477]

Harlan Hahn similarly underscores "altering the external environment", i.e. accessibility as a crucial aspect of the restriction of composite life opportunities.[478] As

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[475] UPIAS, 1975, p. 14.

[476] UPIAS, 1974, para. 1.

[477] Oliver, 1981, p. 30.

[478] Hahn, 1996, p. 45.

mentioned just above, Hahn strategically focuses on attitudes in order to make the case for the eradication of tangible barriers. However, this does not take away from the centrality he accords such barriers, but rather appears as the strategy chosen to address these.[479]

ICF also recognises the importance of the accessibility of the physical environment, of transport and of the communicative and information environment in restricting access to composite life opportunities. Environmental factors, which covers the "physical, social and attitudinal environment"[480] contains the Domains "Natural environment and human-made changes to the environment"[481], "Products and technology"[482] and "Services, systems and policies"[483]. The latter two address the physical environment and transportation, as well as communication. For example, the Domain "Products and technology" includes the categories "Products and technology for personal indoor and outdoor mobility and transportation"[484], "Design, construction and building products and technology of buildings for public use"[485], "Design, construction and building products and technology of buildings for private use"[486] and "Products and technology for communication"[487]. The Domain "Services, systems and policies" includes the categories "Architecture and construction services, systems and policies"[488], "Open space planning services, systems and policies"[489], "Communication services, systems and policies"[490] and "Transportation services, systems and policies"[491].

Finally, as mentioned above, the categorical depiction of the causality of Handicap in ICIDH points unequivocally to levels and modes of functioning of the body and mind (Impairment and Disability) and not to any aspect of the environment, neither the attitudinal nor the physical, transportation, communicative or information environment.[492] However, much like in relation to the attitudinal environment discussed just above, recognition of the effect of the constructed environment is built into the measurement of the potential of the individual to enjoy composite life opportunities. To reiterate the example used above under 2.3., the level of "Physical independence handicap" is categorised differently depending on the presence of "physical obstacles to independence, e.g., structural or architectural barriers such as ladders or stairs"

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[479] See e.g. Hahn, 1999, p. 7, where he refers to tangible barriers as the "penultimate origins" of disadvantage, in turn caused by attitudes. See also Hahn, 1996, p. 53.

[480] WHO, 2001, p. 171.

[481] Ibid., p. 182.

[482] Ibid., p. 173.

[483] Ibid., p. 192.

[484] Ibid., p. 174.

[485] Ibid., p. 178.

[486] Ibid., p. 179.

[487] Ibid., p. 175.

[488] Ibid., p. 193.

[489] Ibid., p. 194.

[490] Ibid., p. 196.

[491] Ibid.

[492] See e.g. WHO, 1980, p. 30.

and depending on whether “the potential to create or provide an alternative environment is available in that culture”.[493]

8.1.2.3. Impairment

The additional prerequisite for “disability”/“disabilities” in Preamble (e) and Article 1 on Purpose is “impairments”. Outside of these two provisions the separation of composite life opportunities and levels and modes of functioning of the body and mind is almost total in the CRPD. Article 25 on Health addresses alteration of impairment (termed “disabilities”), but lack of such alteration is not explicitly instrumentally linked to the enjoyment of composite life opportunities; instead the expressed goal of such alterations is limited to “the highest attainable standard of health”. No instrumental link is created between health (which according to Article 25 includes addressing impairment) and the enjoyment of the composite life opportunities protected in the remainder of the CRPD. Correspondingly, the provisions creating entitlements to particular composite life opportunities in the CRPD, such as education, employment and political participation point to the environment as the variable to change and thus assume levels and modes of functioning of the body and mind as the constant.[494]

The only exception is Article 26 on Habilitation and rehabilitation. Article 26 (1) reads:

> States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services […].

The first sentence expresses the goals of (re)habilitation and the second sentence the kinds of measures States are obliged to take to achieve these goals. While the immediate correspondence is between measures in the area of “health” and the goal of “full physical [and] mental […] ability” there is no division between the respective goals and measures, indicating that there is no watertight partition between these.[495] Notably, “health” as an area is the first such area to be enumerated, while “full physical [and] mental […] ability” is not first in the enumeration of goals, instead “maximum independence” starts the enumeration. Furthermore, there is no immediate

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[493] Ibid., pp. 188-189.

[494] Preamble (v) on accessibility recognises “health” as an important area, but does not link it to other areas of life.

[495] The Russian Federation is noted during the 7th session as calling for “dividing the concept of physical and mental abilities from developing social and vocational abilities”. This did not generate a debate nor affected the phrasing of Article 26. Daily Summaries 25 January 2006, 7th Session. Furthermore, the Chair’s Closing Remarks after the 7th session [hereinafter Chair’s Closing Remarks, 7th session], 3 February 2006, did not indicate controversy.

correspondence in terms of pairs between the other measure and goals. Particularly the first and the last goal, “maximum independence” and “full inclusion and participation in all aspects of life” could correspond to services and programmes in many areas of life. Consequently, it would seem that Article 26 envisages measures in the area of “health” not only in order to “attain and maintain […] full physical [and] mental […] ability”, but also in order to attain these additional goals. Article 26 thus envisages alteration of levels and modes of functioning of the body and mind as instrumental to composite life opportunities (and lacking alterations as instrumental towards lack of such opportunities).

A contextual interpretation of Article 26 actualises the fact that, outside the depictions of “disability”/“disabilities” in Preamble (e) and Article 1 on Purpose, Article 26 is the only provision in the CRPD which posits a causal relationship between levels and modes of functioning of the body and mind and composite life opportunities. While this would speak against the interpretation above, speaking for it is the fact that the significance and role of levels and modes of functioning of the body and mind is consciously downplayed in the CRPD and references were habitually avoided outside of the context where this was unavoidable, namely the depictions of “disability”/“disabilities”.[496] This fact makes it hard to draw any conclusion about the role of levels and modes of functioning of the body and mind by means of contextual interpretation.

The first individual complaint submitted under the OP-CRPD, H.M. v. Sweden, indicates that the CRPD Committee reads medical (re)habilitation as instrumental to composite life opportunities. The case concerns medical (re)habilitation and the Committee enumerates all the goals in Article 26 as relevant, without making any distinctions among these.[497] In addition, a connection is indeed made between medical (re)habilitation and the opportunity for persons with disabilities “to live and participate in their communities”, as the Committee notes that the lack of such rehabilitation would adversely affect the author, H.M., to the point where she would need to leave her home. This in turn is linked by the Committee to a potential violation of Article 19 on Living independently and being included in the community.[498]

To conclude, the focus on the environment as the cause of restricted composite life opportunities is all but total in the CRPD. Besides the recognition of a causal role of “impairments” in relation to composite life opportunities in Article 1 on Purpose and in Preamble (e), only Article 26 makes such a connection. No provision on composite life opportunities implicates alteration of levels and modes of functioning of the body and mind as instrumental to their realisation (or conversely lacking such alteration as instrumental to lacking enjoyment). Finally, the central article creating entitlements to such alteration, Article 25 on Health, does not justify

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[496] See below under 12.1.1. on concerns in the negotiations of the CRPD about drawing attention to impairment.

[497] H.M. v. Sweden, 2012, para. 8.7.

[498] Ibid., para. 8.9.

itself by way of the life opportunities it creates being instrumental to the enjoyment of composite life opportunities.

Turning to the approaches to disability explored in Part I, the question is how they, in comparison with the CRPD, envisage the causality of restricted composite life opportunities. As apparent from Part I of this book, it is regarding the causal role attributed the two categories of prerequisites for "disability" recognised in Preamble (e): "environmental and attitudinal barriers" on the one side and "impairments" on the other, that the strongest discordance between these approaches emerge.

Beginning with UPIAS, the cause of Disability is included in its very definition as Disability equals "disadvantage or restriction of activity *caused by* a contemporary social organisation".[499] Furthermore, no instrumental link between Impairment and restricted composite life opportunities is recognised by UPIAS. This is later presented as a largely strategic decision, aiming at redirecting attention from Impairment and onto the environment.[500] As argued above under 3.3., this approach is not altogether consistently applied, as UPIAS present medical care (which targets levels and modes of functioning of the body and mind) as relevant to achieving full participation in society.

Michael Oliver similarly refutes any causal connection between Impairment and Disability, and by designating Disability as the depiction of relevant life opportunities he severs any causal connection between Impairment and *relevant* life opportunities.[501] Again, this reads as a largely strategic move, expressed by Oliver as "an attempt to switch the focus away from the functional limitations of individuals with an impairment on to the problems caused by disabling environments, barriers and cultures".[502]

Harlan Hahn recognises the role of impairment as an (albeit of lesser significance) causal factor in relation to his depiction of composite life opportunities, i.e. disability. This is discernible through him forwarding that "disability" does not "result *exclusively* from bodily impairment; in fact, disability is produced *primarily* by the effects of a disabling environment".[503] While it is the environment which is generally problematised in the Minority Group Model of Disability (and remains the focus in this quote as well), impairment is thus here recognised as part of the equation.

Moving on to ICF, both a Health condition (including "diseases, disorders, injuries, traumas, etc.")[504] and Environmental factors are recognised as causing restricted composite life opportunities (Participation restrictions) and ICF makes as point of recognising these on par; neither one should be the sole or even predominant focus.[505]

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[499] UPIAS, 1975, p. 14. Emphasis added.

[500] Finkelstein, 2001, p. 2.

[501] See e.g. Oliver, 1996, pp. 32-33.

[502] Oliver, 2004, p. 20.

[503] Hahn, 2002, p. 180. Emphasis added.

[504] WHO, 2001, p. 8.

[505] See e.g. WHO, 2002, p. 9.

Finally, ICIDH categorically describes the restriction of composite life opportunities (Handicap) as consequences of levels and modes of functioning of the body and mind, referring to such restriction as “stemming from the presence of impairments and disabilities”.[506] This is the remaining impression, irrespective of that this limited perspective is not consistently carried through.[507]

8.2. Causality of impairment

The CRPD does not explicitly address the genesis of levels and modes of functioning of the body and mind (in the terminology used by Preamble (e) and Article 1 on Purpose: “impairments”) albeit, as noted in the negotiations, this has figured as a limitation for access to rights in national contexts (such as limiting entitlements to veterans of war). However, even though such concerns were expressed in the negotiations these did not materialise as language in the final text of the CRPD.[508]

The closest a draft of the CRPD came to explicitly depicting the genesis of impairment was in the context of armed conflict and natural disaster. The following provision, implicating impairment as one of the consequences of such conflict and disaster was included in the Draft Preamble as late as after the 7th session:

> (s) *Concerned* that situations of armed conflict and the occurrence of natural disasters have considerably increased the experience of disability in war-stricken and disaster-prone countries, as well as having especially devastating consequences for the human rights of persons with disabilities[.][509]

Final paragraph (u) of the Preamble retains the latter aspect of armed conflict (its impact on the human rights of the constituency of the CRPD) but not the former (its role as a cause of impairment):

> (u) *Bearing in mind* that conditions of peace and security based on full respect for the purposes and principles contained in the Charter of the United Nations and observance of applicable human rights instruments are indispensable for the full protection

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[506] WHO, 1980, p. 29.

[507] See above under 2.3.

[508] See e.g. Bangkok Draft, Regional Workshop towards a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 14-17 October 2003, Compilation of Proposals before the Working Group, 2004, p. 31 and Japan Disability Forum (JDF), Comments on Important Articles of the Draft Convention Prepared by the Working Group [hereinafter JDF Comments on Draft Convention, 3rd Session], 3rd Session, 2004, p. 25.

[509] CRPD Working Text after 7th Session, 2006, p. 7. Emphasis in original. Like elsewhere in the negotiations of the CRPD and in the CRPD, levels and modes of functioning of the body and mind are termed “disabilities” here. See above under 7.

> of persons with disabilities, in particular during armed conflicts and foreign occupation [.] [510]

In the previous version, the recognition of situations causing impairment (armed conflict and natural disasters) not only draws attention to impairment but in addition implies (through the phrasing "*[c]oncerned*") both a negative valuation of it and the desirability of its prevention, which is arguably why this aspect was removed from the final text.[511]

Article 11 on Situations of risk and humanitarian emergencies similarly avoids any references to the genesis of impairment when noting the importance of international law, including human rights law and humanitarian law, during situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. This article took its form late in the negotiations and was, like the Preamble, subject to the concern that it, due to its de facto connection with the genesis of impairment, would lead to the inclusion of language on the prevention of impairment. An example of such concern is the written submission by IDC before the 7th session, which puts it that "[r]eference to international laws, such as the Geneva Convention, is necessary, but the risk should be avoided to have language that implies protection against a disability".[512]

The closest the final text of the CRPD gets to addressing the genesis of impairment is the references to "minimize and prevent further disabilities" and "population based public health programmes" in Article 25 on Health. Article 25 (a) calls for the extension of "population-based public health programmes" to the constituency of the CRPD but does not specify what causal factors these are to target. In the negotiations, disease (HIV/AIDS and Polio) and lacking sanitation and water were mentioned as targets of such programmes.[513] Article 25 (b), in turn, which requires the prevention of "further disabilities", is limited to the context of medicine. It posits medical intervention as instrumental to the avoidance of "further disabilities" and consequently, lacking medical intervention as instrumental to the emergence of such "further disabilities".

To sum up, the CRPD does not linger on the genesis of impairments, and this is closely connected to the wish to tone down any attention to these, particularly attention implicating the desirability of their prevention.

Turning to the approaches to disability explored in Part I of this book, causality of levels and modes of functioning of the body and mind is not the focus of any of these. While ICF and ICIDH encapsulate this dimension in their universe, their main 'story' begins at the stage where these are already present. ICIDH depict the

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[510] Emphasis in original. This omission was requested inter alia by ICD. IDC Amendments to CRPD Working Text, 8th Session, pp. 7-8.

[511] Emphasis in original. Compare reasoning against the inclusion of a general State obligation regarding prevention of impairment above under 7.1.1.

[512] IDC Amendments to Chair's Draft, 7th Session, p. 26 (source not paginated).

[513] See above under 7.1.1.

Consequences of disease[514] and even though it mentions "genetic abnormality or the consequences of a road traffic accident"[515] as causes of Impairment, its focus is on consequences of Impairment rather than on its causes. ICF similarly focuses on life opportunities once Disability is present.[516]

As neither the Social Model of Disability nor the Minority Group Model of Disability wishes to draw attention to impairment, it follows that they find little relevance in discussing its genesis. However, Michael Oliver does address the fact that injustices impact on the likelihood of acquiring an Impairment:

> Like other social and economic inequalities, the acquisition of individual impairment is related to a whole range of material factors such as geography, age, class, gender and race.[517]

However, presumably as the celebration of Impairment is key to Oliver as well as closely connected to the Social Model of Disability in his writings, the genesis of Impairment (implying it as problematic) is not focused upon in his deliberation of this model.

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[514] WHO, 1980, p. 10.

[515] Ibid., p. 27.

[516] See WHO, 2001, e.g. p. 13, where it is noted that "[i]mpairments are not contingent on etiology or how they are developed".

[517] Oliver, 1996, p. 120. See also Oliver, 1983, pp. 50-54 and Oliver, 1999, p. 169.

9. Solutions to restricted life opportunities according to the CRPD compared to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

The point of the CRPD, like any other human rights instrument or for that matter approach to disability, is for the problems it identifies to be addressed. As stated in Article 4 on General obligations, the aim of the CRPD is "to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability". Thus, no matter if a provision explicitly asks for solutions or not, solutions (or, in human rights terms, 'measures') in some shape or form are envisaged.[518] Some provisions are explicit about what measures States have to take towards a certain goal, while others stop at calling for measures in general terms or even do not mention measures at all. Lacking specificity here is connected to the human rights legal tradition of leaving the question 'how' to achieve something as open as possible to the State. This represents a concession to the diversity among States, as well as to the fact that there are many means to a particular end. Having said that, the CRPD is comparatively detailed in its description of what has to be done, as well as how this is to be done.

Almost every provision makes overarching references to the infrastructure for the realisation of rights, such as to 'policies', 'programmes' and 'services'. In this section I address in further detail the question how the CRPD enviseages the change it demands to happen. What kinds of solutions are envisaged by the CRPD as the way to address the problems it identifies and which actors do these solutions implicate? Below I present the main categories of measures identified in the CRPD. As men-

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[518] Compare Article 17 on Protecting the integrity of the person above under 7.2.7.

tioned above under 8., the interrelatedness and interdependence of rights mean that almost any area of life can be singled out as instrumental in relation to another, with the consequence that the former emerges as a 'measure' towards the latter. Any provision which is designated a primarily intrinsic value in the CRPD, such as Article 24 on Education, Article 27 on Work and employment, Article 29 on Participation in political and public life and Article 25 on Health, can also be designated instrumental value as a vehicle towards the enjoyment of additional life opportunities once removed from its express aim.[519] In the following, I will focus on the provisions I perceive as assigned a *primarily* instrumental character in the CRPD and, as a contrast, add the ones the instrumental value of which is highlighted by the approaches to disability explored in Part I.

9.1. The range of solutions envisaged by the CRPD

The categories of solutions identified in the CRPD and presented below (9.1.1.-9.1.14.) are, in turn: legislative measures, judicial measures, administrative measures, design and technology, mainstreaming, training of professionals, consultation and involvement of (organisations of) persons with disabilities, awareness-raising, accessibility, personal mobility, habilitation and rehabilitation, statistics and data collection, international cooperation and mechanisms for monitoring the implementation of the CRPD. Additional categories identified as accorded an instrumental role in the approaches to disability explored in Part I are noted in 9.2.

9.1.1. Legislative measures

Article 4 on General obligations draws out a number of categories of measures as generally relevant to the implementation of the rights in the CRPD. The first category of measures mentioned in Article 4 (1a) is *"legislative […] measures"*.[520] The role of legislation (among "all appropriate measures") is emphasised in Article 4 (1b) as a tool to "modify or abolish existing *laws,* regulations, customs and practices that constitute discrimination against persons with disabilities".[521] Law is thus presented as potentially both a problem and a solution, reflecting its formal nature.

In addition to Article 4, a number of additional provisions in the CRPD covering particular life opportunities mention legislation. Article 30 (3) on Participation in

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[519] For example, Article 29 on Participation in political and public life covers intrinsically valuable aspects such as participation for the sake of personal gratification as well as instrumental aspects in the sense of such participation contributing to the process of changing public policy. Similarly, as regards Article 27 on Work and employment, employment can generate intrinsic satisfaction and a sense of pride and belonging, but it also generates an income which is instrumental to the enjoyment of other life opportunities.

[520] Emphasis added.

[521] Emphasis added.

cultural life, recreation, leisure and sport explicitly addresses law solely as a barrier, noting the potential of "*laws* protecting intellectual property rights" in restricting access to cultural materials.[522] The remainder of the references to legislation in the CRPD is to law as a tool, as a solution. Article 5 (2) on Equality and non-discrimination requires "*legal* protection against discrimination".[523] The role of law is similarly emphasised in Article 12 (1) on Equal recognition before the law, reaffirming "the right to recognition everywhere as persons before the *law*".[524] Article 15 (1) on Freedom from torture or cruel, inhuman or degrading treatment or punishment calls for "all effective *legislative,* administrative, judicial or other measures" to prevent torture or cruel, inhuman or degrading treatment or punishment.[525] Article 16 (1) on Freedom from exploitation, violence and abuse calls for the taking of "all appropriate *legislative*, administrative, social, educational and other measures" to counter exploitation, violence and abuse.[526] Article 22 (1) on Respect for privacy accords persons with disabilities "the right to the protection of *the law*" in relation to privacy, honour and reputation. [527] Article 27 (1) on Work and employment calls for States to "safeguard and promote the realization of the right to work […] including through *legislation*".[528] Finally, Article 31(1a) on Statistics and data collection calls for "*legally* established safeguards, including legislation on data protection" to protect confidentiality and privacy.[529] This focus on legal measures is perhaps to be expected as the CRPD is itself *law* (albeit international as opposed to national); it certainly does not set the CRPD apart from previous UN human rights conventions.

Turning to the approaches to disability explored in Part I, they all point to the role of law, but to significantly different extents. UPIAS mention the need for "legislative support" of the quest to alter the environment, but law is not identified as a central strategy for change.[530] The works by Michael Oliver studied for the purpose of this book shows ambivalence towards law as a vehicle for change, particularly the ever growing focus on anti-discrimination legislation. Earlier work contains strong calls for anti-discrimination legislation, such as this statement from 1991:

> Politicians may not be certain that anti-discrimination legislation is the way to proceed, but disabled people are. When the new law reaches the statute books, perhaps the walls of exclusion really will begin to tumble.[531]

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[522] Emphasis added.
[523] Emphasis added.
[524] Emphasis added.
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[526] Emphasis added.
[527] Emphasis added.
[528] Emphasis added.
[529] Emphasis added.
[530] UPIAS, 1975, p. 19.
[531] Oliver, Michael and Barnes, Colin, Discrimination, Disability and Welfare: From Needs to Rights [hereinafter Oliver and Barnes, 1991], in Oliver, Michael et al., Equal Rights for Disabled People: The Case for a New Law, Institute for Public Policy Research, London, 1991, p. 17.

However, the same works where such law is called for warns against the pacifying effects of legislative gains on a movement for change; the little returns it yields does not outweigh the mollifying which follows the formal recognition of claims.[532] This point reoccurs in later work where Oliver, in discussing the politics of the Disabled People's Movement in the UK together with Colin Barnes, warns against approaching disability politics as a "rights issue", as this promotes the "illusion of equality and inclusion" which is detrimental to the re-generation of the Disabled People's Movement and "their fight for meaningful change".[533] He condemns "[n]arrow legalistic approaches" as these tend to benefit those working in the "rights industry" rather than the intended beneficiaries.[534] Among those beneficiaries it will in addition yield unjust results as "the singular focus on disability as a rights issue" will at best "benefit only a very small minority of the disabled population; those with plenty of money to spend".[535] Victor Finkelstein, in turn, explicitly wants to sever the ties between the Social Model of Disability and "a legalistic model of disability":

> [The Social model of disability according to Michael Oliver] is quite specific and nowadays most people probably refer to the social model of disability in a much more vague, confused and sometimes totally alien way to the radical version that Mike developed. In recent times the social model of disability has even been so bent out of shape that it is confused with the 'rights' campaign agenda for legal safeguards – e.g. Rachel Hurst refers to the 'social or rights model of disability' and confuses the social model of disability with a *legalistic model of disability*".[536]

The Minority Group Model of Disability is closely connected to law as a vehicle for change, particularly to anti-discrimination law. This approach to disability was introduced as a means for guiding the judicial interpretation of anti-discrimination law, and much faith was put in the potential of such laws:

> Since the law can serve as a crucial means of facilitating political change as well as mirror of pervasive public sentiments, it may be expected to play a pivotal role in attempts to improve the status of disabled people in modern society.[537]

In later writings, Harlan Hahn all but abandons his faith in legislation, much due to the failure of the judiciary to interpret it adequately.[538]

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[532] Oliver, 1996, p. 120.

[533] Oliver, Michael, and Barnes, Colin, Disability Politics and the Disability Movement in Britain: Where Did It All Go Wrong? [hereinafter Oliver and Barnes, 2006], p. 10. Originally published in Manchester Coalition of Disabled People, August 2006.

[534] Ibid., p. 1.

[535] Ibid., p. 12.

[536] Finkelstein, 2001, pp. 2-3. Emphasis in original. He is referring to Hurst, Rachel, International Classification of Functioning, Disability and Health, Disability Tribune, September 2001.

[537] Hahn, 1996, p. 49.

[538] See e.g. Hahn, 2001, pp. 65, 77. This is elaborated further below under 9.1.2. in relation to Judicial measures.

Turning to ICF, like Article 4 (1b), ICF recognises law as a part of the environment which can act either as a Barrier or a Facilitator.[539] Environmental factors contains the category "Legal services, system and policies", in turn containing the category "Legal policies" which is defined as "[l]egislation, regulations and standards, such as laws, customary law, religious law, international law and conventions, that govern the administration of justice".[540] Among Activities and Participation, the Domain "Community, social and civic life" contains the category "Political life and citizenship" which includes "legal rights" as a valuable life opportunity.[541] WHO also addresses anti-discrimination legislation, in noting that ICF can be used for "definitions" in such legislation as well as for "legislative reviews" and "model legislation".[542]

Finally, ICIDH, as part of lacking a systematic focus on the environment, does not exhibit a focus on legislation as a vehicle for change, but stops at referring to it in passing, as part of "behaviour" which engenders the notion of Handicap.[543]

9.1.2. Judicial measures

Article 13 on Access to justice concerns judicial procedures. 13 (1) obliges States to "ensure effective access to justice for persons with disabilities on an equal basis with others […] in all legal proceedings, including at investigative and other preliminary stages". The aim is "to facilitate the effective role [of persons with disabilities] as direct and indirect participants, including as witnesses". To this end, States shall provide "procedural and age-appropriate accommodations". To "help to ensure effective access to justice", 13 (2) requires that "States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff". In essence, Article 13 is about dismantling formal as well as material barriers in judicial procedures, including adjusting and adapting these procedures to make them useable by persons with disabilities.

Article 13 bears witness to the centrality of *judicial measures* in the CRPD and is flanked by other provisions underlining the role of the judiciary in particular contexts. Article 12 (4) on Equal recognition before the law mentions the role of judicial bodies in reviewing measures relating to the exercise of legal capacity. Article 15 (2) on Freedom from torture or cruel, inhuman or degrading treatment or punishment calls for judicial measures to prevent such treatment or punishment. Article 16 (5) on Freedom from exploitation, violence and abuse calls for the prosecution of such instances, "where appropriate". Finally, Article 23 (4) on Respect for home and the family calls for judicial review of any separation of a child from his or her parents against their will. To conclude, the role of the judiciary is explicitly recognised par-

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[539] WHO, 2001, p. 198.
[540] Ibid.
[541] Ibid., p. 170.
[542] WHO, 2002, p. 6.
[543] WHO, 1980, p. 26.

ticularly in relation to instances of abuse to one's person or State intervention in the sphere of the family or the individual.[544]

Turning to the approaches to disability explored in Part I, like in the case of legislation, their attention to and faith in judicial measures differ significantly. Neither UPIAS nor Michael Oliver exhibits a focus on the workings of the judiciary (traceable to the fact that legislation is not their main focus as a vehicle for social change). Additionally, as mentioned just above under 9.1.1., Oliver expresses reservations towards the "rights industry"[545], noting that it mostly benefits professionals rather than disabled persons and only some disabled persons at that.[546] However, the call for accessibility and accommodations in relation to the judiciary and other actors within the administration of justice in Article 13 resonate the general focus of the Social Model of Disability for "contemporary social organisation" to take the needs of persons with disabilities into account in order to deliver its benefits to all.[547] As mentioned above under 7.2.10. and 8.1.2.2., the focus of UPIAS is limited to the requirements of persons with physical disabilities, while Michael Oliver in addition notes the requirements of other segments of the constituency of the CRPD.[548]

Harlan Hahn similarly underscores "altering the external environment", i.e. accessibility, as a crucial aspect of addressing the restriction of composite life opportunities.[549] Hahn thus echoes this general call for accessibility and accommodations and in addition displays a particular focus on the judiciary, linked to the primacy of legislation as a tool for change in the Minority Group Model of Disability. Hahn's main concern with the judiciary is their role as interpreters of law, in particular of anti-discrimination law. He stresses the importance of "examining the association between legal doctrines and social research" as such law gives the judiciary much room to manoeuvre.[550] In earlier writings, Hahn expressed hope that the judiciary would take on board the Minority Group Model of Disability when interpreting leg-

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[544] A question closely related to the role of the judiciary is that which is referred to in human rights terms as 'domestic remedies' or 'national remedies', namely the access to a national framework providing redress in case of a violation of the rights provided by international law. While this includes more than *judicial* remedies, the judiciary is central in the provision of these. The inclusion of a general provision on the right to domestic remedies (judicial and/or others) for violations was debated throughout the negotiations. See e.g. Daily Summaries 30-31 January 2006, 7th Session. The ultimate rejection of a general provision on domestic remedies for violations was based on doubts as to whether current international human rights law provides such an entitlement in relation to economic, social and cultural rights, particularly as such an explicit provision is lacking in ICESCR, as opposed to in ICCPR (see ICCPR Article 2(3)). Ibid. Arguments for and against were forwarded, argument against including the position that an obligation to provide "legal remedies" is implicit in the obligations to take "legislative measures" towards the implementation of the CRPD. See recorded statement by India on Article 4 on General obligations during the 7th session, Daily Summaries 31 January 2006, 7th Session.

[545] Oliver and Barnes, 2006, p. 1.

[546] See Ibid., pp. 1, 11-12.

[547] UPIAS, 1975, p. 14.

[548] See Oliver, 1981, p. 30.

[549] Hahn, 1996, p. 45.

[550] Ibid., p. 43.

islation, in other words, that they would not, simply put, accept individual diversity as a legitimate explanation for restricted composite life opportunities.[551] Due to the failure of this potential to materialise, Hahn ends up relegating litigation to a less prominent position in the strategies forwarded as part of the Minority Group Model of Disability. He notes in 2001 that he "no longer think[s] that the bigotry and bias of dominant non-disabled segments of society can be effectively ameliorated by judicial interpretations of the law".[552] Here, the call for appropriate training for those working in the field of administration of justice" in Article 13 (2) actualises the question to what extent such education should extend not only to the accessibility and accommodation requirements of persons with disabilities, but to the understanding of disability in the CRPD, in cases where this issue affects not only the modalities of legal proceedings, but legal interpretation.

Turning to ICF, Environmental factors contains the category "Legal services, system and policies" which in turn contains the categories "Legal systems" and "Legal services".[553] The latter category is defined as "[s]ervices and programmes aimed at providing the authority of the State as defined in law, such as courts, tribunals and other agencies for hearing and settling civil litigation and criminal trials, attorney representation, services of notaries, mediation, arbitration and correctional or penal facilities, including those who provide these services".[554] In addition, "the right to counsel [and] to a trial" are recognised as valuable life opportunities among Activities and Participation in the category "Political life and citizenship" which in turn is part of the Domain "Community, social and civic life".[555]

Finally, ICIDH does not address the systems and services for the administration of justice.

9.1.3. Administrative measures

Article 4 (1a) also makes a general call for *"administrative [...] measures"*.[556] Additional generic calls for "administrative" measures are made only in Articles 15 and 16 (see quotes above under 9.1.1.). This category of measures swallows much as it covers everything the State apparatus does to *implement* law and policy. To illustrate, Article 13 (2) on Access to justice refers to its area of application as "the field of administration of justice". Such measures are thus part and parcel of implementing the entitlements in the CRPD. The importance of implementing entitlements at *all* levels of society (national, regional as well as local) is emphasised through Article 4 (d) not only obliging the States "[t]o refrain from engaging in any act or practice that is in-

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[551] See e.g. Ibid., p. 55.

[552] Hahn, 2001, p. 65. See also Ibid., pp. 62, 77-78.

[553] WHO, 2001, p. 198.

[554] Ibid.

[555] Ibid., p. 170.

[556] Emphasis added.

consistent with the present Convention" but also to "ensure that public authorities and institutions act in conformity with the present Convention".

Due to the broad and indeterminate character of this category of measures it cannot be meaningfully compared to the approaches to disability explored in Part I. Suffice it to note that they all envisage a State apparatus setting the infrastructure for life and implementing public policy influencing the life opportunities of everyone, including persons with disabilities; with this comes administration.

9.1.4. Design and technology

Article 4 (1g) on General obligations makes a general call for "*new technologies*"[557] in the realisation of the entitlements and obligations in the CRPD. It obliges States to "undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities". Priority shall be given to technologies "at an affordable cost".

This call is reiterated in numerous provisions in the CRPD covering particular life opportunities. Article 9 (2g) on Accessibility calls for the promotion of "access […] to […] new information and communications technologies and systems". Article 20 (c) on Personal mobility calls for "access […] to […] assistive technologies". Article 21(a) on Freedom of expression and opinion, and access to information calls for "information […] in accessible formats and technologies". Article 26 (3) on Habilitation and rehabilitation calls for "the availability, knowledge and use of assistive devices and technologies" in its area of application. Article 29 (aiii) on Participation in political and public life calls for "the use of assistive and new technologies" within its realm. Article 32 (1d) on International cooperation calls for "access to and sharing of accessible and assistive technologies and […] the transfer of technologies". Article 4 (1h) stresses the importance of "*accessible information* […] about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities".[558]

Article 4 (1f) is closely related to new technology with its call for *"universal design"*.[559] Here the State is obliged to "undertake or promote research and development of universally designed goods, services, equipment and facilities". States are also to "promote their availability and use, and to promote universal design in the development of standards and guidelines". Central to this concept it that such goods, services, equipments and facilities "should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities". "Universal design" is further defined in Article 2 on Definitions:

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[557] Emphasis added.

[558] Emphasis added.

[559] Emphasis added.

> "Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

The idea is thus to make sure that each part of public policy is designed so that as many as possible can benefit from the organisation of society, including the built infrastructure, goods and services, without further adaptation or adjustment. The requirements of diverse levels and modes of functioning of the body and mind must thus permeate the entire organisation of society. Not as a reactive afterthought, but at the outset of the planning of every aspect of public policy. However, it is emphasised that to the extent that the entire functional range of a population is not catered for, more personalised solutions are required. Paragraph 4 (1f) and Article 2 exhaust this subject in the CRPD.

Turning to the approaches to disability explored in Part I of this book and beginning with UPIAS, they clearly attach great importance to technological advances, calling generally for "technical [...] help [...] to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives"[560] and noting that segregated institutions had become "seriously out of step with the changed social and technological conditions of Britain today".[561] In comparison, technological advances emerges as a less central theme in the writings of Michael Oliver.

Harlan Hahn emphasises the potential of technology and presents a vision resonate of "[U]niversal design" as defined in Article 2 of the CRPD:

> [T]he ultimate objective of [programs to change the environment] is probably an environment adapted to the needs of everybody, which seems to be in the reach of technological feasibility, even if it might not yet be in the grasp of human imagination.[562]

The mission of universal design resonate with the aims of both these approaches, in as much as they call for the end to 'special' measures and systems which address the needs of their constituencies in a 'parallel' world.

The idea that life should be designed to fit everyone is at the heart of ICF, noting as WHO does the use of the classification of Environmental factors in answering the question: "How can we make the social and built environment more accessible for all person, those with and those without disabilities?".[563] Further, "universal design" is explicitly stated by WHO as a mission of ICF, through noting that information on Environmental factors can be used to "develop and implement guidelines for univer-

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[560] UPIAS, 1974, initial paragraph on Aims.

[561] Ibid., para. 7

[562] Hahn, 1996, p. 46. See also e.g. Hahn, 1999, p. 6, Hahn, 1987, p. 6 (source not paginated) and Hahn, 1985, p. 91.

[563] WHO, 2002, p. 6.

sal design and other environmental regulations".[564] Generally, the Domains among Environmental factors which most closely mirror the areas envisaged for universal design in the CRPD are "Products and technology"[565] and "Services, systems and policies"[566].

Finally, ICIDH does not resonate with the vision of universal design, as it does not categorically or systematically implicate the environment in the solutions it advocates. Technology generally is likewise not focused on, but indirectly included in passing, as a factor the availability of which determines what level of Disability and/ or Handicap should be assigned to the individual.[567]

9.1.5. Mainstreaming

Article 4 (1c) on General obligations calls for States "[t]o take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes". This call for '*mainstreaming*' in Article 4 (1c) is flanked by a similar provision in Preamble (g), where "mainstreaming disability issues" is identified as "an integral part of relevant strategies of sustainable development". Article 33 on National implementation and monitoring addresses the organisational aspect of mainstreaming, through obliging State to "in accordance with their system of organization […] designate one or more focal points within government for matters relating to the implementation of the present Convention". In addition to coordinating governmental work, States "shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels", i.e. in society at large. In short, the point is that the entitlements of the constituency of the CRPD relate to the organisation of our entire societies and must thus inform *all* public policy as an integral part.

Turning to the approaches to disability explored in Part I, the Social Model of Disability, the Minority Group Model of Disability and ICF implicate mainstreaming across the board, in relation to all parts of the public policy which sets the infrastructure for life. ICIDH, on the contrary, even though it requires the medical profession to take account of the remainder of life, it does not implicate the environment for change and consequently not the organisational aspect of such change either.

9.1.6. Training of professionals and staff

Article 4 (1i) on General obligations singles out the importance of "*training of professionals and staff*", by obliging States "[t]o promote the training of professionals and

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[564] Ibid., p. 8.

[565] WHO, 2001, pp. 173-181.

[566] Ibid., pp. 192-207.

[567] See above under 2.3.

staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights".[568] This general call for training of professionals and staff in order to realise the rights in the CRPD is flanked by situated calls in subsequent provisions. Article 9 (2c) on Accessibility calls for training on accessibility issues for "stakeholders". Article 13 (2) on Access to justice calls for "appropriate training for those working in the field of administration of justice, including police and prison staff". Article 20 (c) on Personal mobility calls for "training in mobility skills to persons with disabilities and to specialist staff". Article 24 (4) on Education obliges States to "train professionals and staff who work at all levels of education". Article 25 (d) on Health calls for "raising awareness [for health professionals] of the human rights, dignity, autonomy and needs of persons with disabilities through training". Article 26 (2) on Habilitation and rehabilitation calls for "initial and continuing training of professionals and staff" working in this area. Finally, the exchange and sharing of "training programmes" is part of the "capacity-building" incumbent upon States through Article 32 (1b) on International cooperation.[569]

The issue of training was raised repeatedly during the negotiations and after numerous suggestions during preceding sessions it was decided during the 7th session to include a general provision on training of professionals and staff in Article 4.[570] Still, as illustrated just above, specific references stayed in a number of articles where this issue was felt to be particularly pertinent. Two intertwined aspects of training emerge from the provisions referred to here and were similarly present in the discussion on training in the negotiations, namely the 'know-how' aspect of carrying out ones work in relation to the constituency of the CRPD (i.e. methods and procedures) and the 'value-proofing' of this work against the perception of the constituency and its demands according to the CRPD. Training of professionals thus must include the 'know-how' of 'doing what they do' in relation to this group. In addition, *how* this is done must live up to the values of the CRPD; it must be compatible with e.g. dignity, autonomy, choice, equality and non-discrimination, independence and respect of difference and acceptance of human diversity.[571] It should be noted that 4 (1i) requires training "in *the rights recognized in the present Convention* so as to better

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[568] Emphasis added.

[569] Some of the provisions above simultaneously call for training of persons with disabilities (see Articles 9 (2c) and 20 (c)).

[570] On the decision to include a general requirement for training of professionals see record of discussions of a proposal to this effect by Bahrain made in relation to what was to become Article 8 on Awareness-raising, Daily Summaries 31 August 2004. See also Report of the Coordinator to the Fourth Session of the Ad Hoc Committee [hereinafter 4th Session Report by Coordinator, 2004], 2004, Annex III to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Fourth Session [hereinafter 4th Session Ad Hoc Committee Report, 2004], 14 September 2004, UN doc: A/59/360, p. 11, para. 17. The final provision on training ending up in 4 (1i) was included in the CRPD Working Text after 7th Session, 2006, p. 10 as Draft 4 (1h). See also Chair's Closing Remarks, 7th Session.

[571] See further above under 7.3.

provide the assistance and services *guaranteed by those rights*". [572] This entails that all professional activity must correspond to the requirements of the CRPD at large, and not merely be executed in a manner which is effective towards a goal or a principle generally accepted within an implicated profession.

The implementation of the solutions envisaged by the CRPD requires knowledge on behalf of many professional groups, including those who have not traditionally been made aware of the requirements of the constituency of the CRPD through their professional training. Obvious examples of professions which are instrumental to the usability of the life world, yet are not made proficient in this respect are architects or information technology professionals, but this ignorance really is likely to include any profession operating outside of the field of health and (re)habilitation. Here, the mere relevance of the constituency of the CRPD to what they do may be news. At a very basic level, even the thought that the lives of the constituency can and should be such as to actualise the area of life in question, or for that matter should be prioritised, may need a deeper change of perception. The professional areas which have traditionally dealt with the constituency of the CRPD, those relating to health and (re)habilitation, will not need to be initiated into the connection between what they do and this constituency. However, they will still need to improve procedures, and the need for a change in the perception of the requirements and demands of the constituency appears just as strong.

The second aspect of training, 'value-proofing', connects with Article 8 on Awareness-raising and it was actually in the context of this article that the discussion on a general provision of training of professionals took root in the negotiations.[573] While the final version of Article 8 does not contain any specific obligation in relation to professionals and staff, the latter are included in the obligation to "raise awareness throughout society" in 8 (1a) and the obligation to promote "awareness-training programmes regarding persons with disabilities and the right of persons with disabilities" in 8 (2d).

The need for 'value-proofing' was emphasised in the negotiations in particular in relation to the medical profession. It is symptomatic of the negotiations that out of the particular provisions addressing training Article 25 (d) on Health is the one emphasising this aspect, rather than 'know-how'.[574] According to this provision States Parties shall "[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care". The risk for abuse at the hands of, inter

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[572] Emphasis added.

[573] See the record of discussion of a proposal to this effect by Bahrain during the 4th session, Daily Summaries 31 August 2004, 4th Session.

[574] In contrast to Article 25 on Health, Draft Article 21 on Right to health and rehabilitation in the Working Group Draft contained both a provision on 'know-how' (21 (g)) and on 'value-proofing' (21 (h)). Working Group Draft, 2004, p. 27.

alia, professionals and staff in general is recognised in Article 16 (3) on Freedom from exploitation, violence and abuse, requiring as it does that States "ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities", in order to "prevent the occurrence all forms of exploitation, violence and abuse". Article 16, which targets professionals and staff in general, primarily envisages as its task addressing abuse which is tantamount to breaking legal rules and regulations and with them, supposedly, professional rules and ethics. However, it is likely that many practices in the name of 'care' which are currently regarded as both legal and ethical will not hold up to the scrutiny of the CRPD. While this issue is relevant to all professions, the medical profession was the epicentre of questioning the 'neutrality' of professional concepts of 'good' service in the negotiations. Here, the floating line between professionally sanctioned 'services' or 'care' and actions infringing Article 10 on Right to Life, Article 12 on Equal recognition before the law, Article 14 on Liberty and security of person, Article 15 on Freedom from torture or cruel, inhuman or degrading treatment or punishment, Article 16 on Freedom from exploitation, violence and abuse and Article 17 on Protecting the integrity of the person was emphasised, such as in the following contribution by IDC to the 7th session:

> Medical experimentation without consent, on people with disabilities who are inmates of institutions with no legal right to protect themselves and no freedom to leave, is the rule rather than the exception. Such experimentation, in a setting where doctors had little inclination or incentive to investigate non-violent types of treatment, resulted in today's so-called "therapeutic treatments" such as electroshock and neuroleptic drugs, which paralyze the will and destroy human initiative.[575]

Similarly, Draft Article 21 (k) on the Right to health and rehabilitation in the Working Group Draft referred to above under 7.1.2., through expressly obliging States to "[p]revent unwanted medical and related interventions and corrective surgeries from being imposed on persons with disabilities", illustrates this questioning of professional authority and the suspicion towards professional knowledge in relation to what constitutes 'good' services or care.[576] In addition to outright abuse, the consequences of the perception by professionals of the abilities of the constituency of the CRPD was underscored, such as here by New Zealand in the Working Group:

> Early identification and intervention for PWD [persons with disabilities] and families is very important as they help both parties understand their capabilities. The training

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[575] Intervention on behalf of IDC on Article 15, Freedom from torture and other cruel, inhuman or degrading treatment or punishment [hereinafter IDC Intervention on Article 15, 7th Session], 7th Session, 19 January 2006, p. 2 (source not paginated).

[576] Working Group Draft, 2004, p. 27. As mentioned above under 7.1.2. the latest language to this effect was included in the working text of the CRPD after the 7th session, in CRPD Working Text after 7th Session, 2006, p. 15.

> of professionals is needed here because they can "set the tone" at this early stage, and often they have outdated ideas of PWD full capacity.[577]

In a submission to the 3rd session, WHO noted the importance of balancing the power relationship between health and rehabilitation professional and the constituency of the CRPD, by addressing the attitudes of professionals:

> Recognizing the importance of combating stereotypes and prejudices about persons with disabilities, WHO is committed to provide technical assistance and expertise in promoting positive attitudes towards persons with disabilities. In particular, WHO is committed to working towards a paradigm shift so that health and rehabilitation professionals work in partnership with persons with disabilities rather than simply prescribing treatment to them.[578]

To sum up, State obligations relating to the training of professionals relate both to 'know-how' and to the values and principles of the CRPD. The text of the CRPD, as well as the negotiations, reflect a view of professionals as potentially both friend and foe. The profession singled out in particular as a target for 'value-proofing' was the medical profession.

Turning to the approaches to disability explored in Part I of this book and beginning with UPIAS, their quintessential call on professionals was to relinquish "the stranglehold that professions have over disabled people"[579] and to resign as "social controllers"[580]. UPIAS noted that the medical profession had traditionally held such a position, but that "sociologists" as "social administrators" were gaining ground.[581] While they pointed out that, even in the existing segregated institution, there were "some staff and volunteers doing their best to help the residents", they noted that this was unlikely to be successful as long as the professional context remained:

> [T]heir efforts are systematically overwhelmed by the basic function of segregated institutions, which is to look after batches of disabled people - and in the process convince them that they cannot realistically expect to participate fully in society and earn a good living.[582]

Above and beyond the issue of control, UPIAS display a general ambivalence towards professionals. The recognition above in relation to sociologist is part of an expression amounting to resentment that professionals make a living by intervening in the lives of disabled people. It is not always clear if the problem is that such intervention is done in the wrong way (quality aspects of professional intervention),

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[577] Recorded statement by New Zealand, Daily Summaries 12 January 2004, Working Group Session.
[578] WHO Position Statement on Working Group Draft, 3rd Session, p. 3.
[579] UPIAS, 1975, p. 8.
[580] Ibid., p. 18.
[581] Ibid.
[582] UPIAS, 1974, para. 7.

that it is done by the wrong profession, or professional activity per se.[583] Michael Oliver expresses a similar ambivalence. He problematises that the medical profession has “spawned” professions “in its own image”, however the main critique seems to target the *character* of the business of those professions, referred to by Oliver as “the restoration of normality”.[584] As both UPIAS and Oliver recognise the place for professional services (compare e.g. the call by UPIAS for “the necessary financial, medical, technical, educational and other help”[585] and the scholarship by Oliver on “Social Work with Disabled People”[586]) the critique is probably to be read as targeting the quality and value basis of professional activity as well as professional activity ‘out of bounds’, such as when medical professionals are assigned non-medical tasks. The primary concern remains the control of disabled people over life in general and services in particular, expressed by Oliver as the need “to alter professional practice so that it is the disabled person who is in control and not the social worker or another professional”.[587] If not, no professional activity may be better than defective professional activity:

> “[T]he majority of criticism is that social workers, like *all* other professionals, have operated with inappropriate models or theories of disability, and it is in a sense perhaps fortunate that social work intervention has been so limited up to now [1983].[588]

The above points to the primacy of training of professionals and while the focus is largely on the professions traditionally involved in the lives of disabled persons, it can be assumed from the aims to change “social organisation”[589] that the entire battery of professionals involved in shaping and executing such organisation would be prospective clients of training. Such training would include ‘know-how’ as well as ‘value-proofing’, the latter aspect concerning in particular refraining from excerpting control over disabled persons and ceasing to hold and transmit low expectations on the lives of disabled persons.

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[583] See e.g. the following excerpt from UPIAS, 1975, p. 18: “While the medical profession has long been the traditional, dominant group in “disability”, sociologists have been engaged in chipping away at this privilege for some time and it is this group the sociologists who instinctively gain from an incomes approach to “disability”. The achievement of a national incomes policy would of necessity require an army of social administrators who would be given enormous power over physically impaired people. In this way sociologists would oust the medical profession and replace them as the dominant group in the field. The Alliance’s structure and its ability to gain “authority” as the voice of disabled people, enables social administrators to use disabled people (just as they used other experts earlier) to become the dominant profession in our lives. In other words, if we as disabled people do not become our own experts, but concede that role to the Alliance, we will be helping them to advance their cause as our new social controllers!”. For a background to this exchange between UPIAS and the Disability Alliance, see above under 3.

[584] Oliver, 1996, p. 37.

[585] UPIAS, 1974, initial paragraph on Aims.

[586] Oliver, 1983.

[587] Ibid., p. 136. See also Oliver, 1990a, pp. 5-7 (source not paginated).

[588] Oliver, 1983, p. 15. Emphasis in original.

[589] UPIAS, 1975, p. 14 and Oliver, 1981, p. 28.

Turning to Harlan Hahn, as discussed above in relation to judicial measures, earlier expressions of the Minority Group Model of Disability attached considerable hope to related professional categories. Hahn later withdraws this faith, noting that the failure of "non-disabled lawyers and judges" to apply a "'minority group' paradigm of disability" amounted to these having "abrogated their historic role of defending disadvantaged minorities and seeking to fulfil the promise of equality".[590] He notes that the only alternative if judicial measures are to be useful is "re-educating the judiciary and the public about the nature and meaning of disability".[591] Like UPIAS and Oliver, Hahn similarly questions the contributions of the medical profession, noting "grave violations of ethical principles"[592] by health professionals as well as a drive to "'fix' what they view as unacceptable bodily anomalies"[593]. In addition to the drive to normalise and its consequences Hahn notes, here in the context of employment, that not only doctors but other professionals involved in rehabilitation have been trained in a "clinical tradition that incorporated prevailing assumptions about disability and employability", in other words, which assumed inability.[594] Finally, he notes the unwillingness among "[n]on-disabled specialists" to transfer authority to those using their services, for fear that "the value of their professional training might be diminished or that their control might be undermined".[595] To conclude, Hahn echoes many of the concerns of the Social Model of Disability just described and points to the need for re-training of professionals. In addition to the medical profession, Hahn emphasises in particular the legal profession. Training of professionals is however not a major theme pursued by later accounts of the Minority Group Model of Disability, which reflects its change of focus onto the role of persons with disabilities rather than categories of professionals as the engine for change. As will be discussed in the next section, this focus is even more apparent in the Social Model of Disability.

Turning to ICF, Environmental factors includes the Domain "Support and relationships" which is explained as "people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities".[596] In this Domain, three categories of professionals are included: "Personal care providers and personal assistants", "Health professionals" and "Other professionals".[597] The first category is explained as "[i]ndividuals who provide services as required to support individuals in their daily living activities and maintenance of performance at work, education or in any other life situation, provided either through public or private funds, or else on a voluntary basis, such as providers of support for

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[590] Hahn, 2001, p. 62.
[591] Ibid.
[592] Hahn, 2002, p. 173.
[593] Ibid., p. 174. See also Hahn, 1985, p. 89.
[594] Hahn, 1985, p. 92.
[595] Hahn, 2001, p. 64.
[596] WHO, 2001, p. 187.
[597] Ibid., p. 188.

home-making and maintenance, personal assistants, transport assistants, paid help, nannies and others who function as primary caregivers".[598] The second category is explained as "[a]ll service providers working within the context of the health system, such as doctors, nurses, physiotherapists, occupational therapists, speech therapists, audiologists, orthotist-prosthetists [and] medical social workers".[599] The third and last category is explained as "[a]ll service providers working outside the health system, including social workers, lawyers, teachers, architects, and designers".[600] In an additional Domain of Environmental factors, "Attitudes", such attitudes are registered in the named professional categories: "Individual attitudes of personal care providers and personal assistants", "Individual attitudes of health professionals" and "Individual attitudes of other professionals".[601] Such attitudes are further explained in relation to each category as "[g]eneral or specific opinions or beliefs of [the professional from the respective category] about the person or about other matters (e.g. social, political and economic issues), that influence individual behaviour and actions".[602] Environmental factors also contains the Domain "Services, systems and policies" which includes "those who provide these services".[603] From the above it emerges that ICF displays a focus on the potential of professionals as Barriers or Facilitators in the realisation of life opportunities. Compared to the approaches discussed above its language is neutral, even positive (compare the above reference to "support, nurturing, protection, assistance and relationships"). However, the construct of Facilitators/Barriers enables the registration of positive as well as negative aspects. As already noted, WHO recognised the need to address the attitudes of health and rehabilitation professionals in a submission to the 3rd session.[604] Among professional categories health professionals and other caring professionals are in focus also in ICF, through being designated as particular categories. However, it should be noted that the category "Other professionals" explicitly includes categories of professionals not traditionally implicated as central to the constituency of the CRPD, as does the categories of personnel covered under "Services, systems and policies".[605]

Turning to ICIDH, its focus, not only among professionals but overall, is the medical profession. The ultimate aim is for medical professionals to provide their services in a way which is conducive to the rest of life, for them to "see beyond the walls of their hospitals" when providing services.[606] No need for training is however communicated in the manual and ICIDH assumes benevolent and compe-

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[598] Ibid.

[599] Ibid.

[600] Ibid.

[601] Ibid., p. 191.

[602] Ibid.

[603] Ibid., p. 192.

[604] WHO Position Statement on Working Group Draft, 3rd Session, p. 3.

[605] See WHO, 2001, p. 188 and pp. 192-207.

[606] Matinvesi, Seppo, Perspectives and Applications of the ICIDH, in The Use and Usefulness of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), Proceedings from an International Workshop under the Council of Europe, Council of Europe Publishing, Strasbourg (France) 25-26 March 1996, p. 55.

tent professionals. Nowhere in the manual is the problem of lacking 'know-how' or 'value-proofing' recognised, not even as regards the possibility of a clash between the interests of the professional and the implicated individual. The goal remains for professional advice to be taken unquestioned. Bearing witness to this perceptive, the manual notes as a challenge that chronic conditions entail "the persistence of problems [which] implicitly reveals limitations in the potency of medical treatment, so that professional advice is often accepted with less assurance".[607] The ideal situation is instead presented as an acute condition which "encourages unquestioning capitulation to professional advice".[608]

9.1.7. Consultation and involvement of (organisations of) persons with disabilities

According to Article 4 (3) States are to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations". This mirrors the mantra of IDC throughout the negotiations: "Nothing about us without us.".[609] A situated such demand is included in Article 32 (1) on International cooperation, envisaging that States work "as appropriate, in partnership with [...] in particular organizations of persons with disabilities", in Article 33 (3) on National implementation and monitoring, demanding that "persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process" and in Article 34 (3) on the Committee on the Rights of Persons with disabilities, inviting States to take Article 4 (3) into account when nominating candidates for the named Committee. Article 29 (bii) on Participation in political and public life reaches behind the consultation stage by obliging States to encourage the "[f]orming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels". Similar references were included in numerous other provisions at different stages of the drafting process but were consolidated into Article 4 (3) during the 7th session with the understanding that, as a general obligation, 4 (3) applies in relation to all other provisions.[610] To conclude, the CRPD is unequivocal on the instrumental role of organisations of persons with disabilities in the implementation and monitoring of the rights in the CRPD.

The negotiations themselves put the mantra of IDC to the test as such negotiations are traditionally conducted by State representatives with the role of NGO's

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[607] WHO, 1980, p. 24.

[608] Ibid., p. 23.

[609] See e.g. IDC Amendments to CRPD Working Text, 8th Session, p. 1.

[610] See Draft Article 4 (3) on General obligations, Chair's Draft, 7th Session, 2005, pp. 19-20. In the accompanying letter, the Chair noted that he had "consolidated into paragraph 3, the elements contained in old draft articles 5 (2) (d), 6 (c), 18 (c), 19 (2) (g) and 21 (m)." Letter from the Chair to the Ad Hoc Committee, dated 7 October 2005, 7th Session, p. 4, para. 27.

being limited to lobbying. However, when the negotiations reached a state of concretion that led some States to call for a circumscription of NGO involvement this did not reach consensus among States. Indeed, some States threatened not to participate in the negotiations should this be found acceptable.[611] The outcome was modalities for NGO's to be present as well as to address the Ad Hoc Committee. The importance of the contributions of NGO's towards an informed instrument was repeatedly acknowledged during the negotiations.[612]

Regarding the text of the CRPD, there was no opposition in the negotiations to it reflecting the call of IDC. Language to the effect of Article 4 (3) on General obligations was present already in the Working Group Draft, calling for States to operate "in close consultation with, and include the active involvement of, persons with disabilities and their representative organizations".[613] While this recognition was unequivocal on the level of principle, discussions concerned what levels of decision-making are included and the weight to be accorded the views of organisations.[614] Regarding the latter aspect, suggestions were made for stronger text, such as a proposal by New Zealand to include language requiring the implementation of the CRPD to be done "in partnership with disabled people".[615] Other calls aimed at emphasising the role of the constituency include a proposal by Canada during the 7th session that the former "be afforded an appropriate leading role on issues concerning persons with disabilities".[616] The position that the constituency should have "more than equal standing" on such questions in light of their expertise were in addition put forward by present NGO's.[617]

To complement the role accorded *organisations* representing persons with disabilities, three provisions directly address the role of *individuals* among the constituency without reference to organisations as their representative intermediary. Preamble

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[611] See record of statements by Canada and New Zealand, Daily Summaries 3 June 2004, 3rd Session.

[612] See e.g. record of a statement by the Chair during the 5th session on the lack of NGO participation leading to an "unbalanced" discussion on what was to become Article 12 on Equal recognition before the law (Draft Article 9). Daily Summaries 27 January 2005, 5th Session. See also statements to this effect during the discussions on limiting NGO participations during the 3rd session, Daily Summaries 3 June 2004, 3rd Session.

[613] Draft Article 4 (2) on General obligations, Working Group Draft, 2004, p. 11.

[614] The question of levels of decision-making was raised during the Working Group session, see recorded statements by Japan and Ireland. Daily Summaries 9 January 2004, Working Group Session.

[615] New Zealand's View of a Convention on the Rights of Disabled People, in Compilation of Proposals before the Working Group, 2004, p. 54. This stronger formulation is used in Article 32 on International cooperation.

[616] The proposal by Canada was for Draft Article 4 and referred to a similar proposal by IDC for Draft Article 29 on Participation in political and public life. IDC Amendments to Chair's Draft, 7th session, p. 61 (source not paginated).

[617] Recorded statement by PWDA along with AFDO and NACLC, Daily Summaries 1 June 2004, 3rd Session. See similar statement by PWDA during 6th session. Daily Summaries 4 August 2005, 6th Session. See also statement by WNUSP during the 3rd session (Daily Summaries 24 May 2004, 3rd Session) and by IDC during the 6th session (Daily Summaries 4 August 2005, 6th Session). The latter is recorded as demanding that "PWDs [persons with disabilities] have to be given primacy of voice on matters related to disability".

(o) calls for the involvement of *persons* with disabilities in policy making through "*[c]onsidering* that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them".[618] Article 33 (3) on National implementation and monitoring quoted above similarly carves out a role for "persons" with disabilities in such activities. Finally, according to Article 34 (4) on the Committee on the Rights of Persons with disabilities, States are to give "consideration" to the "participation of experts with disabilities" in electing the named Committee. It should be noted that, as opposed to the final text of Article 4 (3) which only calls for the involvement of person with disabilities "*through* their representative organizations"[619], Draft Article 4 (3) in the Working Group Draft asked for the involvement of "persons with disabilities *and* their representative organizations".[620] Before this change was made during the 7th session, it was suggested based on concerns to accord "power and authority" to organisations.[621]

Relating back to the previous section, two articles seek to complement the role of professionals with that of the constituency through the demand for "peer support", indicating a need to complement professional knowledge with knowledge reflecting peer experiences. Article 24 (3) on Education calls for facilitation of "peer support and mentoring" in relation to learning "life and social development skills" and Article 26 (1) on Habilitation and rehabilitations calls for "peer support" in its area of application. One article in the final version of the CRPD recognises that being part of the constituency of the CRPD and being a professional tasked with the implementation of the CRPD are not mutually exclusive positions. Article 24 (4) on Education calls for the intersection of these as it obliges the State "to take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille".[622]

To conclude, as a human rights instrument, the CRPD contains obligations of *States* and thus the role of organisations is only spelled out in as much as these should be enabled to provide input into the fulfilment by States of those obliga-

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[618] Emphasis in original.

[619] Emphasis added.

[620] Draft Article 4 (2) on General obligations, Working Group Draft, 2004, p. 11. Emphasis added.

[621] Recorded statement by Yemen, Daily Summaries 30 January 2006, 7th Session. See also recorded statement by the Arab Organization of Disabled People, Daily Summaries 31 January 2006, 7th Session.

[622] The Working Group Draft had put this question on the table in the form of a footnote, but it was not part of Draft Article 17 on Education. See Working Group Draft, 2004, p. 22, note 59. Instead, the only explicit call for intersectionality between professionals and the constituency of the CRPD in the Working Group Draft was in Draft Article 21(g) on Right to health and rehabilitation, calling for States to "[e]ncourage the development of sufficient numbers of health and rehabilitation professionals, including persons who have disabilities". Ibid., p. 27. This language did not make it to the final version of the CRPD but proposals to this effect continued throughout the negotiations. Notably, such a proposal by IDC during the 6th session portrayed it as flowing from the concept of "nothing about us without us". IDC, 2nd Information Sheet, Article 21 Health [hereinafter IDC 2nd Information Sheet, Article 21 Health, 6th Session] 6th Session, 2005, p. 2 (source not paginated).

tions. The only exception is the obligation in Article 29 (bii), obliging the State to be instrumental towards the forming of and joining such organisations. The upshot in relation to the interaction between organisations and/or the constituency of the CRPD on the one side and States on the other in the implementation of the CRPD is that irrespective of where the limits of the obligations expressed in Article 4 (3) and the other provisions mentioned are set, such obligations, by virtue of principle, are fundamental to the CRPD. They must be approached in good faith to provide meaningful and result oriented interaction. The expertise of the constituency and the representative role of organisations are straightforwardly recognised in the instrument and were accepted in the negotiations of the CRPD, in principle as well as in practice.

Turning to the approaches to disability explored in Part I and beginning with UPIAS, the political organisation of disabled people is seen as the decisive factor for changing society.[623] Michael Oliver similarly emphasises this key point: it is from "growing consciousness and political power of disabled people that ultimately solutions to the problem of disability may emerge".[624] In sum, emphasis on organisations of disabled persons as political actors driving change and exerting control over public policy (the collective equivalent of the person being in control of his or her life) emerges as the core of the Social Model of Disability. Compared to the provisions of the CRPD described above, the recognition of the role of persons with disabilities and organisations in these thus resonate with the Social Model of Disability. However, the heeding of calls to create a stronger authoritative position for organisations would have done so even more.

Harlan Hahn's unanswered faith in the judicial system directed him towards an increased focus on the political organisation of persons with disabilities as the hub of social change.[625] As mentioned above under 5.4., Hahn emphasises the role of a political movement not only for political and thus social change, but also for the well-being of the individual, including his or her self-regard.[626]

ICF recognises the role of organisations of persons with disabilities as political actors but without the same emphasis as the approaches above. The manual, in an Annex titled "ICF and people with disabilities", recognises the importance of the participation of DPI in the process of creating ICF.[627] In addition, in the same Annex, emphasis is put on the participation of persons with disabilities in the work of applying and improving ICF:

> It is hoped that disabled people themselves will contribute to the use and the development of ICF in all sectors[,] as researchers, managers and policy-makers.[628]

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[623] See e.g. UPIAS, 1975, p. 16 and UPIAS, 1974, paras. 16-17.

[624] Oliver, 1983, p. 116.

[625] See e.g. Hahn, 2001, pp. 74-76, 78 and Hahn, 2002, pp. 181-184.

[626] See e.g. Hahn, 1985, p. 100.

[627] WHO, 2001, Annex 5 ICF and People with Disabilities, p. 242.

[628] Ibid., p. 243.

Furthermore, ICF includes under Environmental factors the Domain “Services, systems and policies” which in turn includes the category “Associations and organizational services, systems and policies”.[629] The latter category is explained as “[s]ervices, systems and policies relating to groups of people who have joined together in the pursuit of common, noncommercial interests, often with associated membership structure”.[630] Further on this topic, Activities and Participation, includes the Domain “Community, social and civic life” which in turn includes the category “Political life and citizenship”, the latter covering “the right[...] of freedom of [...] association”.[631] Thus, while associations in general are recognised as pertinent parts of the environment there is no particular role carved out for organisations of persons with disabilities.

Finally, ICIDH does not touch upon the role of organisations of persons with disabilities.

9.1.8. Awareness-raising

The question of awareness-raising has been discussed in Chapter 8, as the target of Article 8, “attitudinal [...] barriers”, are recognised as a *cause* of “disability” in Preamble (e). In the following, the primary function of Article 8 is in focus, namely as demanding *measures* towards the realisation of life opportunities. Summarising the account above under 8.1.2.1., Article 8 on Awareness-raising demands the State to take measures to raise awareness about persons with disabilities as proprietors of rights and to change misrepresentative perceptions about persons with disabilities.[632] These subjects for awareness (capabilities, contributions, skills, merits and abilities) all relate to *positive* aspects of a person and Article 8 explicitly demands States not only to “combat stereotypes, prejudices and harmful practices relating to persons with disabilities” but to use awareness campaigns to “promote *positive* perceptions […] towards persons with disabilities”.[633] At its core, Article 8 amounts to a demand to raise awareness of persons with disabilities as both *capable* of enjoying and executing the life opportunities covered in the CRPD as well as *worthy* of them, as in of equal importance, dignity and rights.

The concept of “awareness-raising” overlaps with those of “training” and “information”. As noted in Chapter 8 Article 8 (2d) on Awareness-raising calls for “awareness-*training* programmes”, Article 25 (d) on Health calls for “*raising* awareness of the human rights, dignity, autonomy and needs of persons with disabilities through *training*” and Article 23 (3) on Respect for home and the family calls for

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[629] Ibid., p. 198.
[630] Ibid.
[631] Ibid., p. 170.
[632] Article 8 (1).
[633] Article 8 (1b, 2aii). Emphasis added.

"early and comprehensive *information*" to families of children with disabilities.[634] Notwithstanding differences in terminology, elements of the general call for awareness-raising in Article 8 regarding persons with disabilities, dignity and rights are thus reiterated and directed towards particular actors through provisions such as these.

As noted in Chapter 8, Article 8 does not spell out its ultimate aims, as in the reasons for which perceptions are to be changed. On a general level, this aim can be inferred from the purpose of the CRPD as expressed notably in Article 1 on Purpose ("to promote, protect and ensure the full and equal *enjoyment of all human rights and fundamental freedoms* by all persons with disabilities, and to promote *respect for their inherent dignity*").[635]

To conclude, the message of Article 8 is that by actively portraying persons with disabilities in a certain manner perceptions are changed, which in turn is instrumental towards the general realisation of valuable life opportunities. In addition to according to awareness-raising this general instrumental role, as discussed under 8.1.2.1. above, the direct effect of changed self-regard of individuals among the constituency was put forward in the negotiations. Notwithstanding this, the main focus of the negotiations remains to target the perceptions of those who are not part of the constituency of the CRPD.

For the comparison of Article 8 to the approaches to disability explored in Part I, see above under 8.1.2.1. Suffice it to note here that they, albeit to dramatically different extents, all recognise the effects of attitudes on the enjoyment of life opportunities and that only ICIDH does not implicate such attitudes as targets for solutions.

9.1.9. Accessibility

The question of accessibility has been discussed in Chapter 7 (as a General principle) and in Chapter 8 (as the target of Article 9, "environmental barriers" are recognised as a cause of "disability" in Preamble (e)). In the following, the focus is on the primary function of Article 9, namely the call for accessibility as a category of measures ensuring life opportunities. Summarising the account in Chapter 8, Article 9 on Accessibility encompasses measures to make the existing life world 'fit' the constituency of the CRPD through "the identification and elimination of obstacles and barriers to accessibility". As such, it contains measures of adaptation, of making the infrastructure for all life opportunities 'usable'. As discussed above under 8.1.2.2., Article 9 covers all "facilities and services open or provided to the public" but focuses in particular on the physical environment, transportation, information and communication. This provision has no equivalent in earlier UN human rights conventions.

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[634] Emphasis added.

[635] Emphasis added. In addition, Article 8 itself speaks of "foster[ing] *respect for the rights and dignity* of persons with disabilities" (8 (1a)) and of "nurtur[ing] *receptiveness of the rights* of persons with disabilities" (8 (2ai)). Emphasis added.

Its inclusion illustrates not only the instrumental character of an accommodating physical and communicative environment for the enjoyment of life opportunities by the constituency of the CRPD, but also the current abysmal shortcomings of States in this regard.

Accessibility is one of the most prominent aspects of the CRPD, targeting in a tangible way the environment as the locus for change. As discussed above under 8.1.2.2., accessibility is underscored in the Preamble, it is included as a General principle in Article 3 and it furthermore figures in numerous provision covering entitlements in particular areas or aspects of life, or measures thereto. In addition, many other provisions use the term "access", but in a more general sense of actually enjoying or 'getting' something.[636] Finally, the concept of "reasonable accommodation" in Article 5 (3) on Equality and non-discrimination (defined in Article 2 on Definitions) potentially overlaps with the concept of "accessibility" in Article 9, as both these require adaptation of the world.[637] The teasing out of this relationship well exceeds the scope of this book. It can be noted however that the CRPD Committee addresses this issue in its Draft General Comment on Article 9.[638] In short, the Committee holds that accessibility is "group related" while reasonable accommodation is "individual related".[639] It furthermore illustrates this distinction by noting that the obligations under Article 9 are of an "*ex ante*" nature, in other words they must be provided proactively and not only after a request by an individual.[640] The obligations under Article 5, conversely, are of an "*ex nunc*" nature, which means that they are actualised through the request of an individual and need to be provided only in as much as "it is reasonable and not imposing a disproportionate or undue burden".[641] Irrespective of the distinction thus made, the Committee repeatedly emphasises the link between accessibility and Article 5, noting inter alia that "[a]ccessibility should be viewed in the context of equality and non-discrimination"[642] and that "[d]enial of access to physical environment, transportation, information and communication, and services open to the public constitutes an act of disability- based discrimination that is prohibited by article 5 of CRPD"[643].

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[636] See e.g. Article 12 on Equal recognitions before the law, Article 13 on Access to justice, Article 19 on Living independently and being included in the community, Article 20 on Personal mobility, Article 24 on Education, Article 25 on Health and Article 28 on Adequate standard of living and social protection.

[637] See further on reasonable accommodation above under 7.3.4.

[638] Committee on the Rights of Persons with Disabilities Draft General Comment on Article 9 of the Convention – Accessibility [hereinafter CRPD Draft General Comment on Article 9], Advanced Unedited Version, 10th session, 2013.

[639] Ibid., para. 22.

[640] Ibid. Emphasis in original.

[641] Ibid., para. 23. Emphasis in original.

[642] Ibid., para. 4.

[643] Ibid., para. 31. This poses the question to what extent the standard for obligations adhesive to lacking accessibility as a form of discrimination generally differs from the standard for obligations adhesive to denial of reasonable accommodation in terms of the 'reasonableness' of requirements and the 'burden' imposed, a question which is not further addressed in the Draft General Comment.

For the comparison of Article 9 to the approaches to disability explored in Part I, see above under 8.1.2.2. Suffice it to note here that they, albeit to dramatically different extents, all recognise the effects of the environment on the enjoyment of life opportunities, and that only ICIDH does not implicate the environment as a target for solutions.

9.1.10. Personal mobility

The aim of Article 20 on Personal mobility is "the greatest possible independence for persons with disabilities". To this end, States "shall take effective measures to ensure personal mobility". According to 20 (a) this includes "[f]acilitating personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost". 20 (b) covers the availability and affordability of aids, devices and assistance. It requires States to "[f]acilitat[e] access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost". 20 (c) requires States to "[p]rovid[e] training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities". Finally, 20 (d) addresses the diverse requirements of persons with disabilities by requiring States to "[e]ncourag[e] entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities".

Article 20 on Personal mobility focuses a particular aspect of life, namely to transfer oneself within a life context (such as in a house/workplace/(play)school/park/theatre/playground) and between life contexts (such as between ones house and a workplace/(play)school/park/theatre/playground). It straddles many levels, ranging from optimising the level of functioning of the individual which will then interact with numerous environments (by demanding training in 20 (c)), through providing mobility aids and equipment which can likewise be transferred between numerous environments (by demanding aids and equipment in 20 (b)), to services which are so removed from the individual that they make up those 'immovable' environments (by demanding the facilitation of mobility in and between life contexts in 20 (a)).[644]

Article 20 illustrates the sometimes fine line between characterising the nature of a provision as primarily of intrinsic or instrumental character. The obvious aim of Article 20 is to get to places where life plays out and to be able to participate in that life context "with the greatest possible independence". This is the instrumental aspect of mobility; the importance lies not in the mobility as such but in the context (home life/work/education/rest/play) which is 'opened up' through mobility. However, it can of course be argued that independent mobility is an end in itself, be it the im-

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[644] Outside of the specific context of mobility, the first level is the focus of Article 25 on Health and, to some extent, of Article 26 on Habilitation and rehabilitation. The second level is the focus of Article 4 (f-h) on General obligations and Article 26 on Habilitation and rehabilitation. The third level is the focus of in particular Article 8 on Awareness-raising and Article 9 on Accessibility.

proved physical functioning of the individual or the movement, of being ‘in transit’. In other words, the journey as such is the goal. Either way, the aim of the article remains independence and its main aspects are choice, accessibility and the availability and affordability of mobility assistance and devices.

Article 20 thus addresses mobility on different levels and the approaches to disability explored in Part I accord different degrees of importance to those levels and their implicated targets for intervention. Beginning with UPIAS, to “achieve mobility” is an explicit aim.[645] Targeting physical barriers to mobility is central, exemplified as “flights of steps [and] inadequate public and personal transport”.[646] In addition, “lack of up-to-date aids and equipment”[647] is to be targeted and the “need [for] therapists to help restore or maintain physical function, and to advise us on aids to independence and mobility” is also recognised.[648] Mobility is thus recognised on all levels mentioned above including transport, and “segregated and inferior facilities” such as “antiquated tricycles or specially labelled transport” are condemned.[649] The call for non-segregated transport similarly resonates with Michael Oliver. It should be noted however that the recognition of the value of “help [to] restore or maintain physical function” by UPIAS potentially comes into conflict with Oliver’s questioning of the mission of inter alia physiotherapy, depicted by him in negative terms as “the restoration of normality”.[650]

Harlan Hahn similarly deplores restricted mobility and like the Social Model of Disability his main focus is on the barriers to mobility in the environment.[651] Like Oliver, Hahn has reservations to the medical aspects of rehabilitation, including both its potential to significantly improve functioning of the body[652] and the desirability of this.[653]

The approaches above primarily focus on mobility requirements of physical impairments (UPIAS explicitly so) and it should be noted that Article 20 implicates requirements across the board of impairments covered by the CRPD.[654]

ICF covers all levels of mobility. Activities and Participation includes the Domain “Mobility”, the life opportunities covered by which range from “walking”[655] to “using transportation”[656]. Environmental factors contains numerous Domains relevant to mobility. The Domain “Products and technology” contains the category ”Products and technology for personal indoor and outdoor mobility and transportation” which is depicted as “[e]quipment, products and technologies used by people in activities of

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[645] UPIAS, 1974, initial paragraph on Aims.
[646] Ibid., para. 1.
[647] Ibid.
[648] Ibid., para. 14.
[649] Ibid., para. 2.
[650] Oliver, 1996, p. 37.
[651] See e.g. Hahn, 1996, p. 55 and Hahn, 1987, pp. 11-12 (source not paginated).
[652] See e.g. Hahn, 2002, p. 174.
[653] See e.g. Hahn, 2004, pp. 453-454.
[654] See further below under 10.1.1.
[655] WHO, 2001, p. 144.
[656] Ibid., p. 146.

moving inside and outside buildings, including those adapted or specially designed, located in, on or near the person using them".[657] The Domain "Services, systems and policies" contains the category "Transportation services, systems and policies" which is depicted as "[s]ervices, systems and policies for enabling people or goods to move or be moved from one location to another".[658] Finally, Environmental factors includes the Domain "Support and relationships" which is depicted as "people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities".[659] One category under "Support and relationships" is "Domesticated animals", which explicitly covers "animals for personal mobility and transportation".[660]

Finally, ICIDH approaches mobility as a problem derivative of the individual Impairment or Disability, and although it indirectly recognises the effects on mobility of aids and equipment as well as attitudes and physical barriers it measures only the level of mobility of the individual. ICIDH thus, under "Mobility handicap", measures "inability to cope with public transport"[661], but notes that this should be measured taking into account effects of "aids and appliances and modification or adaptation of [the] immediate environment".[662] In addition, the manual notes, as an afterthought, that "the behaviour of bus drivers [may] preclude the use of public transport", are they not "sympathetic".[663]

9.1.11. Habilitation and rehabilitation

In Chapter 7 Article 26 on Habilitation and rehabilitation was presented and discussed in the context of the valuation of impairment and in Chapter 8 the fact that it posits levels and modes of functioning of the body and mind as instrumental to the enjoyment of composite life opportunities was discussed. Here, the focus is on Article 26 as a category of solutions towards the enjoyment of life opportunities. Article 26 construes (re-)habilitation as primarily of instrumental rather than intrinsic value, as a *road to* valuable forms of doing and being once removed from its primary subject of attention, (re-)habilitation.

Article 26 on Habilitation and rehabilitation commences with emphasising its goals ("maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life") and only after this calls for (re-)habilitation "[t]o that end". The "areas" for (re)habilitation underscored in Article 26 are "health, employment, education and social services". Employment

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[657] Ibid., p. 174.
[658] Ibid., p. 196.
[659] Ibid., p. 187.
[660] Ibid., p. 188.
[661] WHO, 1980, p. 192.
[662] Ibid., p. 193.
[663] Ibid., p. 194.

and education are most readily conceivable as means as well as ends of (re)habilitation (life opportunities to be made possible through (re)habilitation) while "social services" is primarily instrumental (one does not conduct (re)habilitation in order to enjoy social services). Health ("full physical [and] mental [...] ability") as the goal of health-related (re-)habilitation can be conceived of as an end in itself, as discussed in Chapter 7, but it is also in Article 26, as discussed in Chapter 8, instrumentally linked to life opportunities once removed from such ability.

The emphasis on rehabilitation towards employment is furthermore underscored in Article 27 on Work and employment, which obliges States to "tak[e] appropriate steps, including through legislation" to "[p]romote vocational and professional rehabilitation".[664] As mentioned above under 7.1.2., Article 25 on Health holds an additional reference to rehabilitation in the area of health, obliging States to "take all appropriate measures to ensure access for persons with disabilities to health services […] including health-related rehabilitation".[665] Finally, Article 16 (4) on Freedom from exploitation, violence and abuse obliges States to "take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse".

As discussed above under 7.1.2. the reason for creating Article 26 was to emphasise that (re)habilitation is not merely medical. While medical rehabilitation is focused on gaining or regaining affected levels and modes of functioning of the body and mind, other forms of rehabilitation focuses alternative ways of going about life, from using a wheelchair to a new occupation (compare Article 27 (1k)). In its essence, it is about learning.

In Chapters 7 and 8 above, the positions of the approaches to disability discussed in Part I have been contrasted with Article 26 as it regards medical rehabilitation; both regarding medical (re)habiliation as an end in itself and as a measure towards the enjoyment of composite life opportunities. Suffice it to note here that the mission of the Minority Group Model of Disability and particularly the Social Model of Disability is to redirect attention away from such measures and towards measures targeting the environment. ICF, by contrast, recognises these two categories of solutions on par. Lastly, the main mission of ICIDH is to use measures targeting levels and modes of functioning of the body and mind in a way which is conducive to the enjoyment of life opportunities, including composite life opportunities. As noted just above, (re)habilitation in a non-medical sense is a broad area indeed, covering a wide span of measures relating to all of life. Some general points of comparison can however be drawn out. The target is the ability of the individual, rather than the environment at large. Hence, (re)habilitation places itself more at the periphery of the Social Model of Disability and the Minority Group Model of Disability than of ICF and particularly ICIDH. In the words of Michael Oliver, "[r]ehabilitating

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[664] Article 27(1, 1k). The reference here is limited to rehabilitation, which appears to be an oversight.

[665] The reference here is limited to rehabilitation, which appears to be an oversight.

society" is the correct focus of efforts.[666] Notwithstanding such juxtaposition the point of the Social Model of Disability is to redirect attention, and thus solutions, towards measures targeting the environment and not to posit that measures targeting the individual are necessarily meaningless or wrong. This holds true in particular for measures which are not regarded as aiming to 'normalise' individual levels and modes of functioning of the body and mind. Finally, the emphasis of choice in Article 26 (b), that all measures of (re)habilitation "are voluntary" resonates particularly well with the Social Model of Disability and the Minority Group Model of Disability.[667]

9.1.12. Statistics and data collection

According to Article 31 (1) on Statistics and data collection States "undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention". Article 31 thus forwards the collection of information and the production of statistics as instrumental to the implementation of the CRPD. While recognising the potential of the use of statistics and data, Article 31 similarly recognises the risk for misuse. 31 (1a) underscores the need to "[c]omply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities" and 31 (1b) requires the process to "[c]omply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics".

Article 31 (2) addresses the disaggregation of data and the purpose of its use. Accordingly, "[t]he information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights".

Article 31 proved controversial from the beginning. Starting in the Working Group, some actors argued that the collection and use of statistics and data is vital to the development of successful policies to implement the CRPD. Others questioned the usefulness of statistics and data and argued that recording information about persons with disabilities is likely to result in violations of privacy and other forms of misuse.[668] In the negotiations following the session of the Working Group it was

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[666] Title of Chapter 7 in Oliver, 1996, pp. 95- 109.

[667] See above under 7.3.2.

[668] See footnote 23 to Draft Article 6 on Statistics and data collection outlining this difference in views. Working Group Draft, 2004, p. 12, note 23. The concerns regarding inclusion were reproduced as follows: "Other delegations opposed the inclusion of an article on statistics and data collection in the Convention, for several reasons. They expressed a concern for the respect of the right to privacy and the risk of misusing the information, and considered that such an article did not belong in a human rights treaty. They considered that statistics were not useful as a policy tool, and that resources spent in data collection should be used instead in programmes for persons with disabilities. There should be a mainstreaming of surveys and not just surveys for persons

emphasised that the object of the collection of information was the enjoyment of human rights by the constituency of the CRPD and not the prevalence of impairment per se.[669] While the Working Group Draft thus called for information on "disabilities and on the effective enjoyment of human rights by persons with disabilities" as well as for data to be disaggregated according to "type of disability", the final provision in Article 31 consequently skips any references to levels and modes of functioning of the body and mind and moves directly to the goal to "give effect to the present Convention" (31 (1)) through "identify[ing] and address[ing] the barriers faced by persons with disabilities in exercising their rights" (31(2)).[670] The information collected on the basis of Article 31 should however, according to 31 (2), be "disaggregated, as appropriate". Disaggregation according to impairment is thus called for in as much as this is seen as instrumental to ensuring that the situation and requirements of each impairment group is visible, that solutions are tailored to varying require-

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with disabilities.". WNUSP expressed the strongest concerns about privacy and the potential for misuse of data in the Working Group: "In relation to the issue of statistics, that there was concern about issues of privacy when people could be deprived or life, liberty, autonomy, on the basis of disability. In this regard, states could use the data against PWD [persons with disabilities]. The recognition of right to life or survival, in this context, could be implicated by a policy of keeping data.". Daily Summaries 7 January 2004, Working Group Session. Compare also the following justification of a suggestion to add "only" between "used" and "to" in 31 (2) by IDC in the 8th session: "The IDC would like to express its concerns regarding the misuse of Statistics Indicators that presuppose that the lives of disabled people have less value than those of people without disabilities and can be used to discriminating people with disabilities from public and other services, such DALYs (disability adjusted life years [).]". IDC Amendments to CRPD Working Text, 8th Session, pp. 52-53. See also recorded statement by IDC during the 7th session: "IDC expressed concern about the use of statistical indicators that presuppose a lesser value of the lives of PWD. Such indicators can and have been used to discriminate against PWD in terms of accessing health services and other services.". Daily Summaries 27 January 2006, 7th Session.

[669] See e.g. record of discussions during the 3rd session, including the following statement by Lebanon: "Lebanon added that statistics should include at least age and sex, and suggested deleting type of disability […]. After 6(d), in accordance with the move from a medical to a social model, Lebanon suggested "States should move away from statistical investigations that merely enumerate impairments that may become a statistical means of patronizing PWD [persons with disabilities]."". Daily Summaries 25 May 2004, 3rd Session. Draft Article 6 became Article 31 after the 4th session, due to arguments that it fitted better among the monitoring provisions. See Daily Summaries 25 August 2004, 4th Session and 4th Session Report by Coordinator, 2004, p. 11, para. 18.

[670] An example of a proposal to this effect is the position taken by WNUSP on the Working Group Draft during the 3rd session: "If the article is retained in its present form, we urge the deletion of the term "disabilities" in the chapeau, as indicated. Collection of data on disabilities, as opposed to enjoyment of human rights by people with disabilities, is more in keeping with a medical model of disability that objectifies disability and separates it from its social context. While collection of such information may be useful in some circumstances, it also has great potential for misuse, by encouraging classification of people according to their disabilities.". WNUSP Position Paper 3rd Session, p. 20 (source not paginated). See also recorded statement by WNUSP during the Working Group: "Statistics of PWD [persons with disabilities] as a social group within society need to be assessed in order to help meet their needs but data collection, if done, should focus on the human rights and participation PWD, and collection on the medical or impairment conditions of PWD should not be allowed.". Daily Summaries 7 January 2004, Working Group Session.

ments and that the extent of needs requiring such solutions is known.[671] While the disaggregation of information by impairment category is still called for in as much as it is conducive to the implementation of the rights in the CRPD, it is thus clearly not an end in itself, nor is it acceptable if the envisaged end of such disaggregation is incompatible with any of the provisions in the CRPD. Finally, Article 31 (3) addresses dissemination of data and its accessibility. Accordingly, "States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others".

To conclude, Article 31 has two main themes: the obligation to collect information necessary for the implementation of the CRPD and safeguards to make sure that the way in which this process is carried out is not counterproductive to the enjoyment of any of the rights in the CRPD. Article 31 on Statistics and data collection exhausts this subject in the CRPD.

Turning to the approaches to disability explored in Part I of this book and beginning with UPIAS, they do not address the issue of statistics and data collection. Michael Oliver's main objection to the collection of statistics and data seems to concern *what* data is collected (counting disabled persons rather than counting barriers).[672]

Harlan Hahn emphasises the risk for misuse of data, noting its potential to obliterate privacy as well as provide the basis for decisions to the detriment of the individual, including those concerning life and death.[673]

Moving on to ICF, a focus on statistics strongly resonates with the raison d'être of ICF, being as it is a framework for the collection of data, which it envisages as key to policy development:

> In both the health sectors and other sectors that need to take into account the functional status of people, such as social security, employment, education and transportation, there is an important role that ICF can play. It goes without saying that policy development in these sectors requires valid and reliable population data on functional status.[674]

Article 31 similarly stipulates the need for information, including "statistical and research data" to "formulate and implement policies" (31 (1)), emphasising that these should be used to "identify and address the barriers faced by persons with disabilities in exercising their rights" (31 (2)). Similarly, ICF enables the classification as well as evaluation of Barriers through the component Environmental factors:

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[671] See e.g. intervention by Uganda in the 4th session: "Countries already maintain population statistics disaggregated by age and sex, and there is no reason why disability should not be a criterion as well. In disability planning it is essential to know the age and sex of PWD [persons with disabilities]. "Disability is not homogenous" and unless the types of disability are disaggregated it will be difficult for governments to plan.". Daily Summaries 1 September 2004, 4th Session.

[672] See e.g. Oliver, 1990, pp. 2-8.

[673] Hahn, 2002a, pp. 4-12.

[674] WHO, 2002, p. 7.

> ICF also serves as a potentially powerful tool for evidence based advocacy. It provides reliable and comparable data to make the case for change. The political notion that disability is as much the result of environmental barriers as it is of health conditions or impairments must be transformed, first into a research agenda and then into valid and reliable evidence. This evidence can bring genuine social change for persons with disabilities around the world.[675]

However, the point of ICF continually stressed by WHO in relation to all clinical as well as policy work remains as a framework for establishing *when* the best solution is medical intervention and *when* it is intervention in the environment:

> ICF can assist in identifying where the principal "problem" of disability lies, whether it is in the environment by way of a barrier or the absence of a facilitator, the limited capacity of the individual himself or herself, or some combination of factors. By means of this clarification, interventions can be appropriately targeted and their effects on participation monitored and measured.[676]

As the CRPD envisages both composite life opportunities and levels and modes of functioning of the body and mind among its "rights" (compare Articles 25 and 26) as well as envisages both the environment and levels and modes of functioning of the body and mind as potential causal factors of restricted composite life opportunities (compare Article 26), the collection of data aiming at solutions targeting levels and modes of functioning of the body and mind is in line with the CRPD. However, the main focus of the CRPD remains environmental barriers to enjoyment of composite life opportunities and not levels and modes of functioning of the body and mind, neither per se nor as an instrumental to the enjoyment of composite life opportunities.

While ICF emphasises the usefulness of statistics, like the CRPD it also sees dangers with it and the manual includes an Annex titled "Ethical guidelines for the use of ICF". It begins:

> Every scientific tool can be misused and abused. It would be naive to believe that a classification system such as ICF will never be used in ways that are harmful to people.[677]

The guidelines proceed to address the concern addressed in Article 31 (1a) of the CRPD, stipulating that "the information coded using ICF should be viewed as personal information and subject to recognized rules of confidentiality appropriate for the manner in which the data will be used".[678] Article 31 (1b) refers to "ethical principles in the collection and use of statistics", which are not further specified. In comparison, ICF includes three headings in its ethical guidelines. The first one is titled "Respect and confidentiality". In addition to the passage just quoted, it is here stipu-

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[675] WHO, 2001, Annex 5 ICF and People with Disabilities, p. 243.

[676] Ibid.

[677] WHO, 2001, Annex 6 Ethical Guidelines for the Use of ICF, p. 244.

[678] Ibid.

lated that ICF should “always be used so as to respect the inherent value and autonomy of individual persons” and it should “never be used to label people or otherwise identify them solely in terms of one or more disability categories”.[679] Furthermore, clinical use should “always be with the full knowledge, cooperation, and consent of the persons whose levels of functioning are being classified”. As mentioned above under 7.2.3., this is qualified by the passage “[i]f limitations of an individual’s cognitive capacity preclude this involvement, the individual’s advocate should be an active participant”.[680] The second heading is “Clinical use of ICF” and it is here stipulated that “[w]henever possible, the clinician should explain to the individual or the individual’s advocate the purpose of the use of ICF and invite questions about the appropriateness of using it to classify the person’s levels of functioning”.[681] Furthermore, “[w]henever possible the person whose level of functioning is being classified (or the person’s advocate) should have the opportunity to participate, and in particular to challenge or affirm the appropriateness of the category being used and the assessment assigned”.[682] Lastly, it is noted that “[b]ecause the deficit being classified is a result of both the person’s health condition and the physical and social context in which the person lives, ICF should be used holistically”.[683] The third heading is “Social use of ICF information” and under it is noted that ICF information should be used “to the greatest extent feasible, with the collaboration of individuals to enhance their choices and their control over their lives” and “towards the development of social policy and political change that seeks to enhance and support the participation of individuals”.[684] In addition, information should not be employed to “deny established rights or otherwise restrict legitimate entitlements to benefits for individuals or groups”.[685] Finally, it is recognised that “[i]ndividuals classed together under ICF may still differ in many ways. Laws and regulations that refer to ICF classifications should not assume more homogeneity than intended and should ensure that those whose levels of functioning are being classified are considered as individuals”.[686] To summarise, these guidelines recognise the importance of choice and control for the individual in a clinical setting, as well as of not being reduced to a Health condition or that Health condition being presumed to be the sole cause of problems. Policy use of ICF should be aimed at augmenting entitlements and involve persons concerned as well as aim at facilitating social participation. Along these lines WHO notes in Annex 5 “ICF and people with disabilities” that it is “committed to continuing efforts to ensure that persons with disabilities are empowered by classification and assessment, and not disentitled or discriminated against”.[687]

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[679] Ibid.
[680] Ibid.
[681] Ibid.
[682] Ibid.
[683] Ibid., p. 245.
[684] Ibid.
[685] Ibid.
[686] Ibid.
[687] WHO, 2001, Annex 5 ICF and People with Disabilities, p. 243.

Turning to ICIDH, it agrees with the importance attached to the collection of information for the creation of policy in the CRPD.[688] However, Article 31 of the CRPD, as well as the CRPD at large, has a steady focus on the environment as the primary target for change. Because it envisages something very different from a 'head count' only (even one which registers access to composite life opportunities, as ICIDH does through measuring Handicap), the CRPD exceeds the mission, as well as the vision, of ICIDH. In addition, ICIDH does not envisage the need for safeguards in the collection and use of data and statistics.

9.1.13. International cooperation

Article 32 (1) sets out by declaring that States "recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention". It further obliges States to "undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities". Article 32 (1a-d) continue to spell out what such measures "could include, inter alia". According to 32 (1a) such measures could include "[e]nsuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities". 32 (1b-d) exemplify the kinds of measures in which international cooperation could consist. According to 32 (1b) such measures could be "[f]acilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices". According to 32 (1c) such measures could be "[f]acilitating cooperation in research and access to scientific and technical knowledge". Finally, according to 32 (1d), such measures could consist in "[p]roviding, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies".

The development of Article 32 on International cooperation took place towards the end of the negotiating process and was subject to divergent views both on its inclusion per se and its content. Divergence concerned in particular the balance between emphasising the importance of international cooperation and making clear that obligations to implement the CRPD are not subject to the reception of such cooperation.[689] Article 32 envisages cooperation and solidarity among States as instrumental to the implementation of the CRPD. Its vision exceeds a 'cash flow' from North to South, in the sense that the goods it covers include, inter alia, informa-

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[688] See WHO, 1980, e.g. p. 25.

[689] See Summary of the Discussions Held Regarding the Issue of International Cooperation to be Considered by the Ad Hoc Committee, Annex II to the Working Group Report, 2004, pp. 33-34. No article was included in the Working Group Draft and the first version of Article 32 appeared after the 7th session. CRPD Working Text after 7th Session, 2006, p. 25.

tion, experiences, best practices and scientific and technical knowledge. In addition, it covers all geographical directions. While the only other provision in the CRPD covering international cooperation, Preamble (l), notes the particular importance of international cooperation for "developing countries", it does not state with whom such corporation is envisaged. However, the North to South flow was ever present in the negotiations, with States from the South emphasising the need for resources in order to implement the CRPD.[690] At the insistence of representatives from the North, the qualifier was inserted in Article 32 (2) that this article is "without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention".[691] To sum up, international cooperation is an integral part of the obligation to implement the CRPD. Making all existing international cooperation inclusive of and accessible to persons with disabilities is key, as is working with organisations of persons with disabilities to this end.

Turning to the approaches to disability explored in Part I, both the Social Model of Disability and the Minority Group Model of Disability are created within a specific national context and do not (subject to the limitations of this work) display a focus on questions of international solidarity. ICIDH and ICF were created by an international organisation with the whole world as its envisaged area of use. The worldwide sharing of information as well as the establishment of common terminology is envisaged as key tools to improve policy. Thus, while ICIDH and ICF do not enter into the issue of solidarity in the distribution of knowledge and resources, they have international collaboration, facilitated through comparability of information and research, at their core. Again, in contrast to ICF, the object of cooperation according to ICIDH is limited by its focus on measures targeting impairment.

9.1.14. Mechanisms for monitoring the implementation of the CRPD

The CRPD creates general monitoring mechanisms to ensure its implementation, on the national as well as the international level. As noted above under 9.1.5., Article 33 on National implementation and monitoring emphasises coordination of efforts at all levels in the national context, including the coordination of efforts within government as well as government coordination of efforts on other levels of society. The other mechanism foreseen by Article 33 is the independent monitoring of such

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[690] See Daily Summaries 1 August 2005, 6th Session and 2-3 February 2006, 7th Session.

[691] See Ibid. The Chair is recorded as summarising these deliberations as follows: "Despite the emergence of some clear trends, there obviously remained a number of issues to be resolved, most notably how to balance the obligation to provide international cooperation with the desire of some delegations to make clear that this does not diminish the obligations of states to implement the convention. The Chair noted that this seemed to be a non-issue as the two elements complement each other. States have obligations they are required to meet, but, for a number of provisions, international cooperation is very important to ensure effective and timely implementation. There appeared to be no disagreement over that point, however there was some difficulty finding language that could be agreed.". Daily Summaries 3 February 2006, 7th Session.

efforts. Accordingly, 33 (2) requires that "States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the States Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention". The key feature of such a framework is that it is to be independent from the State. Furthermore, Article 33 (2) foresees that States in the establishment or designation of such a mechanism "take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights".[692] The main theme of those principles echoes the concern of independence and in addition they illustrate the kinds of activities associated with such a mechanism, as well as provide details of what is needed in order for effective independent monitoring to be possible. Article 33 (3), as discussed above under 9.1.7., requires that "[c]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process". In sum, the CRPD requires independent monitoring in the national context, inclusive of the constituency of the CRPD as well as of other parts of civil society.

The only other explicit reference to monitoring on the national level in the CRPD is in Article 16 (3) on Freedom from exploitation, violence and abuse, which requires that "all facilities and programmes designed to serve persons with disability [be] effectively monitored by independent authorities". In addition, Article 12 (4) on Equal recognition before the law requires that the implementation of safeguards relating to the exercise of legal capacity is "subject to regular review by a competent, independent and impartial authority or judicial body". This provision illustrates that judicial measures are a particular form of monitoring: monitoring of law executed by judicial bodies.

In addition to national monitoring, Articles 34-39 and the OP-CRPD set up a framework for international monitoring to further national implementation. This monitoring is exercised by an international committee of experts, the CRPD Committee (Article 34 on the Committee on the Rights of Persons with Disabilities). Regarding the composition of the Committee, 34 (4) stipulates that "[t]he members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities". Furthermore, according to Article 34 (3), the members of the Committee "shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention". As mentioned above under 9.1.7., in addition to the participation of experts with disabilities on the Committee, a role is envisaged for organisations of persons with disabilities in the selection of candidates to be nominated by States. Article 34 (3) states that "[w]hen nominating their candidates, States Parties are in-

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[692] See Principles Relating to the Status of National Institutions. Adopted by the UN General Assembly 20 September 1993. UN doc: A/RES/48/134.

vited to give due consideration to the provision set out in article 4, paragraph 3, of the present Convention".

Articles 35-39 of the CRPD and the OP-CRPD set up four monitoring mechanisms: the consideration of reports on implementation submitted by States (Articles 35 on Reports by States Parties and Article 36 on Consideration of reports), the issuing of "general recommendations" (Article 36 (1) and Article 39 on Report of the Committee), the consideration of "communications from or on behalf of individuals or groups of individuals" (Articles 1-5 of the OP-CRPD) and the initiation of inquiries into "grave or systematic violations by a State Party" (Articles 6-7 of the OP-CRPD). Articles 34-39 of the CRPD and the OP-CRPD largely mirror earlier UN human rights instruments and represent the international contribution to implementation through the creation of an independent body with monitoring functions.[693] The establishment of an international mechanism which was on par with existing mechanisms was seen by many as a crucial matter, broadcasting the importance of this convention.[694]

Turning to the approaches to disability explored in Part I of this book, these monitoring mechanisms, particularly the international ones, are seldom addressed outside the discussion of human rights law and so it is to be expected that such mechanisms do not represent a focus of these approaches. On a very general level, one can of course note that as judicial measures, particularly the mechanism of individual complaints, they mirror particularly well the sentiments of early work by Harlan Hahn developing the Minority Group Model of Disability. In addition, the role carved out for persons with disabilities as well as organisations of persons with disabilities echo concerns central to this approach, as well as to the Social Model of Disability.

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[693] For a discussion on missed opportunities to reform traditional treaty body monitoring in the negotiations see Bruce, Anna, Negotiating the Monitoring Mechanism for the Convention on the Rights of Persons with Disabilities: Two Steps Forward One Step Back, in Alfredsson, Gudmundur et al. (Eds.), International Human Rights Monitoring Mechanisms: Essays in Honour of Jacob Th. Möller, Martinus Nijhoff Publishers, The Hague, 2009.

[694] See e.g. record of statement by Brazil during the 6th session, warning against the CRPD being "seen as a second-rate treaty". Daily Summaries 11 August 2005, 6th Session. In the context of international mechanisms towards implementation, it should be mentioned that the CRPD also envisages a reoccurring "[c]onference of States Parties" where States shall "consider any matter with regard to the implementation of the present Convention" (Article 40 on Conference of States Parties).

9.2. Additional provisions accorded an instrumental role in ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

The choice of provisions above is based on the meaning they are attributed in the CRPD, namely as primarily of instrumental rather than intrinsic value in the sense that they are *roads to* valuable forms of doing and being once removed from their primary object of attention. In addition, some of the other provisions of the CRPD mirror issues which have been accorded clear instrumental value by the approaches to disability explored in Part I. For example, the subject matter of Article 29 on Participation in political and public life is underscored by the Social Model of Disability and the Minority Group Model of Disability (particularly its later accounts) as the main road towards change.[695] This includes particularly the political organisation of persons with disabilities as addressed in 29 (bii). While awareness-raising about the rights and capabilities of persons with disabilities is the mission of Article 8 on Awareness-raising, the Social Model of Disability emphasises awareness-raising *among* persons with disabilities about the oppressive character of social organisation, this being the key mechanism to change according to this approach.[696] While the topic of Article 8 resonates with the main focus of Harlan Hahn, like the Social Model of Disability he emphasises the personal awareness of societal barriers as key to self-regard as well as to freeing political energy and will.[697] Additionally, the Social Model of Disability, particularly UPIAS, accords employment an instrumental role towards ending oppression at large.[698]

Finally, it is indisputable that ICIDH sees the subject matter of Article 25 on Health as instrumental to all composite life opportunities. While it attributes intrinsic value as well to the life opportunities covered by Article 25, their instrumental character towards composite life opportunities was the rationale behind the conception of Handicap.[699] Similarly, ICF is open to finding solutions to composite life opportunities in the area of health, thus according such solutions a general instrumental (in addition to intrinsic) value.[700]

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[695] See above under 7.2.16. and 9.1.7.

[696] See e.g. UPIAS, 1975, p. 16 and Oliver, 1983, p. 116.

[697] See e.g. Hahn, 1985, p. 100.

[698] UPIAS, 1975, pp. 15-16.

[699] See above under 2.2.

[700] See above under 4.2.-4.4.

10. The constituency of the CRPD compared to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

Article 1 on Purpose depicts the constituency of the CRPD, "[p]ersons with disabilities". As will be illustrated in Chapter 12, the depiction of "[p]ersons with disabilities", as well as the depiction of "disability", is central to the mission of the CRPD to change perceptions.[701] In addition to concerns stemming from the awareness that the portrayal of its constituency will influence how people are perceived, the depiction of "[p]ersons with disabilities" actualised an equally central concern; *who* can call upon the rights in the CRPD? As a human rights convention the CRPD was to create legal obligations and entitlements and so the question to whom these apply was central to negotiating States and NGO's alike. This is why the depiction of "[p]ersons with disabilities" was placed in the legally binding part of the CRPD while the depiction of "disability" was left in the Preamble.[702]

Opinions differed in the negotiations as to the wisdom of defining 'disability' and/or 'persons with disabilities'. The main concern for both those speaking for and those speaking against a definition emerges as avoiding that persons who should be covered by the CRPD would be excluded from its protection.[703] Those speaking for a definition felt that such a definition would be an insurance against unduly limiting na-

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[701] See below under 12.1.3.

[702] Report by ICD on First Informal Discussion on a Definition of Disability led by Korea [hereinafter IDC Report from Informal on Definition of Disability, 8th session], 8th Session, 17 August 2006. The additional point of placing the former depiction in Article 1 on Purpose is to protect it from reservations. This follows from that reservations are not allowed against the "object and purpose of the treaty", see VCLT Article 19 (c).

[703] See e.g. the record of the deliberations on whether or not to define "disability" in the Working Group. Working Group Draft, 2004, p. 10, note 12.

tional definitions[704] while those speaking against a definition held that any definition which was agreeable to all would be an unduly limited one.[705] I refer to the accounts of "disability"/"[p]ersons with disabilities" in Preamble (e) and Article 1 as 'depictions', as it was a conscious decision not to "define" these concepts, furthermore visible from the fact that they are not included under Article 2 on Definitions.[706]

The question if and how to depict 'disability'/'persons with disabilities' was deferred to the final stages of the negotiations and ended up one of the last questions to be settled at the 8th session. The modus of shaping entitlements without setting the common ground of to whom these were to apply was questioned by some.[707] However, the silence of the majority on this issue seems to echo the following statement of India: "We understand very clearly when we talk of persons with disabilities.".[708]Another indication of this felt clarity of who "persons with disabilities" were was the constant provision of a numerical measurement, amounting to that the CRPD was about "600 million" alternatively "650 million" persons.[709]

The first section below will elaborate on who are in fact covered by the CRPD and compare this with the constituencies of the approaches to disability explored in Part

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[704] See e.g. Ibid. See also submission by IDC before the 8th session: "IDC finds it absolutely needed with a broad and inclusive definition on "disability", to safeguard that no State will exclude any PWD [person with disabilities] from being protected by this Convention due to a more narrow national definition. If we do not have a definition in this convention, there would be as many definitions on "disability" as there are countries.". Working Text as Amended by the IDC According to the Chair Proposed Program for the 8AHC 1st Week, 8th session, 2006, p. 21. See also interventions by Yemen, Iraq and Brazil during the 7th session. Daily Summaries 31 January 2006, 7th Session.

[705] See e.g. intervention by the EU and New Zealand during the 7th session. Daily Summaries 31 January 2006, 7th Session. Some did however speak against a definition for the purpose of allowing States "flexibility" as regards whom they choose to include. See e.g. interventions by South Africa in the same discussion. Ibid.

[706] The reason for this conclusion seems to have been that no consensus, considering the many national and otherwise definitions suggested and considered, could be reached on forwarding something in the terms of a "definition". Schulze, 2010, pp. 34-36. Marianne Schulze describes Preamble (e) as "an open description of disability" and Article 1 as a""non-definition" of disability". Ibid., p. 25. Both Preamble (e) and Article 1 forward a way to 'understand' disability in terms of what the problem the CRPD is to address entails and stipulates its salient components and that (albeit not *how*) these interact to produce the problem. Article 1 arguably comes closer to a 'definition' than does Preamble(e), as it has the additional purpose of delineating (admittedly in loose and open-ended terms) who is and who is not covered by the CRPD.

[707] Morocco is recorded in the Working Group session as finding it "hard to understand how one could negotiate, discuss, and prepare this Convention without defining PWD [persons with disabilities] or disability". Daily Summaries 16 January 2004, Working Group Session. Later such calls for a definition related to concerns about the implementation, rather than the shaping, of entitlements. See e.g. record of intervention by the Syrian Arab Republic during the 7th session. Daily Summaries 31 January 2006, 7th Session.

[708] Submission regarding Draft Article 2 on Definitions by India during the 7th session in support of not defining "disability" or "persons with disabilities" in the CRPD, 7th Session, 2006.

[709] See e.g. record of statement by the Chair (Daily Summaries 24 May 2004, 3rd Session), by Jamaica (Daily Summaries 5 August 2005, 6th Session) and by IDC (Daily Summaries 9 August 2005, 6th Session). The above examples refer to 600 million, while later references set the number at 650 million. See e.g. IDC News Page for 24 August, 8th Session, 24 August 2006.

I (10.1.). The second section draws out one particular aspect of such coverage which separates these approaches to disability, namely the subscription to a 'minority' or a 'universality' approach (10.2.). The third section emanates from the critique of approaches in Part I and explores how the CRPD handles the fact that its constituency is diverse in terms of factors such as sex, age or indigenous status (10.3.). Again, how these issues are addressed in the CRPD is compared with how they are addressed by the approaches to disability explored in Part I and to the critique of these approaches explored there.

10.1. Who is in and who is out?

According to Article 1 on Purpose "[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". The criteria provided by the text for qualifying as a "[p]erson[...] with disabilities" can be broken down into the following ones: 1) "physical, mental, intellectual or sensory", 2) "impairments", 3) which are "long-term", 4) which are "ha[d]" and 5) which "may", in interaction with various barriers create relative disadvantage in participating in society.

The wording of Article 1 establishes that the constituency "*include[s]*" (i.e. is not limited to) those fitting these criteria and also emphasises that the right in the CRPD should be realised for "*all*" persons with disabilities.[710] While the latter expression, strictly speaking, does not make it any clearer who "[p]ersons with disabilities" are (*Who* are included among persons with disabilities? *All* persons with disabilities.) both expressions reflect that the main express concern during the negotiations was over exclusion, rather than over inclusion. Having said that, it remains that persons with disabilities were talked about as a group which it is possible and useful to delimit from others. Even if the main concern was over exclusion, the function of Article 1 is to draw this, albeit inclusive, line between those who are covered by the CRPD and those who are not.[711]

10.1.1. Impairment categories covered

To begin with, one must thus determine which "impairments" qualify as "physical, mental, intellectual or sensory" according to Article 1. While some levels and modes of functioning of the body and mind are included by common connotation or even

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[710] Emphasis added.

[711] Additional persons covered by virtue of an extension of Article 5 on Equality and non-discrimination to persons associated with persons with disabilities is separate from the inclusion *as a person with disabilities* to which Article 1 remains the gate. See above under 7.3.4.

explicit mention elsewhere in the CRPD[712], outside this core of those who are "safely 'there'"[713], these terms have no established outer limits. The enumeration "physical, mental, intellectual or sensory" is short compared to some versions put on the table during the negotiations. For example, the version submitted by the Chair of the Ad Hoc Committee during the 7th session as a basis for discussion referred to "physical, sensory, psychosocial, neurological, medical or intellectual":

> "Disability" results from the interaction between persons with impairments, conditions or illnesses and the environmental and attitudinal barriers they face. Such impairments, conditions or illnesses may be permanent, temporary, intermittent or imputed, and include those that are physical, sensory, psychosocial, neurological, medical or intellectual.[714]

In comparison, the final text substitutes "mental" for "psychosocial" and lacks "neurological" and "medical". In addition to longer lists of categories of impairments, calls were made, such as the following one by Chile during the 4th session, to not mention categorisations of impairments at all, but rather to include a broad reference to "corporal structures and functions":

> It will suffice to make a broad reference to deficiencies from the viewpoint of corporal structures and functions, which will make it possible to consider many persons whose limitations do not fall strictly within the physical, sensory, mental and psychic spheres.[715]

Regarding which categorisations to include in Article 1, the main subject of discussion was which term(s) to be included to represent what ended up as "mental [and] intellectual [...] impairments". IDC argued during the 8th session for the inclusion of both "intellectual" and "psychosocial" instead of "mental" impairment (which was at one stage proposed to cover the two former).[716] Here, "mental" was referred to by IDC as "old fashioned terminology".[717]

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[712] The latter category includes e.g. "persons […] who are blind, deaf or deafblind", explicitly included in Article 24 (3c) on Education.

[713] Expression borrowed from Ruth Pinder. Pinder, 1997, p. 304.

[714] Possible Definition of "Disability": Discussion Text Suggested by the Chair, 7th session, 2006.

[715] Proposal for Draft Article 3 on Definitions by Chile, 4th Session, 2004. Though Chile's proposal refers to "corporal", this is explicitly noted to include the "psychic". In addition, letting the body subsume the mind is also the approach of ICF, which is referred to as the basis for this proposal.

[716] IDC, News Page for Monday 21 August, Reaction the AHC8 Compilation of Proposals in Attachment [hereinafter IDC News Page 21 August, 8th Session], 8th Session, 21 August 2006, p. 1 (source not paginated). Such a proposal was made e.g. by Argentina. Personal communication with Kicki Nordström, Coordinator on Definitions with IDC.

[717] IDC News Page 21 August, 8th Session, p.1 (source not paginated). Subsequently, IDC accepted the retention of "mental", provided both "psycho-social" and "intellectual" were included as well. This reads as a concession to the importance of broad coverage, at the expense of preferences for current terminology. IDC Proposed Text on Definitions [hereinafter IDC Proposed Text on Definitions, 8th Session], 8th session, 2006.

A category which received some attention, particularly towards the end of the negotiations, was "medical disabilities", also depicted as "chronic illnesses" or "chronic diseases". As exemplified by this statement by IDC during the 7th session, the discussion focused on recognition of the importance of health care for this group:

> Finally, we would like to draw attention to the fact that for large groups of people with chronic illnesses/chronic diseases or as it is sometimes called in Europe "medical disabilities", health care is crucial for their survival and well-being. Examples of such groups are people with asthma, diabetes and rheumatism. Thus, the retention of a comprehensive article on the right to health to all people with disabilities is important for a large proportion of the world's population, and we welcome the strong endorsement for this article by the WHO.[718]

PWDA addressed the issue of the inclusion of people with, inter alia, "long-term health conditions" under the protection of the CRPD in the discussion on definitions during the 7th session, noting that "courts in many states have ruled that [a definition limited to mental, physical and sensory impairments] excludes conditions such as epilepsy, learning disability, and long-term health conditions such as HIV/AIDS".[719]

To conclude, the final list of categories of "impairments" included in Article 1 of the CRPD is comparatively short, however, as mentioned above, it is not exhaustive. In addition, these categories are broad enough to provide extensive coverage, particularly if the inclusive approach setting the tone for the negotiations is applied in implementation.

10.1.2. The concept of impairment

The question of inclusion of different categories of impairments connects to the hurdle that the term "impairments" may create in itself. To compare again with the definition put on the table by the Chair during the 7th session, it included "impairments, conditions or illnesses", as opposed to the final text including only "impairments".[720] Consequently, any "conditions" or "illnesses" may have to, in addition to fulfilling the other criteria in Article 1, qualify as "impairments". This poses the question what it is that makes something qualify among "impairments", and if there are "conditions" and "illnesses" which do not amount to "impairments". This would then produce the same effect as the omission of a reference to 'medical' as a

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[718] IDC Statement on Article 25 Health [hereinafter IDC Statement on Article 25 on Health, 7th Session], 7th Session, 25 January 2006. RI (speaking for IDC) similarly recognised the situation of this segment of the constituency during the 6th session in relation to (re)habilitation: "RI highlighted the fate of persons with epilepsy who are not represented at this meeting, who form part of the large group of PWD [persons with disabilities] often referred to as people with chronic illness, chronic disease or medical disability.". Daily Summaries 8 August 2005, 6th Session.

[719] Daily Summaries, 31 January 2006, 7th Session.

[720] See quote above under 10.1.1. referenced in note 714, Part II.

category of "impairments". Something which is commonly viewed as falling within the category "impairments" such as being deaf or being paralysed is included per automatique while a person with chronic conditions more commonly thought of as 'illnesses' or as 'medical' will have to qualify as a "[p]erson[...] with disabilities" in the sense of Article 1 through the display of 'symptoms' qualifying as "impairments" (and "physical, mental, intellectual or sensory" at that), rather than by 'label' or 'diagnosis' of such 'conditions'/'illnesses' per se. Had a reference to 'medical' impairments remained in the CRPD, or indeed one to 'illnesses', it would have created a connection between "impairments" and conditions though of more in terms of 'health' or 'illnesses'. Now the inclusion of such levels and modes of functioning of the body and mind must take the route via one of the categories of "impairments" explicitly enumerated in Article 1, a relationship which cannot be determined en masse but rather has to be done in each case. Failing this, through the phrasing "include" in Article 1, such conditions may also seek inclusion on their own terms.

The first communication submitted under the OP-CRPD, H.M. v. Sweden, concernes a person with a chronic illness, namely a chronic connective tissue disorder called Ehlers-Danlos Syndrome (EDS). In describing the "[s]ubject matter" of the case, the Committee refers to the author of the complaint as "a person with a physical disability".[721] In the summary of the facts as presented by the author the effects of EDS are described:

> Ehlers-Danlos Syndrome (EDS) [...] has led to hypermobility (excessive over-flexibility of joints), severe luxations and sub-luxations (dislocation of joints), fragile and easily damaged blood vessels, weak muscles and severe chronic neuralgia. She [H.M] has not been able to walk or stand for the last eight years, and she has difficulty sitting and lying down. Her impairment has resulted in her being bedridden for the last two years, which has weakened her even further.[722]

From this it can be deduced that the Committee does not make an issue out of the inclusion of persons with chronic illness per se, but rather, through the description of symptoms, or, if you will, "impairments", implicitly establishes a link to one of the categories enumerated in Article 1.

The omission of the term 'conditions' will not only negatively affect the obviousness of persons with certain health conditions being included under the CRPD; it is also likely to affect who, for reasons connected to self-regard, choose to call upon the entitlements in the CRPD. IDC emphasised this issue throughout the negotiations. As late as the last days of the 8th session, IDC "proposes to add the term "conditions" to impairments, as some groups of people with disabilities don't agree with the term "impairment" and prefer the term "conditions"".[723] The News page from 23 August

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[721] H.M. v. Sweden, 2012, front page.

[722] Ibid., para. 2.1.

[723] IDC Proposed Text on Definitions, 8th Session.

related this demand to "intellectual and psychosocial disability".[724] WNUSP elaborated the rationale for this demand in its submission to the Working Group, noting that "[i]t would also be desirable to obtain a definition that is comfortable both for people with disabilities who identify with medical terminology and diagnosis, and for those who reject medical terminology and identify with disability as a social and political category only".[725] By using the term 'conditions' the medical connection perceived as inherent in the term 'impairments' is thusly seen as avoided.

Consequently, the term 'condition', due to its broad meaning, could potentially have served to stretch the coverage of what ended up as "impairments" in Article 1 in two directions: both through extending the possibility of coverage for conditions associated more with 'illnesses' than with 'impairments' (i.e. towards medicine) and, as noted by IDC, through making the CRPD suitable for persons who do not identify with the term 'impairments' due to its perceived connection with medicine (i.e. away from medicine).

10.1.3. Level of impairment as a threshold

Further on the implications for coverage of the term "impairments" in Article 1, the question poses itself if there is a 'level' threshold for something to qualify as "impairments". The existence of such thresholds on the national level was called upon as a reason for providing a definition of "disability" in the CRPD by an Australian organisation, NACLC, in a submission for the 7th session providing the "simple illustration […] that someone with a visual impairment that falls short of total blindness may be considered to be a person with disability in one State but excluded from the protection of the Convention in another".[726]

The question of levels of impairment primarily figured in the negotiations in relation to the question whether to emphasise or create additional State obligations in relation to persons among the constituency of the CRPD with "severe" impairment. The Working Group Draft makes such references in two places. Draft Preamble (m) expresses concern "about the difficult conditions faced by persons with severe

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[724] "We reject the use of the term "impairment" to refer to intellectual or psychosocial disability." IDC News Page 23 August, 8th Session, 2006.

[725] WNUSP, Compilation of Proposals before the Working Group, 2004, pp. 40-41.

[726] NACLC, Comments on the Chair's Text, 7th Session, 19 December 2005, p. 7. Evidence to this effect was given in the negotiations. See e.g. the recorded statement by Yemen during the 7th session, arguing for the need for a definition of disability and noting views that "depression" does not "reach the level of a disability": "It [Yemen] also noted a connection with the medical field, in which there are some psychiatric illnesses that do not reach the level of a disability, such as depression, and thus a definition of disability is needed for the sake of clarity.". Daily Summaries 31 January 2006, 7th Session. It should be noted that it is not clear if this limitation is supported, as opposed to simply noted, by Yemen. See further a recorded statement by Iraq during the 7th session in the context of calling for a definition of disability: "It [Iraq] noted, for example, a law that once existed in Iraq that stated if a person were 50% disabled, they would qualify for assistance; considering the variety of 182 countries and NGOs, a single, comprehensive definition would be necessary.". Ibid.

or multiple disabilities".[727] Draft Article 23 (1c) on Social security and an adequate standard of living obliges states to take measures to "ensure access by persons with severe [...] and multiple disabilities, and their families [...], living in situations of poverty to assistance from the State to cover disability-related expenses (including adequate training, counselling, financial assistance and respite care)".[728] Over and above being perceived as indeterminate[729] these references to "severe" and similar propositions[730] were opposed as "negative labeling", i.e. as implicating impairment as negative and stigmatising those with high levels of impairment[731] and as representing "a medical model rather than a social model of disability"[732]. In addition, they were opposed as creating "a hierarchy of disability"[733], which was problematic against the

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[727] Working Group Draft, 2004, p. 8. For deliberations on this aspect of Draft Preamble (m) see particularly Daily Summaries 4 June 2004, 3rd Session. In the Chair's Draft for the 7th session the reference to "severe and multiple" in Draft Preamble (m) is removed. Chair's Draft, 7th Session, 2005, p. 17.

[728] Working Group Draft, 2004, p. 30. For deliberations on this aspect of Draft Article 23 see in particular Daily Summaries 2-3 June 2004, 3rd Session and 8-9 August 2005, 6th Session. In the Chair's Draft for the 7th session the reference to "severe and multiple" in what had then become Draft Article 28 (2c) on Adequate standard of living and social protection is removed. Chair's Draft, 7th Session, 2005, p. 30.

[729] See e.g. Working Group Draft, 2004, p. 30, note 101 and Daily Summaries 8-9 August 2005, 6th Session.

[730] See e.g. proposal by Israel for the addition of an article on rehabilitation during the 3rd session containing language obliging States to "ensure that access to such services will be open to all persons with disabilities without discrimination of any kind, and particularly without regard to the kind or severity of the disability". Compilation of Proposals before the 4th Session, 2004, p. 55. IDC similarly called for language during the 7th session to the effect that such services apply to "all persons with disabilities irrespective of […] degree, duration and complexity of disability" in their proposal for what had then become Draft Article 26 on Habilitation and rehabilitation. IDC Amendments to Chair's Draft, 7th Session, p. 54 (source not paginated). Thailand proposed during the 4th session that the obligation in Draft Article 5 (1c) on Promotion of positive attitudes to persons with disabilities to "[p]romote an image of persons with disabilities as capable and contributing members of society sharing the same rights and freedoms as all others and in a manner consistent with the overall purpose of this Convention" be specified by inserting that this applied irrespective of ""type, severity and complexity" of disability". Daily Summaries 25 August 2004, 4th Session. See also deliberations on this proposal in Daily Summaries 31 August 2004, 4th Session.

[731] Referring to Draft Preamble (m), II and WNUSP are recorded as referring to such references as "negative labeling". Daily Summaries 24 May 2004, 3rd Session. It would seem that the term "severe" is opposed here by virtue of the dual implication of using the term "severe" in relation to levels and modes of functioning of the body and mind: that implicated levels and modes *per se* is a negative thing (as only a high level of something *bad* is 'severe') and that "severe" such levels and modes are worse yet. Similarly, the record of the deliberations on this issue in the Working Group, contained in a footnote to Draft Article 23 on Social security and an adequate standard of living, noted the position that references to "severe" were "prejudicial": "Some members of the Working Group questioned the use of the word "severe" on the grounds either that it was difficult to define or that it was prejudicial. The Ad Hoc Committee may wish to consider whether to omit it.". Working Group Draft, 2004, p. 30, note 101.

[732] Record of statement by Canada during the 3rd session in relation to this aspect of Draft Preamble (m). Daily Summaries 4 June 2004, 3rd Session.

[733] Recorded statement by Mexico in relation to Draft Preamble (m) during the 4th session. Daily Summaries 23 August 2004, 4th Session. See also recorded statement by Canada during the 3rd session. Daily Summaries 4 June 2004, 3rd Session.

background that "people with less severe disabilities are often left out of programmes from which they could benefit".[734] The outcome of the "severity" debate is that the final version of the CRPD does not contain any reference to the particular situation or demands of persons with "severe" impairment. Instead, Preamble (j) recognises "the need to promote and protect the human rights of all persons with disabilities, *including those who require more intensive support*".[735]

This debate thus concerned both justice for those at the higher end of the 'severity'/'intensive support' spectrum as well as justice for those at the lower end. It also illustrates the State practice of differentiating based on *levels* of functioning of the body and mind, a practice which extends to the determination of who is recognised as a person with a disabilities and who is not. The question of levels of impairment emerges through Preamble (j) as salient for ensuring implementation of the entitlements of the CRPD for *all,* for the *entire* constituency. The question of levels of impairment will also determine who is coved by the CRPD at all, as a threshold criteria as to level of functioning of the body and mind is inherent in the term "impairments" in Article 1. Pursuing the example provided by NACLC above, it seems clear that every person departing from a medial visual capacity will not qualify among those seen as having "impairments" and thus as potentially qualifying as a person protected by the CRPD. This poses the question where this line is to be drawn. The text of the CRPD does not define "impairments" nor does it otherwise indicate an answer to this question. As opposed to the question of differentiating *among* the constituency of the CRPD based on levels of impairment, the question of levels of impairment in relation to inclusion in the constituency of the CRPD was to my knowledge not the subject of informative discussions in the negotiations. The closest the Ad Hoc Committee got to this issue was the discussion and subsequent refutation of a related 'level' criterion, namely a requirement that a person in order to be covered by the CRPD must experience a "substantial limitation" of "essential activities of everyday life".[736] Had such a requirement made it into the CRPD it would potentially have entailed that those persons whose level or mode of functioning were

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[734] Record of statement by Japan during the 3rd session. Daily Summaries 2 June 2004, 3rd Session.

[735] Emphasis added. The origin of this provision is a proposal by IDC during the 7th session. IDC Amendments to Chair's Draft, 7th Session, p. 5 (source not paginated). This proposal was included verbatim in Draft Preamble (h) of the Working text after the 7th session, with the only subsequent change being "persons with disabilities" substituting the original wording "people with disabilities". CRPD Working Text after 7th Session, 2006, p. 6.

[736] The reasons for refutation were expressed in detail by PWDA during the 7th session: "PWDA was also concerned about the potential incorporation of "substantial limitation" or a similar term in the definition. It noted that this term occurs in the U.S. and U.K. definitions of disability and has been interpreted by courts to deprive persons who have certain impairments of the protection of non-discrimination legislation on the basis that with a particular aid appliance or medication the person does not experience a substantial limitation. […] It also believed the reference to "essential activities of everyday life" was potentially restrictive; it questioned whether the ability to use a mobile phone or attend a theater performance, for example, would be ruled "nonessential."". Daily Summaries 31 January 2006, 7th Session. The proposals reacted to thusly include the following by Kenya for the 7th session: "Disability" includes any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community

mediated through aids or medicine would not qualify as covered by the CRPD irrespective of negative social responses encountered. It would also have required that the life opportunity in question be understood as "essential" in order for coverage to ensue.

The upshot is that "impairments" in the sense it is used in CRPD Article 1, as well as in general, signifies a certain *level* of functioning of the body and mind. Consequently, this question is part and parcel of the 'gate' to the protection of the CRPD. However, little indication is given as to where this line is to be drawn.

10.1.4. Impairment as long-term

The most obvious bottleneck in Article 1 is perhaps the express depiction of "impairments" as "long-term". To compare again with the version put on the table by the Chair for the negotiations during the 7th session, it referred to "permanent, temporary [or] intermittent".[737] This temporal aspect of who qualifies for the protection of the CRPD was part of definitions suggested throughout the negotiations. Submitted proposals included requirements establishing such a temporal threshold (such as "long-term"[738] or "last[ing] for a significant period of time"[739]) as well as calls to exclude such terms[740] or letting them be flanked by a reference to expressions negating such qualifications (such as "temporary").[741] The fear of too wide a coverage regarding the temporal aspect of "disability" was present already in the Working Group, where Japan is recorded as questioning the reference to "temporary" as an exemplification of a definition being "too wide in scope".[742] Reflecting the opposite concern, IDC opposed the "long-term" requirement throughout the 8th session, emphasising that it would allow states to limit the coverage of the CRPD.[743]

In line with the concerns expressed by IDC, the final inclusion of the term "long-term" raises the questions what threshold this creates. At the outset, this meaning

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to have, a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities.". Position of Kenya, 7th Session, 10 January 2006.

[737] See quote above under 10.1.1. referenced in note 714, Part II.

[738] See e.g. the proposed definition by Kenya quoted above in note 736, Part II, including the term "long-term" (albeit qualified by the addition of "[or] substantial").

[739] Proposal for definition of "disability" to the Working Group by WBU: "A physical, psychiatric, intellectual, or sensory impairment, (whether permanent or temporary, provided that it lasts for a significant period of time), that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic and social environment.". Compilation of Proposals before the Working Group, 2004, p. 51.

[740] IDC noted during the 8th session that "IDC opposes the use of "longterm" or "persistent" to be used in this paragraph [Article 1]. This would still allow States Parties to take a decision at national level, whether or not to use this additional "qualifier". IDC Proposed Text on Definitions, 8th Session.

[741] Late examples of this are intervention by Australia and South Africa during the 8th session in a structured informal discussion on a definition. IDC Report from Informal on Definition of Disability, 8th Session.

[742] Daily Summaries 13 January 2004, Working Group Session.

[743] See note 740, Part II, above.

would exclude its antonym, and thus any level or mode of functioning characterised as ‘short-term’. However, “long-term”, by common connotation, sets a threshold which is lower than for example ‘permanent’ and will thus cover “impairments” which are present but have only lasted/are only likely to last for a limited time. The extent of this time, while being somewhere between ‘short-term’ and ‘permanent’, cannot however not be pinpointed from the wording of Article 1 or its context or purpose, nor from the records of the negotiations. Finally, again, as the depiction of “[p]ersons with disabilities in Article 1 is preceded by the word “include”, this carries a, yet unidentified, potential to qualify the limitations inherent in the expressions chosen for Article 1, including that of “long-term”.

10.1.5. Impairment as present

The Chair’s text expressly included the term *“intermittent”*, which is not included in the final text of the CRPD.[744] With this omission, it is unclear how the reference to “long-term” in Article 1 affects the inclusion of cases where “impairments” come and go. Another phrasing that may have bearing on the inclusion of persons with intermittent “impairments” under the CRPD is the term “have”, i.e. that “impairments” have to be somehow ‘had’. This is so as persons with intermittent “impairments” many “have” no current manifestation of these. This phrasing may also have bearing on a number of other situations, including when one has previously had “impairments” which are now gone, when someone is somehow disposed towards future “impairments” (through genetics or the diagnosis of a condition which habitually leads to “impairments”) or when someone who has no “impairments” is perceived as having such “impairments”. Neither of these situations is explicitly covered by Article 1. In comparison, the Draft provided by the Chair before the 7th session contained an explicit reference to “impairments” including instances where this was “imputed”.[745]

The explicit inclusion of protection in these situations, either in a definition of “disability” or in a definition of “discrimination”, was suggested in the negotiations. In a summary of the discussions of Draft Article 7 on Equality and non-discrimination in the 4th session, the Coordinator reports that “[a] number of delegations would like to include other aspects within the definition [of discrimination on the basis of disability], such as [...] record of disability; condition relating to previous disability; or perception of disability, whether past or present”.[746] The least discussed case, due to its late appearance on the agenda, was the inclusion of persons disposed to future impairment. The US made a proposal regarding protection against misuse of genetic information during the 7th session, to be included in Draft Article 25

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[744] Emphasis added. See quote above under 10.1.1. referenced in note 714, Part II.

[745] See quote above under 10.1.1. referenced in note 714, Part II.

[746] 4th Session Report by Coordinator, 2004, p. 12, para. 22, note c.

Health or, as suggested later, in the Draft Preamble.[747] While these proposals received recognition as important from some negotiators due to the speedy progression in this field, they were viewed with suspicion by others who questioned the wisdom of linking the issue of genetics to the constituency of the CRPD.[748] Another controversial case, at least to certain States, was the explicit inclusion of protection for persons falsely perceived by others as having an impairment.[749]

As a general point, it was repeatedly asserted in the negotiations that that omission of enumerations or 'lists' does not implicate exclusion. This was asserted also in relation to the cases under discussion here, to the effect that the term "disability" or "discrimination" potentially or actually covers all the situations described above. The following statement by the EU was recorded during the 4th session, in the discussion of Draft Article 7 on Equality and non-discrimination:

> [N]ot mentioning elements such as past, present, perceived does not mean that they are not included in the definition. Thus EU member states already prohibit discrimination based on past disability. The real risk lies in legitimizing a reasoning that absence of elements means their exclusion from coverage.[750]

The upshot is that the reference to "impairments" as something one 'has' in order to qualify among "[p]ersons with disabilities" according to Article 1, taken together with the lack of explicit inclusion of the situations described above in Article 1 or Article 5 on Equality and non-discrimination, leaves the question of their inclusion under the

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[747] Proposals by the US for a new paragraph (e) to be included in Draft Article 25 on Health: "[R]equire that prior, free, informed and express consent be obtained for the collection of genetic data from persons with disabilities or their legal representative, that such consent also be obtained for subsequent processing, use and storage of genetic samples, whether carried out by public or private institutions except as provided for in specific procedures for waiver of consent set forth in domestic law, regulation, or policy, or in regional conventions, consistent with the principles of this Convention.". Alternatively, the US proposed the addition of the following paragraph to the Preamble: "Recognizing the need to protect the privacy of persons with disabilities subject to genetic testing and bearing in mind in this regard the ethical principles embodied in the UNESCO International Declaration on Human Genetic Data;". Proposals by the US during the 7th Session, 2006.

[748] See record of deliberations from the 7th session, in particular Daily Summaries 2 February 2006, 7th Session.

[749] In particular India and China repeatedly opposed such inclusion. See Daily Summaries 25 August and 1 September 2004, 4th Session, Daily Summaries 4 February 2005, 5th Session and 19 January 2006, 7th Session. The pertinent issue regarding to whom the protection of the CRPD extends relates to the situation where there is no disagreement over what is an impairment, but rather when a person is falsely thought to have an impairment and is disadvantaged based on this perception. In the deliberations, this situation was not always clearly delimited from the situation when the person does not agree that his or her level or model of functioning of the body and mind is 'an impairment', in the sense ascribed by Article 1. For example, the explicit protection against "perceived" impairment was present in the definition of discrimination in Draft Article 7 (2b) on Equality and non-discrimination in the Working Group Draft, with the following footnote attached: "The Ad Hoc Committee may wish to consider the scope of this term, and whether it should apply to the individual's perception of themselves, or society's perception of them.". Working Group Draft, 2004, p. 13, note 25.

[750] Daily Summaries 2 September 2004, 4th Session.

protection of the CRPD without a straightforward answer. Turning to the purpose of the CRPD, as well as the context of these articles, it is undeniable that these situations all actualise the core position of the CRPD, namely to focus on the role of the environment rather than on "impairments" as decisive for negative outcomes. This is the core of all these situations in the sense that no "impairments" are present but notions about impairment lead to disadvantage. If one turns to the preparatory works for guidance, the case for the inclusion of "impairments" which are falsely attributed the person by others displays the least strength, as certain States repeatedly expressed a strong preference for such situations not being covered under the CRPD.

10.1.6. Barriers hindering participation and ensuing disadvantage

So far, the discussion here has concerned requirements adhesive to "impairments", i.e. to the individual. In addition, the depiction of "[p]ersons with disabilities" in Article 1 includes an environmental requirement, namely the existence of "various barriers [the interaction with] which may hinder [...] full and effective participation in society on an equal basis with others". To qualify as covered by the CRPD such barriers must exist and must, in connection with "impairments", result in restricted "participation in society". The environmental prerequisite ("various barriers") is broad and so it is not likely that this will present any real obstacle to coverage. Indeed every call on the CRPD will be made by a person in a context and that context is likely to entail barriers in some form, influencing access to one or more areas of life protected in the CRPD. Similarly, the prerequisite of disadvantage in relation to "participation in society" can be assumed to be of limited significance as a legal criterion, as the only required link between impairment, barriers and disadvantage is that the latter "may" be the result of the interaction between the former two. In other words, actual restricted "participation in society" does not have to be shown in order for the CRPD to be applicable, rather the impairment in question has to be perceived as 'generally' connected to such disadvantage in order to offer prima facie membership among the constituency of the CRPD. It is unclear where "may" places itself on a scale from 'likelihood' to 'possibility' in the evaluation of the habitual social responses to the impairment in question. However, it can be concluded that disadvantage does not have to *manifest* itself in order for the individual seeking the protection of the CRPD being prima facie included under its coverage among "[p]ersons with disabilities".[751]

A potential limitation, at least in theory, is inherent in the concept "participation in society". To qualify as a person covered by the CRPD through Article 1, one has to demonstrate that barriers interacting with one's "impairments" result in restricted such participation. However, ones actual complaint under the CRPD may concern

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[751] It is another issue that *actual* disadvantage must be shown in order for a violation of the CRPD to be found, however this comes *after* the establishment of whether the CRPD applies to a person or not.

e.g. lack of wanted medical intervention, the consequence of which may not easily qualify as restricted "participation in society". The question poses itself if the disadvantage falling under "participation in society" must be once removed from the "impairments" or other conditions the medical intervention is to target. Must it be shown that lacking medical care either constitutes or leads to restricted "participation in society" (in addition to its direct effect on "impairments" or other conditions) in order for the person affected to qualify as covered among "[p]ersons with disabilities"? While such a link can be shown in as much as the medical intervention would facilitate such participation, a contextual interpretation of "participation in society" would run into the fact that Article 25 of the CRPD has been shaped *not* to assume or support a link between levels and modes of functioning of the body and mind and enjoyment of composite life opportunities. In addition, one of the objectives of the CRPD is to downplay such a link.[752] However, as the requirement regarding "participation in society" in Article 1 is that it "may" be restricted in relation to the "impairments" in question, such restriction need not consist in the actual violation complained of. Consequently, it appears enough that "impairments" are generally subjected to barriers the interaction with which produces restrictions amounting to hindered "participation in society". As mentioned above under 8.1.2.3., the first complaint submitted under the OP-CRPD, H.M. v. Sweden, indicates that the CRPD Committee reads medical (re)habilitation as instrumental to "participation in society" (at least in as much as it overlaps with being included in the community). This is so as it is noted that the lack of such rehabilitation would adversely affect the author to the point where she would need to leave her home and consequently would result in a violation of Article 19 on Living independently and being included in the community.[753]

The CRPD thus establishes the answer to the question if a person qualifies among "persons with disabilities" based not only on the existence of impairment, but also on the existence of barriers and ensuing disadvantage. However, the upshot of the above is that these criteria will be of secondary consequence in the determination of if a person is covered by the CRPD or not. This is so as "barriers" are defined broadly, as restricted "participation in society" does not have to actually have taken place and as such restricted participation does not have to relate to the subject matter of the actual concern in question.

However, one effect of the inclusion of environmental criteria and a disadvantage criterion in the determination of who is covered by the CRPD through Article 1 is that the coverage of persons similarly situated regarding "impairments" will differ from State to State. This is of course always the case in the subsequent determination of if a violation exists, but since the CRPD is the first UN instrument which defines the group through the disadvantage incurred this question comes into play already at the stage of determining who is covered. In other words, if the development of

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[752] See below under 12.1.1.

[753] H.M. v. Sweden, 2012, para. 8.9.

barrier removal in a State reaches a level where a person is no longer disadvantaged in relation to "impairments", he or she ceases to qualify among "[p]ersons with disabilities" and is thus no longer part of the constituency of the CRPD.

Regarding the level of restriction required, Article 1 uses the term "equal", to define the level of restriction of "participation in society" necessary in order to qualify as a "person[…] with disabilities" under the CRPD. In other words, any comparative disadvantage in such participation suffices to qualify for coverage under the CRPD.

The upshot then, is that the coverage of Article 1 remains deliberately open-ended, leaning towards inclusion rather than exclusion by virtue of the insertion of the term "include" as well as the term "all". However, this does not mean that the specifications of the article are just random examples. The fact that it was deemed necessary to explicitly include these specifications illustrates that the coverage of Article 1 *has outer limits*; the function of Article 1 as part of a legal document remains to draw a line between those covered and those not covered. Among these specifications, the analysis above suggests that the bottleneck of the protection of the CRPD will be connected to questions surrounding "impairment", rather than to "barriers" or ensuing disadvantage. Having said this, a contextual interpretation actualises the focus in the CRPD on the environment, attitudinal and otherwise, in the creation of disadvantage. This gives rise to the argument that any potential limitations, disregarding the inclusive character of Article 1 and focusing narrowly on the scope of "long-term physical, mental, intellectual or sensory impairments" need to be weighed against this character, as long as the situation in question is coupled with a disadvantage in social participation relative to others. Finally, through the logical overlap between what "disability" is according to Preamble (e) and who "[p]ersons with disabilities" are according to Article 1, all of the above is subject to a possible 'wildcard' affecting who the constituency of the CRPD are, or will become. Paragraph (e) of the Preamble recognises that "disability is an evolving concept", thusly linking this recognition of change to the building blocks of "disability": "impairments", "barriers", "participation", as well as to the terms used to specify these. True to its function as a 'wildcard' however, Preamble (e) does not indicate in what direction this 'evolution' will, or should, develop. In addition, its interpretative value is limited by the fact that it is part of the Preamble rather than of the legally operative part of the CRPD.

10.1.7. The constituency of the CRPD compared to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

Turning to the approaches to disability explored in Part I of this book, it should be noted at the outset that they do not share the concern of the CRPD to draw the line between who is in and who is out, in other words of being able to ascertain if a particular individual does, or does not, qualify among their constituencies. Beginning with the Social Model of Disability, while presupposing Impairment as a criterion for inclusion, UPIAS as well as Michael Oliver emphasise that what ties the constituency together is the experience of externally imposed disadvantage caused by social barriers.[754] The Social Model of Disability does not linger on the issue of Impairment, largely in order to redirect attention towards such externally imposed disadvantage. Having said that, UPIAS do define Impairment, a definition later reproduced by Michael Oliver as the Social Model of Disability, in terms of "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body".[755] Impairment is thus understood as a negative departure from a medically related norm for the body, and this norm is not further questioned or elaborated on. In the words of Michael Oliver: "impairment is, in fact, nothing less than a description of the physical body".[756]

UPIAS do not problematise the category Impairment as such, neither as a tool to distinguish a phenomenon nor a constituency. Michael Oliver, irrespective of the neutral view of what is an Impairment convened in the statement above, elsewhere recognises the relativity of Impairment and the interest and mechanisms of the social context in separating out a group based on such a criterion.[757] In addition, his critique of normalising tendencies within the medical and other professions concerns not only striving to restore "normality" but also to define it as such, noting as he does that "[n]ormality is a construct imposed on a reality where there is only difference".[758] The practice of designating something as an Impairment is however only problematised on a general level and does not amount to a questioning of "the reality of impairment"[759] or using Impairment as one criterion to separate disabled people from non-disabled people.[760] Turning back to the CRPD, it does not define the "impairments" it refers to in Article 1 nor does it problematise the designation of something as "impairments". Indeed, like the Social Model of Disability, one of its aims is to direct focus from levels and modes of functioning of the body and mind and towards the social responses of the environment.[761] Concerning categorisations of Impairment, while UPIAS for strategic reasons limited its application to "physically impaired" persons[762] Michael Oliver extends the application of the Social Model of Disability potentially indefinitely.[763]

Compared to the CRPD, the UPIAS definition of Impairment above contains no qualifications connected to 'level' or temporal aspects. Regarding levels of Impairment, UPIAS restricts its membership to "residents of Britain who are *significantly* physically

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[754] See e.g. UPIAS, 1975, pp. 14-15 and Oliver, 1996, p. 5.
[755] UPIAS, 1975, p. 14 and Oliver, 1981, p. 28.
[756] Oliver, 1996a, p. 42.
[757] See e.g. Oliver, 1990 and Oliver, 1999.
[758] Oliver, 1996, p. 88.
[759] Oliver, 1996a, p. 42.
[760] Oliver, 1996, p. 5.
[761] See below under 12.1.1.
[762] UPIAS, 1974, paras. 20, 22.
[763] Oliver, 1981, p. 30.

impaired"[764] and Michael Oliver appears to stipulate no such 'level' requirement. This is testimony to the focus on socially imposed disadvantage rather than on levels and modes of functioning of the body and mind as the key commonality of disabled people. Neither Oliver nor UPIAS explicitly assumes a temporal criterion. However, the problems they address as the problems of disabled people are not problems which would affect someone with a shorter experience of implicated levels and modes of functioning of the body and mind, nor does the emphasis on the organisation of disable people forwarded this as something a person joins forces with for a short time. In other words, the notion that every person is either a disabled person or a non-disabled person does not rhyme well with the notion of 'short-term' members.

Regarding the situations where inclusion among the constituency of the CRPD through Article 1 is questioned due to "impairments" not presently being 'had', the result of an analysis of the Social Model of Disability pulls in different directions. At the outset, a requirement of materialisation of Impairment in order to receive protection from externally imposed disadvantage based on ideas of Impairment would fly in the face of the core of the Social Model of Disability, which remains that Impairment is, for all intents and purposes, irrelevant to such disadvantage. However, the inclusion of these situations does complicate the aim of the Social Model of Disability to clearly separate disabled people from non-disabled people and Oliver does require the presence of Impairment in order for someone to be "a disabled person".[765] Finally, by separating "disabled people" from "persons with impairments" based on ideological grounds Oliver appears to include a criteria amounting to agreeing with the major tenets of the Social Model of Disability in order to be part of its constituency.[766]

Turning to the Minority Group Model of Disability, like the Social Model of Disability, the 'glue' of the constituency is socially imposed restrictions and Harlan Hahn discourages "stressing the functional traits that divided them [disabled persons] rather than the external obstacles which they faced as a common problem".[767] Hahn does not define or linger on impairment, but rather presupposes it and then focuses on the disadvantage imposed by external barriers. He does not seem to problematise the category 'impairment' as a tool to distinguish a phenomenon or a constituency. When he notes that "disability, like most other human phenomena, is socially and culturally constructed" this reads as referring to social disadvantage, rather than to questions of the existence of levels and modes of functioning of the body and mind or the designation of these as 'impairments'.[768] In addition, since Hahn regards impairment as a positive factor in life, it follows that it is both seen as 'existing' in terms

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[764] UPIAS, 1974, para. 20. Emphasis added.

[765] Oliver, 1996, p. 5.

[766] Ibid.

[767] Hahn, 1987, p. 1 (source not paginated).

[768] Hahn, 1996, p. 47.

of it constituting reality and that the designation of something as an impairment is not problematic.[769]

Compared to the CRPD, the Minority Group Model of Disability does not categorically stipulate particular categories of impairments as its coverage. Regarding the temporal aspect of impairment, Hahn assumes the chronicity of levels and models of functioning of the body and mind, in the sense that "disabilities represent chronic conditions that cannot be cured through therapeutic interventions".[770] Concerning the issue of 'levels' of impairment, Hahn expresses the importance of a focus on "citizens with major disabilities"[771], which is indicative as to whom he sees as the core constituency of the Minority Group Model of Disability. Regarding the situations where inclusion among the constituency of the CRPD through Article 1 is questioned due to "impairments" not presently being 'had', a requirement of materialisation of impairment in order to receive protection from externally imposed disadvantage is as foreign to the Minority Group Model of Disability as it is to the Social Model of Disability. Hahn explicitly notes, while deploring a position taken by the US courts, that persons who are disadvantaged due to being suspected of carrying the HIV virus "might be especially deserving of this type of protection".[772] Finally, both models just discussed set the standard of when restricted enjoyment of composite life opportunities amounts to disability through the level of enjoyment by others, the Minority Group Model explicitly so through its consistent reliance on the concept of equality and non-discrimination.[773] Turning to ICF, it is characterised by inclusiveness, its entry gate being a broad understanding of the concept Health condition:

> *Health condition* is an umbrella term for disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition.[774]

Adding to the inclusive character of ICF, it is thus not restricted to persons experiencing conditions of a particular duration; it covers persons with acute or chronic conditions alike. In order to be covered by ICF, one has to, in addition, experience Disability. The standards used to decide at what point a level of Functioning becomes Disability (i.e. Impairments, Activity restrictions or Participation limitations) are referred to as a "generally accepted population standard".[775] In relation to Impairments, such "accepted population standards in the biomedical status of the

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[769] See e.g. Hahn, 2001, p. 60 and Hahn, 1987, p.14 (source not paginated).

[770] Hahn, 1999, p. 4.

[771] Hahn, 2001, p. 72.

[772] Hahn, 1996, p. 46.

[773] See e.g. Hahn, 1987, p. 2 (source not paginated).

[774] WHO, 2001, p. 212. Emphasis in original.

[775] Ibid., pp. 12, 15.

body and its functions"[776] consist in "established statistical norms"[777]. These statistical norms are used to identify a set point, "a threshold level"[778], where the level of "deviation"[779] from these norms amount to a qualitative conceptual leap; from levels of Functioning to levels of Impairment. An Activity or Participation becomes an Activity limitation or Participation restriction when it represents "discordance" from "an individual without a similar health condition".[780] The designation of particular experiences as Disability, or the designation of the point where they move there from Functioning, is not further problematised. Regarding the situations where inclusion among the constituency of the CRPD through Article 1 is questioned due to "impairments" not presently being 'had', these are explicitly noted as covered by ICF. This includes those who have a genetic predisposition for a Health condition, those who have previously experienced such a Health condition as well as those falsely suspected of having a Health condition.[781]

Turning to ICIDH, it is the existence of Impairment, existing or previous, which determines if a person is covered or not. Compared to the categories of "impairments" explicitly noted in Article 1 of the CRPD, ICIDH recognises the diversity of Impairment by including the category "other" in its enumeration of impairment categories.[782] Regarding a temporal requirement, the manual refers to "chronic and disabling conditions"[783] but notes elsewhere that these can be "temporary or permanent"[784]. Impairment is defined by ICIDH as "deviation from some norm in the individual's biomedical status".[785] The manual notes that all of its three concepts (Impairment, Disability and Handicap) "depend on deviations from norms" and that "the amount of deviation regarded as being present" is dependent on "a definition of the norm in question".[786] While it is noted in relation to the category Impairment that "value orientation relates to social interest [and] [d]epartures from the norm thus need to be regarded in such a way that views are tempered by consideration of the feasibility and desirability of intervention to restore the norm", this is presented by way of an explanation and not further problematised.[787] Questions

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[776] Ibid., p. 12.

[777] Ibid., p. 213.

[778] Ibid., p. 13.

[779] Ibid., p. 213.

[780] Ibid., p. 15.

[781] Ibid., Annex 4 Case Examples, pp. 238-241.

[782] WHO, 1980, p. 45.

[783] Ibid., p. 18.

[784] Ibid., pp. 27-28. Elsewhere in the manual it is stated as a choice what to record with ICIDH: "[O]ne might well wish to restrict considerations to relatively persistent impairments, eliminating transitory states and other trivia by adopting duration and severity criteria.". Ibid., p. 37.

[785] Ibid., p. 27.

[786] Ibid., p. 33. Disability is defined as "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". Ibid., p. 28. Handicap is defined as "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal". Ibid., p. 29.

[787] Ibid., p. 34.

connected to the relativity of whether a level or mode of functioning is a problem or not is thus addressed in general terms only.

On the question whether coverage depends on a certain 'level' of Impairment, the manual notes that the users of ICIDH may apply criteria of "severity" to determine who to include depending on the purpose for the use of the scheme. This does not however read as decisive as to at what point a person, through the departure from a norm, becomes covered by ICIDH.[788] Regarding the situations where inclusion among the constituency of the CRPD through Article 1 is unclear due to "impairments" not presently being 'had', only persons with a history of Impairment are covered by ICIDH, i.e. situations when Impairment has been but is no longer present and may or may not come back.[789] According to the manual, "latent impairment constitutes a contradiction in terms"[790] and "impairment ensues only when the agent has initiated a reaction by the body so that pathological processes develop"[791]. In addition, disadvantage by association is not included due to that "their [the associates] disadvantage is not consequent upon their own impairment or disability".[792] This is put down to the need to follow the definition of Handicap "with rigour".[793] As concluded in above under 2.5., this is taken to indicate that persons disadvantaged in connection with being predisposed to Impairment or falsely suspected of having an Impairment are not covered by ICIDH.

The question of not *how* but *if* it is an adequate approach to depict the issues facing the constituencies of these approaches as delineating a particular segment of humanity, 'persons with disabilities', is addressed in the following section.

10.2. A universality or a minority view?

Approaches to disability differ as to if they portray the constituency of the ideological and political platform they create as a minority or as encompassing all of humanity. The approaches analysed in Part I are illustrative here: the Minority Group Model of Disability uses the very term "minority"[794] as its label and ICF emphasises that it espouses a view of disability as a "universal human experience".[795] Furthermore, irrespective of whether an approach to disability expressly asserts such a label it can be assigned one according to the criteria just described and elaborated below.

The *'minority view'* portrays persons with disabilities as a distinct grouping among human beings. The 'glue' of the group can consist either in impairment or in access

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[788] Ibid., p. 37.
[789] Ibid., p. 31.
[790] Ibid., p. 27.
[791] Ibid.
[792] Ibid., p. 43.
[793] Ibid.
[794] See above under 5.1.
[795] WHO, 2002, p. 3.

to composite life opportunities (which in turn may be defined in terms of causality or not), but uniting minority approaches is that they assume and pursue as relevant a dividing line between 'persons with disabilities' and 'others' through such criteria. The minority view is how disability, as an ideological, political and legal platform is most often approached. It is, so to say, the default position to use the platform of disability to address concerns portrayed as specific to 'persons with disabilities', as opposed to addressing concerns of 'everyone'. As will be discussed below, three out of the four approaches to disability analysed in this book espouse the minority view.

A minority view which separates out persons with disabilities from others based on impairment comprehend some levels and modes of functioning as making some people relevantly different from others, which merits approaching them, their situation and their legitimate expectations separately from those of others. For minority views which separate out persons with disabilities based on their access to composite life opportunities being hindered by external barriers, the criteria creating the commonality of the group is the social responses to impairment and the ensuing disadvantage, rather than the impairment. Being the target of such responses is seen as creating a commonality within the group which merits approaching them, their situation and their legitimate expectations separately from those of others. To conclude, while approaches espousing a 'minority' view may differ on how exactly they delimit their constituencies they, for different factual and strategic reasons, assume, pursue and forward a dividing line between 'persons with disabilities' and 'others' as relevant. Any perceived potential or existing commonality with others outside the group (to the extent that this is recognised) is deemed less relevant than differences along this dividing line. Consequently disability as a political, ideological and legal platform is reserved for 'persons with disabilities' as a distinct group among human beings.

An approach characterised as a *'universality view'* emphasises that everyone has the potential for all levels and modes of functioning of the body and mind and consequently for the disadvantageous effects of social responses to these. As indicated above under 5.7., Irving Kenneth Zola is the main source of the universality view. As emerged from the statements by him quoted there, the fact that everyone may, or is even likely to become a 'person with disabilities' at some point in life is used to question the adequacy of the delimitation between 'person with disabilities' and others.

While Zola points out similarities in need with a number of segments of the population, his main argument remains the connection between chronic levels and modes of functioning of the body and mind and ageing. This connection results in his endeavour to "reinforce empirically and conceptually what many have long thought necessary – a unified agenda in health care policy for those who are ageing and those who have disabilities".[796] He targets the conceptual separation between the two categorisations through questioning the levels and modes of functioning of the

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[796] Zola, Irving Kenneth, Ageing and Disability: Toward a Unifying Agenda [hereinafter Zola, 1988], Educational Gerontology, Vol. 14, No. 5, 1988, p. 365.

body and mind connected with the disability platform as “static” and the levels and modes associated with ageing as “progressive” (his main point being that the levels and modes of functioning of the body and mind connected with the disability platform are much more fluctuating than habitually acknowledged).[797]

While the call in the article quoted above relates to *health care* policy, the universality view as originating from Zola presents as one of its core premises that “the issues facing someone with a disability are not essentially medical (Hahn 1984, 1985, 1986; Zola 1982). They are not purely the result of some physical or mental impairment […] but rather of the fit of such impairments with the social attitudinal, architectural, medical, economic, and political environment”.[798] Consequently, commonality and ensuing universal relevance is established based on similarities regarding levels and modes of functioning of the body and mind, health needs created by these and barriers faced in relation to the fulfilment of such needs. In addition, similarities are found in relation to barriers faced regarding the enjoyment of composite life opportunities. From the universality view, this demands a “Necessary Universalizing of a Disability Policy”, in the sense of transforming disability into an ideological, political and legal platform where social responses are demanded on the basis of the explicit recognition that these concern *everyone*.[799] The upshot is that while the importance of medicine as well as the larger area of health remains explicitly recognised by Zola both in relation to ageing and disability, this by no means entails that the social responses needed in relation to disability and/or ageing are limited to this field. Neither does it entail an uncritical approach to the workings of ‘medicine’ and ‘health’ (as concepts or as practices) in society. Indeed Zola expresses the same concerns as those who caution against making connections between the ideological and political platform of disability and the concepts and practices of medicine or health:

> When health becomes a paramount value in society and the promotion of that value (the prevention, diagnosis, and treatment of illness) has been monopolized by a specific group [health professions], that group is in a position to exercise great control over what people should and should not do to attain that paramount value. Therein lies great danger, for the labels *health* and *illness* have the remarkable ability to depoliticize an issue. By locating the source and the treatment of problems in an individual, other levels of intervention such as the social or political are effectively closed (Crawford, 1977, 1979). The very labeling of a condition as an illness or a medical problem defines it as an undesirable state, something to be controlled or eliminated.[800]

The analysis above yields that while the universality view according to Zola perceives dangers with connecting the ideological and political platform of disability to the idea and practice of health, it persists in doing so. The reason for doing so is the perception of these connections as both empirically significant and strategically vir-

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[797] Ibid., pp. 368-370.

[798] Zola, 1989, p. 401.

[799] Ibid., title.

[800] Zola, 1988, p. 373.

tuous. Empirically, Zola holds that levels and modes of functioning of the body and mind implicated by the platform of disability have a significant overlap with ageing and in addition, that the progressive nature of conditions connected to ageing does not separate these from levels and modes of functioning of the body and mind at other life stages. Strategically, the case is made that since ageing is relevant to all of us and thus concerns us all, making us acknowledge this (and its overlap with the levels and modes of functioning of the body and mind implicated by the platform of disability) will transform public policy to the benefit of all. The required change is thus one of "perception" as much as of "architecture".[801] Zola puts it that if society is made aware of that "the needs and abilities of people are constantly changing", then this "might alter its attitudes towards the built environment from one of "permanence" and "maintenance" to one of "flexibility" and "adaptation"".[802]

10.2.1. ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability as universality or minority oriented

Turning to the approaches to disability explored in Part I of this book, ICF explicitly espouses and forwards a universality view of disability as it "'mainstreams' the experience of disability and recognises it as a universal human experience".[803] Through its "universal application" ICF calls for policy which, by following the cue of ICF is not "only about people with disabilities [but instead] it is about *all* people".[804] Although ICF addresses levels and modes of functioning of the body and mind as well as composite life opportunities, the entry point of ICF is a Health condition and so the potential for this is the nexus of the commonality asserted. As discussed above under 4.5., the commonality of those to whom ICF is *applied* is narrower as it concerns those who actually experience a Health condition[805] and in connection with this experience Disability (Impairments, Activity limitations or Participation restrictions). Even at this, its coverage is broad and makes no difference between acute or chronic Health conditions or between "progressive, regressive[,] static[,] intermittent or continuous" Impairment.[806] "Health" (or its mirror image – 'ill-health') is broadened beyond limited notions, such as being "sick":

> Impairment may be part of an expression of a health condition, but do not necessarily indicate that a disease is present or that the individual should be regarded as sick.[807]

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[801] Zola, 1989, p. 410.

[802] Ibid.

[803] WHO, 2002, p. 3.

[804] WHO, 2001, p. 7. Emphasis in original.

[805] To this should be added those who are predisposed to such a condition, have earlier experienced such a condition or are suspected of experiencing such a condition.

[806] Ibid., p. 12.

[807] Ibid., p. 13.

"Health" is also broadened to encompass "well-being", which in turn covers the enjoyment of composite life opportunities ("health-related" areas of life).[808] By naming problems in relation to all of the above Disability this term becomes a platform for the needs of everyone. As a consequence, everyone who experiences Disability (in the broad ICF sense) becomes 'a person with disabilities' and this label collapses as a minority marker. Through this exercise disability as an ideological and political platform merges with "health" as an ideological and political platform and 'persons with disabilities' merge with 'everyone', or more correctly people experiencing problems in connection with a Health condition (which is approximated to everyone, through its wide scope):

> ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity.[809]

The connections made by ICF between "health" and disability thus build on perceived common ground, namely the connection between experiencing any Health condition and restricted life opportunities. For WHO, this commonality creates potential common concerns both in relation to the accommodation of diversity in broad society *and* measures aiming at modifying or eliminating the Health condition (or its effects in terms of Impairments and Activity limitations). The former concern (accommodation) is not envisaged as limited to 'persons with disabilities' (traditionally understood) and the latter concern (modifying the functioning of the body and mind) is not limited to persons with 'health conditions' (traditionally understood).

Moving to the Social Model of Disability and the Minority Group Model of Disability, they emerge as minority approaches through understanding disability fundamentally as a minority marker rather than as a universal human condition. The key feature separating their constituencies (disabled people) from others (non-disabled people) is seen as the disadvantage caused by externally imposed barriers. The discrepancy between how disadvantage is distributed between these groups constitutes relevant difference amounting to a conceptual leap meriting the designation of two groups of human beings. Also, impairments are seen as markers for celebration and pride.[810] In addition to finding this distinction the most representative factual description these approaches hold that the minority perspective has strategic virtues. To these approaches, the key is the social situation connected with impairment and any reference to universality clouds this social situation as operatively separating some persons, and through this some levels and modes of functioning, from others. In the words of Harlan Hahn, this lead to less attention to their implicated constitu-

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[808] See Ibid., e.g. p. 3.

[809] WHO, 2002, p. 3.

[810] See Oliver, 1996, p. 89. See Hahn, 1987, p. 14 (source not paginated), Hahn, 2001, p. 60, Hahn, 2001a, p. 41 and Hahn and Belt, 2004, p. 453.

encies, namely “citizens with major disabilities”.[811] While Hahn refers to universality as “founded on the fundamentally accurate premise that nearly everybody has or will experience some form of disability during their lifetimes”, he holds that using this principle as the basis for politics would be disadvantageous for those with “major disabilities”.[812]

In addition, as rallying around a shared situation is key to these approaches, both as a vehicle for social change as well as for the well-being of the individual, the understanding of their constituencies as a minority, rather than as diluted into all of humanity, appears vital.[813] This is particularly so as espousing a minority or a universality view is decisive for who gets to speak from the ideological and political platform of disability; a minority view reserves this platform for a section of the population experiencing relatively larger unjust social responses consequent to their levels and modes of functioning of the body and mind.

In addition to not wanting to be subsumed into a platform including everyone, these approaches particularly object to such a platform being conceptualised in terms connected to ‘health’. Thus, while Oliver notes the factual overlap between “what disabled people would call impairment and what medical sociologists would call chronic illness”[814] he notes that disabled people find the language used in “medical discourse” offensive as well as non-representative of experience.[815] He exemplifies this by noting that “in particular the term chronic illness is for many people an unnecessarily negative term”.[816] In addition, a focus on health brings disability questions onto the medical arena, a move contrary to the Social Model of Disability.[817] Similarly, Harlan Hahn questions the link between disabled people and ‘health’, expressing doubt as to its relevance as well as cautioning against its dangers:

> It is entirely possible to have a significant disability and to be perfectly ‘healthy’, in the conventional meaning of the term, simultaneously. […] For many disabled people, breathing an atmosphere forced by ideas that characterise ‘a healthy life’ as ‘living without a disability’ has been permeated by the stale, sweet taste of death.[818]

These approaches are very clear that the meaning they attribute to “disability” (as a restriction of composite life opportunities) is to be severed form notions of “illness” or “sickness”. It is not however always clear what the relationship between such notions and impairment (i.e. the levels and modes of functioning of the body and mind

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[811] Hahn, 2001, p. 72.

[812] Ibid.

[813] See UPIAS, 1975, e.g. pp. 7, 16 and Oliver, 1996, p. 89. See e.g. Hahn, 1985, p. 100.

[814] Oliver, 1996a, p. 40.

[815] Ibid., p. 43.

[816] Ibid.

[817] See e.g. UPIAS, 1974, paras. 14-15 and Oliver, 1990, pp. 33-37.

[818] Hahn, 2002, p. 180. See also Ibid., p. 178: “People with chronic conditions frequently seek health care for secondary conditions, but may seldom ‘need’ medical treatment because of permanent impairments. Often the most that doctors can do for disabled individuals is to treat ordinary health problems or to monitor increases or decreases in functional capabilities.”.

of a person who are subjected to disability) is. The following statement by Hahn illustrates this point:

> Disability is defined exclusively[in Disability Adjusted Life Years (DALYs)] both as a negative factor that detracts from a healthy life and as a form of ill health that imposes a substantial 'burden' on society as well as the individual. Part of the fallacy of this concept appears to reflect confusion about the concepts of disability, sickness or illness, disease and impairment. Disability is neither a disease, a term that often stands for diagnostic classification, nor a sickness, a word that usually implies an acute health problem from which a person can be expected to recover fully. Nor does it result exclusively from impairment; in fact, disability is produced primarily by the effects of a disabling environment.[819]

It is clear that "disability" here is separate from "sickness", but what about "impairment"? While it is indicated that chronicity is key, this does not differentiate "impairment" as understood by Hahn from 'chronic' illness, defined as the latter is by its chronicity. To conclude, it would seem that the remaining question is the potential overlap between *impairment* (as understood by Hahn and Oliver) and 'illness', 'sickness', 'health' and 'medicine' and not the relationship between the latter and *disability* (as understood by Hahn and Oliver). In any event, the opposition of these approaches to the collapsing of the ideological and political platform of disability into the platform of 'health' is beyond questioning. This is so both for reasons of preserving the borders between these concepts and because eradicating these borders collapses the concerns and the voice of disabled persons as a minority group with the concerns and voice of everyone, threatening to dilute the former.

Finally, turning to ICIDH, it too approaches its constituency as a minority. The minority marker of the group are levels and modes of functioning of the body and mind understood as Impairments. These are depicted as "threshold phenomena" deciding who is included under ICIDH.[820] The manual recognises that everyone is likely to have *some* Impairment, but the focus of ICIDH remains on one Impairment at a time and from this perspective it is not "universal" (as each Impairment is not "universal"):

> Specific individual impairments or disadvantages are not themselves universal, although when they are taken in aggregate, most of us fail to escape some departure from the norm.[821]

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[819] Ibid., p. 180. Compare the statement by Michael Oliver just above, implying that "impairment" and "chronic illness" are the same thing or at least overlap. Thus Oliver denies with emphasis that "illness and disability" [...] are interrelated" (Oliver, 1996, p. 33) but notes that "[i]t may well be [...] that real similarities exist between chronic illness and impairment" (Oliver, 1996a, p. 35). In other words, the point made appears limited to that just as "impairment" and "disability" are unrelated, so are "illness" and "disability".

[820] WHO, 1980, p. 36.

[821] Ibid., p. 34.

The justification of the need for ICIDH refers to a changing "burden of morbidity"[822]: that "[d]isorders like these [residue of condition] are coming to dominate current morbidity experience in some countries and they are especially noteworthy as causes of disability".[823] In addition, the manual notes that "demographic changes […] increase the proportion of the population at greatest risk, the elderly".[824] However, this assertion of growing prevalence is not called upon as an illustration of the universal relevance of Impairment, Disability and Handicap, nor is any *potential* universal relevance of ICIDH (in terms of that we all age) addressed. Consequently, as opposed to ICF, ICIDH sees persons with disabilities as a minority, in the sense that they are grouped together as separate from others. As opposed to the Social Model of Disability and the Minority Group Model of Disability, this group is designated as such primarily through being a particular group of clients of health policy and practice.

10.2.2. CRPD as universality or minority oriented

Turning to the CRPD, its chosen title is "Convention on the Rights of Persons with Disabilities" as opposed to e.g. 'Convention on Disability' (or another title which connotes a phenomenon the relevance of which is universal rather than limited to a particular grouping of people). Furthermore, its provisions, with very few exceptions, centre on the ascribed beneficiaries as "persons with disabilities", specifying obligations, entitlements and measures with this grouping as its express nexus.[825] Thus, the CRPD embraces the idea of a 'group' and presents the entitlements due and obligations owed to that group. Article 1 on Purpose presents the purpose of the CRPD as the full and equal enjoyment of human rights and respect for dignity of "all persons with disabilities" and, as discussed under 10.1. above, proceeds to state who is included in the group "[p]ersons with disabilities", namely "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". Preamble (e) prima facie depicts disability as a phenomenon, rather than in terms of whom it concerns, however, "disability" as a phenomenon is delimited as something concerning "*persons* with impairments".[826]

In these provisions, the key 'glue' of the group is the experience of lacking participation in society. The commonality of persons with disabilities as a group (extending beyond the experience of lacking social participation) is further recognised in Article 30 (4) on Participation in cultural life, recreation, leisure and sport through an entitlement to recognition and support of "their [persons with disabilities'] specific

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[822] Ibid., p. 9.

[823] Ibid., p. 10.

[824] Ibid., p. 40.

[825] The exceptions are Preamble (a- b, w).

[826] Emphasis added.

cultural and linguistic identity, including sign languages and deaf culture". Turning back for a moment to the approaches to disability explored in Part I, this resonates the Social Model of Disability and the Minority Group Model of Disability.

A further indication of a minority view in the CRPD is the recognition in Preamble (g) of the importance of "mainstreaming disability issues". The idea of mainstreaming is not adopted on a level where these *issues* are portrayed as "mainstream", rather "disability issues" should have their place *in* the mainstream, much as 'others' have the issues which concern them there.

Turning now to the universality view, the CRPD also carries features which resonate with this notion. Firstly, Article 4 (1f) on General obligations makes a call for "universal design", which is defined in Article 2 on Definitions as "the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design". This clearly echoes an idea of commonality of needs and solutions among humanity, resonating with the ideological and strategic underpinnings of ICF. However, this very definition goes on to emphasise the complementary view of such design through noting that ""[u]niversal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed". The definition of "[u]niversal design" is furthermore preceded in Article 2 by the definition of "[r]easonable accommodation", which is defined as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms". This context of the reference to "[u]niversal design" indicates that it amounts to one of many ways of realising the rights of the group in view, namely "persons with disabilities", who remain the centre of gravity.[827]

Secondly, Article 3 (d) on General principles emphasises everyone's commonality as human beings, calling as it does for "[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity". Still, 3 (d) does not make connections with others by expanding the relevance of impairment or restricted composite life opportunities to all of humanity but rather appears limited to securing a place for the constituency of the CRPD next to 'others' under the umbrella concept of "humanity".

Additional question marks regarding whether the CRPD can be said to espouse a universality view actualises what is *not* included therein. Firstly, it contains no general gesture towards a universality view in the space accorded for such visionary, ideological and principled statements: the Preamble, Article 3 on General principles

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[827] Compare also the phrasing of the obligation to apply the principle of universal design in Article 4 (f), obliging the State "[t]o undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines".

or Article 8 on Awareness-raising.[828] As mentioned above, a minority view is the default position in discourses on disability and so a wish to communicate a universality view would arguably have necessitated express recognition. Another feature the absence of which is indicative is ageing. In addition to not recognising in a principled manner any overlap in legitimate concerns either with existing older persons or with everyone as potential older persons, the CRPD contains only two references to older persons and these amount to recognitions of intersectionality rather than to explicit emphasis on overlap.[829] While the overlap of old age and forming part of the constituency of the CRPD was recognised in the negotiations, it only materialised in few actual proposals for text.[830]

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[828] Indeed, Article 8 is phrased as calling for awareness about "persons with disabilities", rather than about "disability". Some language recognising the universal potential for disability was proposed in the negotiations, for example the proposition by Kenya to the 4th session that "States Parties to this Convention shall [...] b) recognize that all ages and any population or group of people can experience disability".

[829] See further below under 10.3.1.3.

[830] See e.g. text proposed for the Draft Preamble during the 4th session, 2004, by Chile: "Noting the worldwide trend towards gradual ageing of the population in a process of demographic transition, recognized by the Madrid International Plan of Action on Ageing, 2002, which affects the increase in the population of older persons and therefore the appearance of disability in that age group.". Only one proposal for a separate article on older persons was submitted. See proposal submitted by El Salvador for an Article 16 (bis) Older Persons with Disabilities at the 7th session, 2006:
"1. State Parties shall undertake actions to ensure that Older Persons with Disabilities can grow older, with dignity and security empowering their own capacity, so that they can participate in their family and community lives, as individuals, with full rights, in equal standing with others.
2. State Parties undertake actions to:
a) Encourage that older persons with disabilities receive a just and dignified treatment, regardless of the presence of a particular disability.
b) Eliminate the differences and discrimination related to age, as far as the provisions of receiving health and rehabilitation services, so that older persons with disabilities can receive the specialized needed attention, in accordance with their disability, in the same manner as other younger persons with disabilities.
c) Generate appropriate conditions to reduce or eliminate the levels of disabilities related to age, promoting an autonomous and independent lifestyle of the older person.
d) Ensure that older persons with disabilities remain in their families and communities, encouraging strategies to promote self-care and the provision of technical assistance and capacity building to their caregivers, in order to guarantee the integration of the older person in their home, without prejudice to their disability.
e) Promote that older persons with disabilities, who remain productive and capable of working, can continue to do so, be it paid or volunteer work, based on their capabilities and without prejudice to age or to their disability
f) Facilitate and promote the establishment of self-help organizations for older persons with disabilities and to their caregivers.". This proposal did not generate general support or even extensive discussion. Australia included a call for attention to older persons in a broader provision ("Article 5bis – Specific Population Groups") proposed at the 7th session, 2006, which met with the same fate:
"Recognition of specific population groups
States Parties shall recognise the particular vulnerability and additional disadvantage of specific population groups of persons with disability, including:
(a) women with disability
(b) children and young persons with disability

Finally, a feature which would have indicated a universality view is the inclusion of a general provision on prevention of impairment, exposing as it would the fact that inclusion in the constituency of the CRPD is potentially universal and the legitimate expectations codified therein therefore of universal concern. As discussed above under 7.1.1. and 8.2. the reasons for not including such a provision hinged upon the negative valuation of impairment it implies, rather than on its implications for universality.[831] However, it is indicative that the arguments in the negotiations against the inclusion of a general obligation to prevent impairment were phrased as that the CRPD should be 'about persons with disabilities'.[832] A related feature is the decision not to explicitly include any references to future impairment or protection against misuse of genetic information.[833] Both these aspects would have served to extend the relevance of the CRPD to all persons as potential acquirers of impairment and would consequently have forwarded a universality view.

In gauging the balance between a minority approach and a universality approach in the CRPD, its function as a legal instrument with the ensuing need to delimit what obligations States are shouldering must be accounted for. As discussed above under 10., taken that the CRPD creates legal obligations for States, it was deemed important to clarify who the CRPD applies to. However, this could have been done through the depiction in Article 1 addressing the phenomena ('disability') rather than who it affects as a group ("[p]ersons with disabilities"). This way, one would not have to 'generally' qualify as a "[p]erson[...] with disabilities" before it could be decided whether the disadvantage experienced amounted to 'disability'. To conclude, on balance the CRPD emerges as a minority rather than universality approach to disability.

10.3. Attention accorded to diversity unrelated to impairment

As discussed in Part I, a critique which has been forwarded towards the Social Model of Disability is to what extent and how attention is accorded to diversity unrelated to impairment within the constituency. Drawing on this critique, the issue here is

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(c) elderly persons with disability
(d) persons with severe and/or multiple disability
(e) persons with disability from racial, ethnic, linguistic, and/or religious minority groups
(f) Indigenous persons with disability, and
(g) persons with disability living in rural, remote and small island communities.
State Parties shall take all appropriate measures, including any special measures, to ensure for these groups the full and equal enjoyment of the rights set out in this convention.". The same proposal was forwarded during the 4th session.

[831] See further below under 12.1.2.

[832] See above under 7.1.1.

[833] See above under 10.1.5.

to what extent and how the CRPD pays attention to the fact that its constituency is heterogeneous by virtue of features unrelated to that which represents the common core and the outer marker of the group according to Preamble (e) and Article 1 ("impairments" and "disability"/"disabilities"). In the following this question will be put to the CRPD as well as to the four approaches to disability explored in Part I. 10.3.1. will focus on the CRPD and in 10.3.2. the focus is on the approaches to disability explored in Part I.

10.3.1. CRPD and attention accorded to diversity unrelated to impairment

The question here is not who is 'in' and who is 'out', but rather how the 'ins' differ among themselves and how this is dealt with in the CRPD. Indeed, this question was subject to much discussion in the negotiations. As a result, the CRPD is the first UN human rights convention which explicitly addresses the role of intersectionality of different forms of human diversity for the nature and extent of disadvantage experienced, as well as for the remedies to such disadvantage. Preamble (p) notes "the difficult conditions faced by persons with disabilities who are subject to *multiple or aggravated forms of discrimination* on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status".[834] Similarly, Article 5 (2) on Equality and non-discrimination obliges States to "guarantee to persons with disabilities equal and effective legal protection against discrimination *on all grounds*".[835]

Two such aspects of diversity, female sex and child status, received the lion's share of attention and are consequently addressed in separate articles: Article 6 on Women with disabilities and Article 7 on Children with disabilities. While it was long undecided whether the best way to address the concerns of these two sub-groups was explicit attention in the form of separate articles, the question how to handle these two groups received continuous attention.[836] The final version of the CRPD pays

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[834] Emphasis added.

[835] Emphasis added.

[836] In his concluding remarks after the 7th session the Chair summarised the "trend in the room" as a call for separate articles but this was not finally settled until the 8th session. Chair's Closing Remarks, 7th Session, 3 February 2006. Some actors, particularly the EU argued throughout the negotiations that explicit attention to sub-groups in the form of separate articles was counterproductive, as it may indicate that such groups are "entitled to fewer rights than others". EU proposal on Draft Article 16 on Children with disabilities, 3rd Session, 2004. For the continued expression of this position see e.g. EU Position on Women and Children in Response to the Joint Facilitator's Proposal, 7th Session, 31 January 2006. Others, particularly Republic of Korea in relation to women, emphasised the need for separate articles. See e.g. Republic of Korea Proposal for Inclusion of a Separate Article, Women with Disabilities, 3rd Session, 27 May 2004. A sign of the centrality accorded women and children in the negotiations, compared to other sub-groups, is that only in relation to these were facilitators assigned to coordinate and develop proposals on how these issues were to be addressed in the text of the CRPD. In addition, already the Working Group

explicit attention to these two aspects both by allocating them separate articles and by including references in additional articles which were seen as particularly relevant to women and/or children.

In addition to these two aspects, old age, rural living, minority and indigenous status, refugee status and sexual orientation were subject to discussion. Out of these, the final instrument includes explicit attention, in varying degrees, to old age, rural living and indigenous status. It should be noted that the CRPD applies to *all* persons with disabilities and that lack of explicit attention does not, per se, mean that particular concerns flowing from any of these aspects are not included under the protection of the CRPD.

10.3.1.1. Children

Article 7 (1) on Children with disabilities expresses its goal as "the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children".[837] In addition to this general assertion, this article contains two specific elements: the principle of "the best interest of the child" (7 (2)) and the right for children to "express their views" and have such views taken into account "in accordance with their age and maturity" (7 (3)). Rather than spelling out the particular situation of children or calling for entitlements in different areas of life, Article 7 thus contains principled statements which apply to the implementation of all rights and freedoms in relation to children. The final version of Article 7 is very different from the one present in the Working Group Draft, which was modelled after Article 23 of CRC and thus contained considerable detail on different forms of care and services.[838]

The difference between the notions in 7 (2) and 7 (3) was discussed at length, noting that as children do not have the same decision-making capacity as adults there is need for those who make decisions on behalf of children to focus on the latter's needs (the best interest of the child). All the while, this essentially paternalistic concept is not an excuse to make decisions on behalf of children where this is not necessary.

Draft contained an article on children, Draft Article 16 on Children with disabilities. Working Group Draft, 2004, pp. 20-21.

[837] This equality provision sets its standards against that of *other children*, i.e. the basis for comparison intended is that of different levels and modes of functioning of the body and mind. In addition, States are according to Article 5 (2) on Equality and non-discrimination obliged to "guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds". As Preamble (p) explicitly recognises "age" as such a prohibited ground for discrimination it is left open if a standard can also be set by comparing the enjoyment of rights by children with disabilities to that of adults with disabilities. Although such a comparative framework is not habitually used to express the claims of children, but rather the claims of older persons, this possibility cannot be excluded. Indeed, the insertion of "age" in what became Preamble (p) was explicitly called for on behalf of children. See intervention by Sierra Leone during the 3rd session. Daily Summaries 4 June 2004, 3rd Session.

[838] Draft Article 16 on Children with disabilities, Working Group Draft, 2004, pp. 20-21. Preamble (r) of the final text of the CRPD emphasises the obligations flowing from CRC as a whole.

Instead children's own views should as far as possible guide decisions affecting them (the right to express ones views and for these to be given effect in accordance with the evolving capacities of the child).[839] The emphasis on the second aspect is visible from its inclusion in Article 3 on General principles; 3 (h) requires "[r]espect for the evolving capacities of children with disabilities" rather than affirms the principle of 'the best interest of the child'.[840]

On a collective level, the requirement to consult the constituency in Article 4 (3) on General obligations was extended during the 7th session to explicitly mention children. After the 7th session, it calls for the consultation and active involvement of "persons with disabilities, including *children with disabilities*, through their representative organization" in all issues relating to disability.[841] The agency of children, here in relation to the implementation of rights, is furthermore explicitly recognised in Article 13 (1) on Access to justice which calls for "age-appropriate accommodations, in order to facilitate their [persons with disabilities] effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages".[842]

A number of other articles in the CRPD address particular situations relating to children. Two sometimes overlapping main themes are discernible: protection of the life, integrity and identity of the child and the interdependence between the child and his or her family. The former theme is part of Article 3 (h) on General principles which requires "respect for the right of children with disabilities to preserve their identities" as well as Article 18 (2) on Liberty of movement and nationality requiring registration "immediately after birth" and the right to a name and to acquire a nationality. The call for registration was made against the background of negative perceptions of impairment and life with impairment leading to the murder of children with disabilities. Registration was forwarded as insurance towards this occurring with impunity.[843] This theme is expressed further in Article 16 on Freedom from exploitation, violence and abuse, which repeatedly calls for "age" sensitivity in relation to all measures to prevent, protect from, investigate and prosecute such exploitation,

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[839] See e.g. Daily Summaries 30 January 2006, 7th Session, particularly interventions by Costa Rica and IDC.

[840] For an account of the attitudinal as well as material challenges to the effective and meaningful implementation of these principles see Byrne, Bronagh, Minding the Gap? Children with Disabilities and the United Nations Convention on the Rights of Persons with Disabilities [hereinafter Byrne, 2012], in Freeman, Michael (Ed.) Law and Childhood Studies: Current Legal Issues Vol. 14, Oxford University Press, Oxford, 2012, pp. 427-431.

[841] See CRPD Working Text after 7th Session, 2006, p. 10. Emphasis added. This formulation remains unchanged in the final version of Article 4 (3).

[842] Although "age-appropriate" was consciously chosen over "child-appropriate" this was done to include considerations of older persons as well and not to exclude considerations in relations to children. The latter group was the original concern of this reference. Daily Summaries 1 February 2006, 7th Session.

[843] See justification by IDC accompanying this proposal during the 7th session. IDC suggested it be placed in Draft Article 12 on Equal recognition as a person before the law. IDC Amendments to Chair's Draft, 7th Session, p. 28.

violence or abuse.[844] In addition, Preamble (q) mentions "girls" as "at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation".[845] Children are also explicitly mentioned in relation to a particular form of abuse: sterilisation. Article 23 (1c) calls for "effective and appropriate measures […] to ensure that: […] [p]ersons with disabilities, including children, retain their fertility on an equal basis with others". The explicit inclusion of a reference to children here was added during the 7th session, based on concerns that general requirements of consent do not automatically apply in relation to children as parents have the, albeit not unlimited, right to make medical decisions on behalf of their children.[846] While this provision does not outlaw sterilisation as an effect of therapeutic medical procedure, the abuse of such procedures in the interest of others (including parents) and against the will or interest of the child is now put up against an explicit recognition of the value of fertility for children with disabilities "equal" to that of other children. Further in relation to the future parenthood of children with disabilities, Article 23 (1b) calls for "*age-appropriate* information, reproductive and family planning education".[847]

The second discernible theme in the attention paid to children in particular provisions of the CRPD is the centrality of family to children. Article 18 (2) reiterates CRC by stipulating, for children with disabilities, "as far as possible, the right to know and be cared for by their parents".[848] In view of the disproportionate risk for children with disabilities of being deprived of not only a good family life, but any family life, Article 23 (3-5) on Respect for home and the family also addresses this issue. Article 23 (3) requires States to "ensure that children with disabilities have equal rights with respect to family life". It further requires States to "provide early and comprehensive information, services and support to children with disabilities and their families" in order to "prevent concealment, abandonment, neglect and segregation". The family is thus to be primed for and assisted in catering for its children

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[844] While these references should be read as covering all ages, including old age, the emphasis during the negotiations was on the situation of children; indeed they came from a proposal from the facilitator for children's rights. Proposal from Facilitators on Women and Children [hereinafter Facilitators Proposal Women and Children, 7th Session], 7th Session, 28 January 2006, p. 4. Article 16 (5) does not use the general expression "age" but explicitly calls for "child-focused legislation and policies" in relation to identification, investigation and prosecution of abuse.

[845] The only other two reference to "girls" as opposed to "children" are in Article 6 on Women with disabilities, recognising that "women and girls with disabilities are subject to multiple discrimination" and in Article 28 (2b) on Adequate standard of living and social protection which highlights the access of "women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes".

[846] See e.g. IDC Response to the Facilitator's Proposal on Children [hereinafter IDC Response to the Facilitator's Proposal on Children, 7th Session], 7th Session, 22 January 2006, p. 7, para. 8 (source not paginated). IDC here proposed the addition of a prohibition on the sterilisation of children to Draft Article 25 on Health. See further below under 12.1.4.

[847] Emphasis added. As biology would indicate, this amendment was called for with younger rather than older person in mind. See e.g. record of intervention by the US. Daily Summaries 23 January 2006, 7th Session.

[848] CRC Article 7(1).

with disabilities. Article 8 (1a) on Awareness-raising emphasises “the family level” as the target of such efforts, including efforts aimed at “foster[ing] respect for the rights and dignity of persons with disabilities”.

While Article 23 (3) thus obliges the State to be a positive force towards children with disabilities enjoying family life, 23 (4) implicitly recognises the occurrence of the opposite situation, where the State with force separates the child with disabilities from his or her family. In this regard, 23 (4) stipulates general safeguards such as legality, judicial review and that such separation is “necessary for the best interest of the child” and adds that such separation may never be “on the basis of a disability of […] the child”. While 23 (3) aims at keeping the child with a disability in his or her original family, enjoying a good family life, 23 (5) addresses the situation where this is not doable. Article 23 (5) states that “States Parties shall, where the immediate family is unable to care for the child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting”. In other words, while the original family is the priority, failing this, institutionalisation is not the answer. To conclude, as for children generally in CRC, the value of the family for children with disabilities is flanked by recognition of the potential for abuse. In Article 23 the family qualify simultaneously as the optimal place to be for any child *and* as a potential source of abuse which needs to be controlled and educated. This dual recognition of family as friend and foe is similarly acknowledged in Article 18 (2), requiring as it does registration as insurance not to be killed by, or with the agreement of, one’s family and at the same time calling for “as far as possible, the right to know and be cared for by [...] parents”.

In addition to these two themes, children are singled out in relation to three areas of life: health, education and play. Article 25 (b) on Health emphasises children in relation to access to health services “needed by persons with disabilities specifically because of their disabilities”. Article 24 (2a) on Education stipulates the right to primary and secondary education for children. Finally, Article 30 (5d) on Participation in cultural life, recreation, leisure and sport emphasises the “equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system”. These are all areas central to children: schooling generally focuses on youth rather than later seasons of life, in relation to “early identification and intervention” in 25 (b) those born with impairments are, of course, children and finally, play is inextricably linked to notions of childhood.

All specific regulations of children are expressions of ideas about ‘who children are’ and thus closely related to ideas about children in general and children with disabilities in particular. It is thus interesting to note that Article 8 (1b) on Awareness-raising since the 7th session explicitly includes “those based on […] age” among the “stereotypes, prejudices and harmful practices relating to persons with disabilities” which States are to combat.[849] Article 8 thus requires an ongoing scrutiny of which conceptions about children are valid and which are not.

Finally, Article 31 (2) on Statistics and data collection requires such information to be "disaggregated, as appropriate". Based on the attention paid to children in the CRPD this can be assumed to include an obligation to disaggregate information on children.[850]

10.3.1.2. Women

Like Article 7 on Children with disabilities, Article 6 on Women with disabilities contains general statements which apply to the implementation of all rights and freedoms in relation to the group in question. 6 (1) starts with the recognition of the problem to be addressed, that women and girls with disabilities "are subject to multiple discrimination". It then moves on to demand measures "to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms". 6 (2) also contains a demand for measures, this time towards a goal expressed differently, namely as ensuring "the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention". While these sections appear repetitive, the focus in 6 (2) is more squarely on the *implementation* of the rights in the CRPD and adds the concepts of "full development and advancement" derived from CEDAW Article 3, to which it adds "empowerment".[851]

Like Article 7 on Children with disabilities, Article 6 sets the standard for enjoyment and emphasises the general demand to implement the provisions in the CRPD for the group in question. Unlike the former, the latter explicitly recognises the problematic situation facing those intended ("multiple discrimination") and does not set up particular principles to take into consideration in the interpretation and implementation of rights.

A number of provisions spanning over all areas of life contain general messages similar to that of Article 6, but are formulated to include implicit or explicit references to both sexes, rather than mentioning only women. Preamble (s) calls for "a gender perspective" in all efforts promoting the enjoyment of right and freedoms of persons with disabilities and Article 3 (g) on General principles recognises "[e]quality

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[849] While these references should be read as covering all ages, including old age, the emphasis during the negotiation was on the situation of children; indeed they came from a proposal from the facilitator for children's rights. Facilitators Proposal Women and Children, 7th Session, p. 4.

[850] Earlier drafts included an explicit obligation to disaggregate data according to "age, sex and type of disability". See Draft Article 6 on Statistics and data collection in Working Group Draft, 2004, p. 12. This was later disregarded and consensus was found during the 7th session around the general formulation "as appropriate". Daily Summaries 27 January 2006, 7th Session. Among the three aspects included in the Working Group Draft, only "type of disability" proved controversial. See above under 9.1.12.

[851] For recognition of the heritage from CEDAW, see Chair's Closing Remarks, 7th session, 3 February 2006. The term "empowerment" was included in the proposal on women's rights by the facilitator during the 7th session. Facilitators Proposal Women and Children, 7th Session, p. 1.

between men and women". Article 8 (1b) on Awareness-raising explicitly includes "those based on sex and age" among the stereotypes, prejudices and harmful practices to be combated by States. While these provisions were included primarily with women in mind, their phrasing creates an obligation to pay attention to and remedy situations disadvantaging men with disabilities.

In the remainder of the provisions of the CRPD, references to "women" or "gender" appear only in relation to three areas of life: violence and abuse, health services and social protection and poverty reduction. Article 16 on Freedom from exploitation, violence and abuse obliges States to address "the gender-based aspects" of such instances (16 (1)) by taking measures to ensure the provision of "gender- and age-sensitive assistance and support", that "protection services are age-, gender- and disability-sensitive" (16 (2) and that the environment for recovery, rehabilitation and social reintegration "takes into account gender- and age-specific needs" (16 (4)). States are also obliged to adopt "women- and child- focussed legislation and policies" to ensure that such instances are "identified, investigated and, where appropriate, prosecuted" (16 (5)). While all references but one are to "gender" rather than to "women", the focus in the negotiations was on the heightened risk of abuse for women. Witness to this is Preamble (q), recognising as it does "that women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation". In relation to poverty reduction and social protection, Article 28 (2b) on Adequate standard of living and social protection requires States to take measures to ensure access to such programmes for "in particular women and girls with disabilities and older persons with disabilities". Article 25 on Health requires "health services that are gender-sensitive, including health-related rehabilitation". Again, while the reference is to "gender" rather than to "women", it was envisaged mainly from the perspective of the situation of women.[852]

In relation to monitoring the realisation of the CRPD, Article 31 (2) on Statistics and data collection requires such information to be "disaggregated, as appropriate" and based on the attention paid to women in the CRPD this can be assumed to include an obligation to disaggregate information according to sex.[853] In addition, Article 34 (4) stipulates that the CRPD Committee is to have a "balanced gender representation".

To conclude, provisions such as the Preamble and Articles 3 and 6 call for attention to gender and the particular situation of women with disabilities to be mainstreamed in all action relating to the implementation of the CRPD. Among the provisions of the CRPD dealing with particular aspects of life, gender, particularly in relation to women, is emphasised overwhelmingly the context of abuse, i.e. as victims. The lack of references in relation to e.g. employment, education and political

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[852] This reference originated from Facilitators Proposal Women and Children, 7th Session, p. 2.

[853] As mentioned above in relation to children earlier drafts included an explicit obligation to disaggregate data according to "age, sex and type of disability". See Draft Article 6 on Statistics and data collection in Working Group Draft, 2004, p. 12.

life is curious, particularly against the background of the goal of "empowerment" of women with disabilities in Article 6 (2). Indeed, calls for explicit attention to the situation of women in Article 24 on Education, Article 27 on Work and employment and Article 29 on Participation in political and public life were made throughout the negotiations.[854] The upshot is that while the situation of women is to be considered in relation to *all* the provisions of the CRPD by virtue of e.g. Preamble (s), Articles 3 (f) and Article 6, no visibility is created in relation to these areas of life.

10.3.1.3. Older persons

As opposed to children and women, the situation of older persons is not addressed in a separate article, nor is it given much attention in the CRPD. The only general recognition is in Preamble (p), which explicitly recognises "age" as a prohibited ground for discrimination. Through this recognition, the obligation flowing from Article 5 (2) on Equality and non-discrimination to "guarantee to persons with disabilities equal and effective legal protection against discrimination on *all* grounds" must be assumed to include an obligation to ensure that older persons with disabilities are not subject to discrimination in their enjoyment of human rights and fundamental freedoms.[855]

As mentioned above under 10.2.2., only two provisions explicitly mention older persons. Article 25 (b) on Health emphasises "children and older persons" in relation to access to health services "needed by persons with disabilities specifically because of their disabilities" and Article 28 (2b) on Adequate standard of living and social protection requires States to take measures to ensure access to social protection programmes and poverty reduction programmes for "in particular women and girls with disabilities and older persons with disabilities". These references to older persons were present already in the Working Group Draft.[856]

As mentioned above in relation to children, Article 8 on Awareness-raising, Article 13 (1) on Access to justice, Article 16 on Freedom from exploitation, violence and abuse and Article 23 (1b) on Respect for home and the family call for attention to

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[854] The call for attention to women in relation to employment is visible from the Working Group Draft. Draft Article 22 on Right to work contains a footnote to the effect that some members called for explicit attention to "the special circumstances of women with disabilities in fulfilling this right". Working Group Draft, 2004, p. 28, note 87. Such calls continued throughout the negotiations, see e.g. Daily Summaries 1 February 2006, 7th Session. Similar calls were made in relation to education and political participation, see e.g. Ibid. The draft after the 6th session contained a reference to "on a basis of equality between men and women" in relation to "participation in public affairs". 6th session Report by the Chairman, 2005, pp. 13-14, para. 61.

[855] Emphasis added. Article 5 is not explicitly limited to the rights and freedoms recognised in the CRPD. See above under 7. The addition of "age" to what became Preamble (p) was done after a well supported proposal by Canada during the 7th session. Daily Summaries 2 February 2006, 7th Session. See Draft Preamble (n) of CRPD Working Text after 7th Session, p. 7.

[856] See Draft Article 21(e) on Right to health and rehabilitation (referring to "the elderly"), Working Group Draft, 2004, p. 26. See Draft Article 33 (1b) on Social security and an adequate standard of living (referring to "the aged"), Ibid., p. 29.

"age" in their implementation. While these references were discussed largely with reference to children, it was noted in the negotiations that a neutral reference to "age" as opposed to a reference to children allowed for coverage of older persons as well.[857]

Finally, Article 31 (2) on Statistics and data collection requires such information to be "disaggregated, as appropriate" and age, including old age, is a contender as such an "appropriate" category, albeit more based on the actual overlap between old age and "impairment" as understood by the CRPD than because of the attention paid to old age in the CRPD.[858]

While the upshot remains that *all* rights in the CRPD are to be implemented on the conditions of *all* persons with disabilities, including older persons, the fact remains that there is little visibility and even less elaboration within the CRPD of the particular challenges facing older persons with disabilities.[859]

10.3.1.4. Persons living in rural areas

Three provisions of the CRPD call for explicit attention to persons living in rural areas. Article 9 (1) on Accessibility makes as general call for accessibility to be provided "both in urban and rural areas" and Article 25 (c) on Health and Article 26 (1b) on Habilitation and rehabilitation calls for services to be provided "as close as possible to [persons with disabilities] own communities, including in rural areas". These references were added late in the negotiations; the ones in Articles 25 and 26 were based on support during the 6th session[860] and the one in Article 9 was based on support during the 7th session.[861]

These three provisions are limited in their scope, as they address only accessibility, health and (re)habilitation services. They are not flanked by any general provision calling for attention to rural areas in the implementation of the CRPD. This as a

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[857] See e.g. intervention by the US during the 7th session calling for the retention of a reference to "age-appropriate" as opposed to "child-appropriate" accommodations in Draft Article 13 on Access to justice for this reason. Daily Summaries 1 February 2006, 7th Session. See also intervention by Australia during the 7th session calling for retaining references to "age sensitive" as opposed to "child sensitive" measures for this reason. The latter kind of references were present in the Facilitators proposal under discussion in relation to Draft Article 16 on Freedom from violence, exploitation and abuse and Draft Article 39 on Reporting by States Parties. See Ibid. and Facilitators Proposal Women and Children, 7th Session, pp. 4-5. As mentioned above in relation to children, the reference in Article 23 (1b) to "age-appropriate" education and information on reproduction and family planning does not seem to hold relevance for older persons.

[858] As mentioned above in relation to children and women earlier drafts included an explicit obligation to disaggregate data according to "age, sex and type of disability". See Draft Article 6 on Statistics and data collection in Working Group Draft, 2004, p. 12.

[859] For proposals on older person see note 830, Part II, above.

[860] See note of such support in 6th Session Report by the Chairman, 2005, p. 18, para. 89. Following this, references are included in Draft Article 25 on Health and Draft Article 26 on Habilitation and rehabilitation in Chair's Draft, 7th Session, 2005, pp. 28-29.

[861] See particularly intervention by Mexico in relation to Draft Article 9 on Accessibility during the 7th session. Daily Summaries 16 January 2006, 7th Session. A reference to "both in urban and in rural areas" was then added to Draft Article 9 (1) in CRPD Working Text after 7th Session, 2006, p. 12.

reflection of the relatively low level of attention paid to this aspect in the negotiations.[862]

Article 31 (2) on Statistics and data collection requires such information to be "disaggregated, as appropriate". One argument which can be put forward towards the inclusion of persons living in rural areas in this obligation is that the CRPD, through the three articles mentioned above, recognises the importance of this group.

The upshot remains that *all* rights in the CRPD are to be implemented for *all* persons with disabilities, including persons living in rural areas. However, as services are often centralised a general recognition of obligations in relation to this group and/or recognition in relation to services other than those in the areas of health and rehabilitation would have created important visibility.

10.3.1.5. Persons of indigenous origin

The only explicit recognition of persons of indigenous origin is as a prohibited ground for discrimination in Preamble (p). Through this recognition, the obligation flowing from Article 5 (2) on Equality and non-discrimination to "guarantee to persons with disabilities equal and effective legal protection against discrimination on *all* grounds" must be assumed to include an obligation to ensure that persons with disabilities of indigenous origin are not subject to discrimination in their enjoyment of human rights and fundamental freedoms.[863] Little attention was paid to this group during the negotiations and the insertion of the reference in Preamble (p) was a last minute addition during the 8th session.[864]

Article 31 (2) on Statistics and data collection requires such information to be "disaggregated, as appropriate". One argument which can be put forward towards

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[862] Some proposals were however made, notably one by Australia, forwarded during the 4th and the 7th sessions on "Recognition of specific population groups". It included as one such group "persons with disability living in rural, remote and small island communities" and called for "all appropriate measures, including any special measures, to ensure for these groups the full and equal enjoyment of the rights set out in this convention". See the entire proposal in note 830, Part II, above.

[863] Emphasis added. As noted above under 10.3.1.3. Article 5 is not explicitly limited to the rights and freedoms recognised in the CRPD. See further above under 7.

[864] Some proposals were however made, notably one by Australia forwarded during the 4th and the 7th sessions on "Recognition of specific population groups". It included as one such group "Indigenous persons with disability" and called for "all appropriate measures, including any special measures, to ensure for these groups the full and equal enjoyment of the rights set out in this convention". See the entire proposal in note 830, Part II, above. IDC emphasised the situation of indigenous persons towards the end of the negotiations. In addition to the reference included in Preamble (p) they suggested the insertion of a new paragraph (g) in Draft Article 4 on General obligations: "To take all appropriate measures to eliminate discrimination on the basis of disability by indigenous, tribal, ethnic or cultural minorities and protect their rights and interests.". In addition, IDC called for the insertion of a requirement for "adequate representation of national, ethnic, indigenous, and minority groups" on the independent monitoring mechanism envisaged by Draft Article 33 on National implementation and monitoring. IDC Amendments to CRPD Working Text, 8th session, pp. 7, 15 and 55. The final inclusion of "indigenous [...] origin" in Preamble (p) was ultimately based on a proposal by Venezuela. See Schulze, 2010, p. 30.

the inclusion of persons of indigenous origin in this obligation is that the CRPD, through Preamble (p), recognises the importance of this group.

As repeatedly mentioned, meagre explicit attention does not mean that the CRPD does not apply in full. However, lacking visibility and recognition in key areas such as cultural rights arguably increases the distance to the actual fulfilment of such rights.[865]

10.3.2. Attention accorded to diversity unrelated to impairment in ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability in light of the CRPD

In Part I of this book, this issue was addressed in relation to the Social Model of Disability. Critique of the Social Model of Disability held it had served to sideline issues important to persons experiencing disadvantage based on grounds additional to Impairment such as sex, ethnicity or age. In the following, this question will be put to all four approaches to disability explored in Part I.

Beginning with UPIAS, they draw parallels with oppression experienced in connection with forms of diversity other than Impairment. UPIAS mention "people who are middle-aged or elderly, who have had break-downs, or are mentally handicapped, black, ex-prisoners, unskilled workers etc".[866] While common concerns and strategies are noted, the intersection of such forms of diversity *in individuals* is not addressed. Instead these groups are referred to by UPIAS as if they were 'parallel' to the constituency of UPIAS. Within this parallel approach, the omission of references to women and children stands out in comparison with the CRPD. As noted above under 3.7.2., Michael Oliver recognised in 1996 that "it is certainly true that the social model of disability has not explicitly addressed the issue of multiple oppression", but held that this was never part of a conscious policy, but rather a sign of the times.[867] Indeed, Oliver addresses the issue in the book where these statements are made, as well as in both previous and subsequent work.[868]

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[865] Compare proposal by IDC during the 7th session for the addition of a new section 4 bis to Draft Article 30 on Participation in cultural life, recreation, leisure and sport: "States Parties recognise the right of indigenous persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that indigenous persons with disabilities have the same cultural rights and access as non disabled indigenous people to their cultural and spiritual activities and practices.". IDC Amendments to Chair's Draft, 7th Session, p. 62 (source not paginated).

[866] UPIAS, 1974, para. 5.

[867] Oliver, 1996, p. 39. See also Oliver and Campbell, 1996, p. 132.

[868] Oliver, 1996, p. 51. Oliver notes here, in relation to sex, sexual orientation and ethnicity (with reference to Jenny Morris and Ossie Stuart) the emergence of "a conceptual framework which allows such experiences [of people who are part of more than one oppressed group] to be seen as simultaneous oppression". Oliver also addresses this issue in relation to research (Ibid., pp. 142-143) and collective organisation (Ibid., p. 151). In Oliver, 1990, pp. 70-77, he addressed the intersectionality of disability, gender and ethnicity. In Oliver, 2004, p. 23, he addresses criticism

Turning to the Minority Group Model of Disability, in the texts covered by this study, Harlan Hahn does not display a focus on the intersectionality of different forms of human diversity. He notes however that impairment is not the only aspect shaping needs or the likelihood of having needs fulfilled:

> The environment has always seemed to be created for a mythical human being who is not only devoid of any disabilities; but also a male, not a female, at the peak of his physical powers.[869]

Hahn thus makes analogies and calls for alliances with other groups in relation to causes of disadvantage (e.g. with women in opposing rigid rules of beauty) as well as solutions to such disadvantage (e.g. the use of devices such as ‘Black is beautiful’).[870] This definition of common concerns and strategies does not however amount to recognition of intersectionality of forms of human diversity *among* the constituency of the Minority Group Model of Disability.

Turning to ICIDH, among the forms of diversity mentioned in the CRPD, the former pays repeated attention only to age, through recognising the overlap of its constituency and older persons several times in passing.[871] Generally, the answer to the question what amounts to a restricted composite life opportunity in the individual case is relative to attitudes about diversity, as Handicap only is present if disadvantage relates to a role “that is normal (depending on age, sex, and social and cultural factors) for that person”.[872] ICIDH is thus relative towards social expectations in relation to e.g. sex. To illustrate, if a woman is not expected to have employment outside the home, then the fact that a woman who is covered by the ICIDH scheme by virtue of Impairment or Disability is thusly hindered does not constitute a Handicap (as it would for a man). From this it can be concluded that ICIDH does recognise the effect of intersectionality of different forms of human diversity for the *expectations* on what an individual will be expected to do, as well as the possibility of doing it, but stays silent on any problematic aspects of such expectations and their effects. By seeking to isolate the variable of ‘health’, disadvantaging ideas based on other forms of diversity thus remain outside the picture. Perhaps this is not so curious against the background of the Handicap concept uncritically accepting expectations on individuals in relation to ‘health’ and attitudes not being registered as determinants of the manifestation of Handicap (as it is a feature extrinsic to the person). In addition, further illustrating an uncritical acceptance of attitudes to di-

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through noting the potential of the Social Model of Disability relating to this issue: “[C]riticism of the social model states that it is unable to incorporate other social divisions, e.g. ‘race’, gender, ageing, sexuality and so on. The fact that the social model has not so far adequately integrated these dimensions does not mean that it cannot ever do so. In my view it is not that the social model cannot cope with these issues. Far better, if the critics had spent less of their time criticising the social model for its perceived failures and instead put more effort into attempting to apply it in practice.”.

[869] Hahn, 2001, p. 70.

[870] See Hahn, 1988, and Hahn, 1996, p. 55.

[871] See WHO, 1980, e.g. pp. 37, 40, 196.

[872] Ibid., p. 183.

versity, “homosexuality”[873] is explicitly pathologised and likewise is the act of “passing”, exemplified by “black passing for white” without further notice of the problems tied to ideas of and indeed social privileges connected to ‘passing’.[874]

ICF, being of a later date, does not repeat these examples. Furthermore, it draws attention to diversity among its constituency by recognising Personal factors as a causal component of Disability. Personal factors are defined as “the particular background of an individual’s life and living, and comprise features that are not part of a health condition or health states”.[875] The manual provides the following examples for illustration:

> These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level.[876]

While the importance of intersectionality of different forms of human diversity and situations among the constituency of ICF is thus recognised, it is not part of the classification scheme of ICF and not much attention is devoted to it in the manual. The importance of these factors in the application of ICF is not stressed, instead the assessment of personal factors is “left to the user, if needed”.[877] In contrast to this stands the development by WHO of a version of ICF adopted to children and youth, ICF-CY. The manual of ICF-CY, in addition to its development per se, indicates the importance of age for analysing Disability:

> The manifestations of disability and health conditions in children and adolescents are different in nature, intensity and impact from those of adults. These differences need to be taken into account so that classification content is sensitive to the changes associated with development and encompasses the characteristics of different age groups and environments.[878]

In ICF, the existence of a restriction of life opportunities emerges through a comparison with “that which is expected of an individual without disability in that culture or society”.[879] Compared to ICIDH, by referring to “an individual”, the Personal

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[873] Ibid., p. 62.

[874] Ibid., p. 149.

[875] WHO, 2001, p. 17.

[876] Ibid.

[877] Ibid., p. 19.

[878] WHO, 2007, p. vii. More precise, ICF-CY “expands the coverage of the main ICF volume by providing specific content and additional detail to more fully cover the body functions and structures, activities and participation, and environments of particular relevance to infants, toddlers, children and adolescents”. Ibid., p. viii.

[879] WHO, 2001, Annex 1 Taxonomic and Terminological Issues, p. 213.

factors recognised in ICF thus do not explicitly make relative *what* restricted life opportunities qualify as a problem for whom.

This section on diversity among the constituency of the CRPD concludes this chapter on who the CRPD covers. This chapter and the preceding three chapters have posed the four questions comprising the analytical framework of this book to the CRPD and has contrasted the answers solicited with those solicited in Part I through posing the same questions to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability there. In the following chapter closing Part II of the book, the main strands of this comparison will be brought out with a particular focus on the correspondence between these approaches and the CRPD in terms of what entitlements they protect and for whom.

11. Concluding comparison of the CRPD to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

In this chapter the main strands of the comparison between the CRPD and the approaches to disability explored in Part I are brought out (11.2.). In the Introduction to this book two main points of contention between these approaches were advertised and in Part I the contours of these were chiselled out. The first one concerns the balance between approaching and forwarding impairment as a valuable form of diversity to be embraced *and* providing entitlements connected to the prevention, minimisation and elimination of impairment. The second one concerns the balance between attributing the causes of and directing the solutions to restricted involvement in different life contexts to the environment alternatively to the impairment. Corresponding to these, the provisions of the CRPD focused on in 11.2. in particular are Preamble (m), Article 3 on General principles, Article 25 on Health and Article 26 on Habilitation and rehabilitation. Before this summarising account, the meaning attributed to the two approaches most visible in the negotiations of the CRPD (the Social Model of Disability and ICF) is explored (11.1.).

11.1. References to and understanding of the Social Model of Disability and ICF in the negotiations of the CRPD

Among the four approaches to disability explored in Part I, two figured explicitly in the negotiations of the CRPD: the Social Model of Disability and ICF.[880] Occasional proposals mirrored closely components of ICIDH and the Minority Group Model of Disability but did not explicitly refer to these.[881] No explicit reference to any of these approaches was included in the CRPD, albeit proposals to that effect were made concerning ICF and the "social model".[882]

The discussion on ICF ranged from proposals and interventions demonstrating knowledge of the approach[883] to others who did not, by inter alia confusing it with ICIDH.[884] IDC remained negative to ICF, positing during the 7th session that "ICF is a very controversial definition of disability that many disability organizations do not accept".[885] The explicit arguments against ICF concerned assumptions that it would be unduly excluding, that "the use of the ICF definition would imply the risk

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[880] These were mentioned in the Working Group Draft in relation to defining disability: "Some members were of the view that no definition of 'disability' should be included in the convention, given the complexity of disability and the risk of limiting the ambit of the convention. Other delegations pointed to existing definitions used in the international context including the World Health Organization's International Classification of Functioning, Disability and Health (ICF). There was general agreement that if a definition was included, it should be one that reflects the social model of disability, rather than the medical model.". Working Group Draft, 2004, p. 10, note 12.

[881] International Disability Alliance called for "[r]ecognition of people with disabilities as a minority" noting that "[b]ecause people with disabilities are not recognized as an insular discrete minority they are foreclosed from democratic processes". Compilation of Proposals before the Working Group, 2004, p. 98. In a record of an intervention during the 7th session, Jamaica enumerated the components of ICIDH (Impairment-Disability-Handicap) but labelled this as ICF. Daily Summaries 31January 2006, 7th Session. Australia is recorded as doing the same, however labelling these components as constituting "the social model of disability". Ibid.

[882] Columbia as well as WFDB proposed during the Working Group that the CRPD explicitly reference ICF as its framework for defining disability. Daily Summaries 13 January 2004, Working Group Session. Landmine Survivors Network (LSN) is recorded, also during the Working Group session, as calling for the Preamble to "include mention of the social model and rights based approach to disability". Ibid. India proposed during the 3rd session that the CRPD should note as a general principle that ""the social model would be preferred over medical model."". Daily Summaries 24 May 2004, 3rd Session. Serbia and Montenegro is recorded during the 7th session as suggesting that the CRPD "include[…] a reference to the ICF classification or the social model approach of disability, possibly in the preamble". It is notable that Serbia and Montenegro saw the need to clarify this statements later in the discussions with that "when it proposed including ICF specifications in the preamble it intended to include elements from the social model of disability as well". Daily Summaries 31January 2006, 7th Session.

[883] See e.g. proposal for the 3rd session by Adaptive Environments, Contextual Bases for Integrating Universal Design into the U.N. Convention on Persons with Disabilities, 3rd Session, May 2004, p. 2. Naturally, this category includes the proposals by the WHO. See WHO Submission ICF, 8th Session, and WHO Position Statement on Working Group Draft, 3rd Session, p. 2 (source not paginated). See also proposal by Chile quoted above under 10.1.1. referenced in note 715, Part II.

[884] See recorded intervention by Jamaica during the 7th session, referenced just above in note 881, Part II.

[885] Record of intervention by IDC. Daily Summaries 31 January 2006, 7th Session.

of leaving certain groups of disabled people out".[886] This proposal does however not specify further why ICF is perceived as carrying this risk, nor was this to my knowledge elaborated elsewhere in the negotiations.

References to the "social model" of disability were considerably more common in the negotiations. These numerous references to the "social model" (and sometimes to a social "perspective"[887] or a social "approach"[888]) taken together with that doctrine next to uniformly hails the CRPD as encapsulating the 'social model' of disability[889] and that the CRPD Committee calls for the implementation efforts of States to reflect it[890] leads to the question of how the 'social model' of disability was understood in the negotiations; what meaning or meanings were attributed to it? What do these references bring out as the core of the 'social model' of disability and do they point to a common understanding? References to the "social model" in the negotiations served a number of functions, including it being called upon as the prospective blueprint for the depiction of "disability"/"[p]ersons with disabilities" which ended up in Preamble (e) and Article 1 on Purpose. It was repeatedly suggested that such depictions should reflect the "social model" of disability, often opposed to the "medical model".[891] In addition, the authority of the "social model" was often called upon in support of or as a weapon against particular obligations, entitlements or phrasings. Most references to the "social model" did not specify further what they meant by the "social model", however some interventions did provide such accounts. A representative such account is the following from PWDA et al.:

> The main tenet of the social model is that, while people may be limited by impairment, it is society that disables people, by establishing and maintaining institutional, social and physical barriers to access and inclusion with society. The social model places the 'problem' of disability in the social environment, rather than in the 'pathology' of the individual. Its action implication is social change rather than personal cure.[892]

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[886] EDF Position Paper on the Draft International Convention Text from the Working Group [hereinafter EDF Position Paper on Working Group Draft, 3rd Session], 3rd session, April 2004, p. 5.

[887] See e.g. Ontario Human Rights Commission, Comment on the Draft Convention [hereinafter Ontario Human Rights Commission, Comment on the Draft Convention, 3rd Session], 3rd session, 15 April 2004, p. 3.

[888] See e.g. record of intervention by Guatemala during the 4th session. Daily Summaries 23 August 2004, 4th Session.

[889] See below under 11.2.5. and 12.3.3.

[890] See below under 12.3.2.

[891] On the topic of defining "[d]isability" the Working Group noted that "[t]here was general agreement that if a definition was included, it should be one that reflected the social model of disability, rather than the medical model". Working Group Draft, 2004, p. 10, note 12. General agreement on this issue is recorded as late as during the 8th session by the Korean Chair (appointed by the Chair of the Ad hoc Committee) of a structured Informal discussion on a definition of disability 17 August 2006. IDC Report from Informal on Definition of Disability, 8th session.

[892] Contribution in Relation to Definitions by PWDA, AFDO, and NACLC, 4th Session, 23 August 2004, p. 3. Compare the very similar account of the "social model" by Costa Rica quoted below under 11.2.3. referenced in note 920, Part II.

The essence of the "social model" is thus that it is barriers external to the person which hinder the enjoyment of composite life opportunities and that efforts should focus on such barriers.[893] This understanding of the "social model" led to suggestions by some that it could not be the sole basis for a definition of disability. Australia noted in the 4th session that "[t]he social model of disability is important, but disability seen purely as a function of the environment would render a definition unworkable".[894] The cause for concern was the need for a definition to implicate who it covered, which was seen as necessitating a connection to impairment.[895] An additional concern expressed was that the "social model" limited *relevant* barriers to those external to the person and that this did not sufficiently cover the requirements of the constituency:

> Australia cautioned that a strict social model approach may lead to the interpretation that, once the barriers created by society are removed, the state has no further obligation toward the person with a disability.[896]

In other words, impairment as such creates requirements which cannot be conceptualised as generated by social barriers. As the scope of the "social model" is understood as limited to the effects of such barriers, reliance on the "social model" would mean that requirements relating to impairment would not be protected under the CRPD.

The "social model" was also attributed the opposite function, as providing insurance against exclusion of a particular segment of the constituency, namely persons with psychosocial disabilities. This group is commonly excluded from the disability platform by virtue of it being perceived as having an 'illness' ("mental illness") rather than impairment. The reasoning was that the focus of the "social model" on externally imposed disadvantage would illustrate the rightful place of persons with psychosocial disabilities on the platform of disability:

> [IDC] pointed out that many states approach psychosocial disabilities using the medical model approach to "mental illness." This excludes people with psychosocial disabilities from the broader realm of PWD [persons with disabilities] and the protections they enjoy. However, the social model approach recognizes that the stigma, prejudices

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[893] See also recorded statement by Thailand during the 5th session in relation to what became Article 12 on Equal recognition before the law: "It [Thailand] expressed support for the social model of disability, i.e., the idea that society imposes disability upon people.". Daily Summaries 25 January 2005, 5th Session.

[894] Record of intervention by Australia. Daily Summaries 23 August 2004, 4th Session.

[895] Ibid. For the need for both these aspects see also record of intervention by New Zealand during the 7th session: "If a specific definition of disability was to be included, it should reflect the social model of disability, be as broad as possible, and provide a sense of the scope and types of impairments that might be included.". Daily Summaries 31 January 2006, 7th Session. In the same vein, calls were made for the definition of disability to "incorporated elements from both the medical and social models" (record of statement by Syrian Arab Republic, Ibid.), "embrace both social and medical models of disability" (record of statement by Yemen, Ibid.) and "optimally combine both the medical and the social approach" (record of statement by the Chair, Ibid).

[896] Record of intervention by Australia. Ibid.

> and stereotypes associated with people with psychosocial disabilities are themselves very disabling and often lead to violation of their human rights.[897]

Similarly, adhering to the "social model" was called upon as a way of ensuring that persons who did not currently have an impairment covered under the CRPD would still receive protection:

> [T]aking the "social model" into consideration, it is necessary to include the provisions such as "a record of an impairment", "being regarded as having an impairment" and "a disability perceived" into the definition of "disability".[898]

The account of the "social model" by PWDA et al. reproduced above flanks the recognition that the *relevant* problem lies in the environment with recognising that it does *not* lie in the individual. In other words, according to the "social model", though it is not denied that impairment may be problematic this is not relevant and "cure" is discredited as a relevant focus for the realisation of life opportunities. As will be discussed further below under 12.1.2., it is not always clear if the denouncing of "cure" in the name of the "social model" in the negotiations is a whole sale rejection or just the rejection of a misguided focus on "cure" in lieu of other measures or concerns. This juxtaposition of the "social model" and issues of health broadly understood sometimes led the negotiators to carve out a place for the "medical model" as complementing the "social model". Thus, while IDC called for the separation of the right to health from the obligations to provide rehabilitation in order to avoid the "outdated medical model of disability"[899], Israel noted this separation as "an affirmation of the social model combined with the medical model", presumably as the CRPD and indeed Article 26 on Habilitation and rehabilitation itself still called for health interventions.[900] In addition to being juxtaposed with entitlements in the area of health and particularly to "cure", the "social model" was relied upon to discourage according attention to impairment as problematic. For example, Canada opposed the reference to "severe or multiple" impairment in Draft Preamble (m) with reference to that this "echoes a medical model rather than a social model of disability".[901] Others reiterated this critique, but by referring to such references as "medical model" without explicitly juxtaposing the latter with the 'social model'.[902] The critique some-

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[897] Record of intervention by IDC, Ibid. See also similar statement by DPI recorded in the 4th session, albeit here not explicitly mentioning persons with psychosocial disabilities: "DPI rejects any definition of disability that excluded people with disabilities from protection under the convention. Many States do not have working definitions of disability in their legislation and many have definitions grounded in the medical model, that exclude people who face barriers to inclusion in society. States must adopt an understanding of disability that is drawn from the social model.". Daily Summaries 23 August 2004, 4th Session .

[898] JDF Comments on Draft Convention, 3rd Session, p. 6.

[899] See submission by ICD quoted above under 7.1.2. referenced above in note 69, Part II.

[900] Record of statement by Israel during the 6th session. Daily Summaries 8 August 2005, 6th Session.

[901] Record of Statement by Canada during the 3rd session. Daily Summaries 4 June 2004, 3rd Session.

[902] WNUSP is recorded at the 3rd session in relation to Draft Article 23 (1c) as "endorse[ing] deletion from 23.1(c) of "severe and multiple," terms which are based on the medical model in making

times extended to calling attention to the diversity of impairments full stop, i.e. without implicating them as problematic.[903] Over and above the question of *diversity* in terms of impairments, the drive not to pay attention to impairments in general terms was similarly called for in the name of "a social model".[904]

Other discernible senses in which "the social model" was referred to include as the basis for emphasising inclusive as opposed to segregated education[905] and as diminishing the power of professionals over persons with disabilities. In relation to (re)habilitations, the "paradigm shift from a medical model to a social model" was called upon as requiring "that persons with disabilities are not the objects of interventions by professionals, but are empowered to make decisions about their lives and bodies".[906]

To sum up, the core meaning attributed to the "social model" in the negotiations emerges as the direction of the focus to environmental barriers to social participation, *and* that this focus is instead of, rather than a complement to, a focus on impairment. Other themes included ending segregation and safeguarding autonomy and choice vis-à-vis health professionals. These themes all correspond to core themes in the Social Model of Disability as the latter is delineated for the purpose of this book and explored in Chapter 3 above.

In the next section, concluding this chapter as well as Part II, the negotiations are left to the side and a distilled account is provided of the main conclusion from the comparison in Part II between the CRPD and ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability.

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distinctions among PWD [persons with disabilities]". Daily Summaries 3 June 2004, 3rd Session. This was echoed by DPI, who is recorded as "suggest[ing] deleting "severe and multiple disability," which is a medical model concept". Ibid. See also record of similar cautioning by the EU in the same discussion. Daily Summaries 2 June 2004, 3rd Session. WNUSP reiterated this point during the 4th session in relation to the Preamble, noting that "the Preamble should avoid any medical model language, differentiating among PWD [persons with disabilities] or referencing differences in functional capacities". Daily Summaries 23 August 2004, 4th Session. Not all made this connection however. India is recorded during the 3rd session as proposing the two following additions to Draft Article 2 on General principles in the same breath: that "special attention will be paid to the situation of persons with severe and intellectual and multiple disabilities" and that "the social model would be preferred over medical model". Daily Summaries 24 May 2004, 3rd Session.

[903] During the 4th session Mexico is recorded as opposing a proposal made by the Philippines during the 3rd session (amounting to that Draft Article 6 on Promoting positive attitudes to persons with disabilities specify that awareness-raising must cover impairment "in various forms") as "reflect[ing] a medical model perspective". Daily Summaries 1 September 2004, 4th Session. For the Philippine proposal see Compilation of Proposals before the 4th Session, 2004, p. 15.

[904] See quote by PWDA et al. below under 12.1.1. referenced in note 990, Part II.

[905] See CSIE, Paper on Inclusive Education, 5th Session, p. 1: "Article 17 should fully reflect the social model of disability, focusing government obligations on removing the barriers to full participation in education by persons with disabilities. Education of some learners in separate settings because of their disabilities or impairments reflects and perpetuates a view of disability premised on the medical and charity models of disability.".

[906] IDC Statement on Article 26 on Habilitation and rehabilitation, 7th Session, 25 January 2006.

11.2. A distilled comparison of the CRPD to ICIDH, the Social Model of Disability, ICF and the Minority Group Model of Disability

As mentioned above under 6.1., all approaches explored in Part I save ICIDH explicitly call upon if not "human rights"[907] so "rights"[908] as their business. Also, they unite with the CRPD in the aim to profess what 'disability' is and who 'persons with disabilities' are, as well as in the aim to stipulate and aid the realisation of a particular range of entitlements for a particular range of persons connected under the umbrella of 'disability'.

However, irrespective of these common features, it remains that only one of the four approaches to disability explored in Part I gives an unequivocal answer as to the role and value they accord human rights conventions generally. This, at the outset, complicates the task to ascertain to what extent the CRPD is compatible with these approaches. To illustrate, the CRPD amounts to a legal instrument, against which Michael Oliver has expressed both support and clear reservations. Reservations are based primarily on the meagre output of law in terms of increased enjoyment of life opportunities as well as its detrimental impact on the collective organisation of disabled people.[909] While Oliver thus criticises law in general as well as international efforts to codify the rights of disabled people such as the World Programme of Action concerning Disabled Persons (WPA)[910] and the UN Declaration on the Rights of Disabled Persons[911], he simultaneously appears to draw on the authority of these instruments to call for the realisation of the requirements they stipulate.[912] Moving on to the Minority Group Model of Disability, Harlan Hahn began with a strong faith in all things legal but ended up relegating such measures to the back-burner. ICIDH, by contrast, does not take a general position on the wisdom of law, neither national nor international. In contrast to these three approaches, ICF explicitly offers itself as "an appropriate instrument for the implementation of stated international human rights mandates"[913], thus seconding such mandates. In addition, WHO expressed clear support for the drafting of the CRPD and suggested ICF as the basis for its definition of disability.[914] In the following, the question marks outlined here regarding

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[907] See e.g. WHO, 2001, pp. 6, 170, Oliver, 1996, pp. 44, 82, and Hahn, 1987 (source not paginated), p. 16 and Hahn, 1988, p. 31.

[908] See e.g. UPIAS, 1974, paras. 9, 25.

[909] See above under 9.1.1.-9.1.2.

[910] World Programme of Action concerning Disabled Persons (WPA). Adopted by the UN General Assembly 3 December 1982. UN doc: A/RES/37/52.

[911] Declaration on the Rights of Disabled Persons. Adopted by the UN General Assembly 9 December 1975. UN doc: A/RES/3447 (XXX).

[912] See Oliver, 1996. Compare reservation expressed on pp. 119-120 with references to these instruments on pp. 60, 148.

[913] WHO, 2001, p. 6.

[914] WHO Position Statement on Working Group Draft, 3rd Session, pp. 1-2 (source not paginated).

the position of approaches to disability on the role and value of international law as such will be bypassed. The following analysis will focus on to what extent the content of the CRPD, rather than its nature as an instrument of international human rights law per se, resonates with these approaches as they are delineated for the purposes of this book.

As has emerged in the preceding four chapters, the CRPD mirrors features of all these approaches to disability, particularly as these converge on principled positions such as the importance of access to a broad range of composite life opportunities and on General principles of the CRPD such as independence, inclusion and participation. However, the points of divergence identified in Part I of this book mean that the CRPD also must take stances which resonate with some approaches and not others. In the following, a balance will be attempted, drawing out and comparing key features of the CRPD with the approaches explored in Part I, gauging towards which approach these features draw. This is structured through the use of the four questions posed to these approaches above in Chapters 2-5 and to the CRPD above in Chapters 7-10. To conclude, an overall appraisal is made of which features of the CRPD resonate the most with each approach, as well as which features of the CRPD are most alien to each approach.

11.2.1. What is a relevant problem?

Beginning with the question of *what is a relevant problem,* as mentioned just above all approaches recognise the importance of composite life opportunities to their constituencies and have an open-ended approach towards which these may be. While Chapter 7 discussed the comparably low level of attention to domestic life generally in the CRPD as mirroring the Social Model of Disability and the Minority Group Model of Disability, other features discussed such as the focus on life in the mainstream resonate with all approaches.[915]

The issue determining which approach the CRPD mirrors most is rather the question of entitlements to prevention, minimisation and elimination of impairment and the valuation this entails. What then, would each approach want from a human right convention in this regard? Had the framers of ICIDH created Article 25 on Health and Article 26 on Habilitation and rehabilitation, (re)habilitation in general would be subsumed under health in Article 25 and the entitlement to prevention, minimisation and elimination of impairment would be a more detailed, as well as a stronger theme than it is in the CRPD.

Similarly, as evidenced through the interventions by WHO in the negotiations, which were closely related to ICF, this approach would have been compatible with more attention and detail to entitlements to prevent, minimise and eliminate im-

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[915] See above under 7.2.18.

pairment.[916] This is expected as WHO, through ICF and elsewhere, straightforwardly recognises prevention, minimisation and elimination of impairment as a central concern and embraces rather than fears a connection between disability, rights and health.

Gauging what features of Articles 25 and 26 should be seen as supported by the Social Model of Disability and the Minority Group Model of Disability is more difficult. Both these approaches recognise that impairment is seen as problematic by parts of their constituencies, but emphasise that this view is neither universal nor necessary and encourage its opposite, namely celebration and pride. The message is to focus as little as possible on impairment as problematic from disability as a platform for social change, to which the CRPD as an international human rights convention amounts. A convention based on these approaches would arguably be quiet on questions of health and to the extent that it was inevitable to be so, such questions would be addressed with as little weight and detail as possible. As the content of Articles 25 and 26 move from 'care' to 'cure', the distance to these approaches increases. This is so as forwarding entitlements to 'cure' is opposed by virtue of carrying high strategic costs (particularly by drawing attention away from the environment as a target for change) as well as due to forwarding a low valuation of impairment. Even more importantly, the relevance, possibility and desirability of prevention, minimisation and elimination of impairment is questioned by these approaches. By contrast, the principled statements tangent to a positive valuation of impairment in Article 3 (d) on General Principles and particularly Preamble (m) closely resonate with these approaches.

Staying with the generic features of the enjoyment of life opportunities recognised in Article 3 on General principles, by virtue of their generality, many of them resonate with near all approaches. The question remains how far they will stretch when applied to a particular situation, as evidenced in uncertainties as to the outcome of the meaning of autonomy and choice as applied through inter alia Article 12 on Equal recognition before the law.[917] However, each approach connects more closely with some of these principles than with others. For example, equality and non-discrimination is the most visible theme in the Minority Group Model of Disability. If the Social Model of Disability must be attributed one such principle, choice and autonomy arguable emerges as its hall mark. However, this does not detract from its strong focus on accessibility, participation and inclusion and respect for difference and acceptance of diversity. ICF, if one principle has to be chosen, display a core focus on participation and inclusion. Turning the focus around, only one approach, ICIDH, appears incompatible with some of the principles in Article 3. The unquestioned faith in medical professionals as knowing what is best for a consumer of health services seems hard to square with any ideal of autonomy and choice and the immutable character of the environment is similarly foreign to the principle of accessibility, which is key to the CRPD as well as to the remaining three approaches.

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[916] See record of intervention by WHO quoted above under 7.1.1. referenced in note 46, Part II.

[917] See above under 7.1.1., 7.2.3.-7.2.5., 7.2.7. and 7.3.2.

11.2.2. What is a relevant cause of problems recognised?

Moving on to the question what these approaches recognise as *relevant causes* of the problems they identify, the aspect addressed by the approaches to disability explored in Part I as well as by the CRPD is the causality of *composite life opportunities*. As concluded above under 8.2. neither these approaches nor the CRPD focus on the genesis of impairment. In the case of the CRPD, the Social Model of Disability and the Minority Group Model of Disability, this is purposefully so in order not to draw attention to impairment, particularly not as something to be wished away. In the case of ICIDH and ICF their accounts are part of a larger framework by WHO which indeed concerns itself with the causality of impairment, however the focus of these two schemes focus on the situation *after* acquiring an impairment.

Returning to the question of the causality of composite life opportunities, as illustrated in Part I, the balance between impairment and the environment as causes of restrictions of composite life opportunities remains the watershed division between the approaches to disability explored there. As emerged in Chapter 8, the causality of restricted composite life opportunities in the CRPD is inferable both from the depiction of "disability"/"[p]ersons with disabilities" in Preamble (e) and Article 1 on Purpose and from the instrument at large. While Preamble (e) and Article 1 on Purpose recognises both impairment and the environment as causal factors to the restriction of composite life opportunities, the CRPD as a whole gives the environment primacy over impairment. It does not attach any instrumental import to impairment in the provisions regulating particular life opportunities and the core focus of the CRPD remains to implicate the environment in relation to the enjoyment of composite life opportunities. The only two provisions envisaging something else are Articles 25 on Health and 26 on Habilitation and rehabilitation and only 26 explicitly links individual features to enjoyment of composite life opportunities, expressed there as "maximum independence […] and full inclusion and participation in all aspects of life". Article 25, by contrast, creates no link between addressing and altering impairment and the enjoyment of composite life opportunities. Thus, in sum, while the CRPD recognises *both* individual and environmental factors as the causes of restricted composite life opportunities, it accords the latter primacy.

The recognition of both these categories of factors appears incompatible with the Social Model of Disability, which categorically and explicitly delimits relevant causes of restricted composite life opportunities as those residing in the environment. Consequently, while the primacy given the environment in the CRPD reflects concerns of the Social Model of Disability, the former departs from the latter by attributing a causal role to impairment in the restriction of composite life opportunities. To do so in the name of disability on the ideological, political and legal platform to which a human rights convention amounts appears incompatible with the Social Model of Disability. The Minority Group Model of Disability is less categorical in this respect and the fact that the overwhelming focus of the CRPD is on the environment may square it with this approach. In comparison, the recognition of both impairment and the environment as causal factors to the restriction of composite life opportunities reflects the core of ICF. However, ICF explicitly recognises these categories on par and thus the primacy accorded to the environment in the CRPD somewhat qualifies the assertion of absolute compatibility between these in this regard. Finally, the least resemblance appears in the comparison of the CRPD with ICIDH, as the latter categorically depicts the restriction of composite life opportunities as the consequence of impairment only.

Moving on to the balance *between* the two categories of environmental causes of restricted composite life opportunities recognised in Preamble (e), "attitudinal" and "environmental", the CRPD does not explicitly rank these. Each is accorded a particular provision (Articles 8 on Awareness-raising and Article 9 on Accessibility, respectively) and both are addressed in Article 3 on General principles (principles (d) and (f), respectively) as well as throughout the CRPD.[918] Comparing with the approaches to disability explored in Part I of this book which recognise the causal effect of the environment, the Social Model of Disability leans towards the primacy of the barriers addressed in Article 9 on Accessibility and the Minority Group Model of Disability leans towards the primacy of the barriers addressed in Article 8 on Awareness-raising. ICF, like the CRPD, does not accord primacy to either category of causes.

11.2.3. What is a relevant solution to problems recognised?

Turning to the solutions, or measures, envisaged by the CRPD, Chapter 9 above displayed its comprehensive package of such measures. These categories of measures do not generally reflect any major points of divergence between the approaches to disability explored in Part I, however some do. The question of what actors to focus on illustrates a difference between the Social Model of Disability and the Minority Group Model of Disability on the one side and ICF and particularly ICIDH on the other. This is so as the former two approaches see their constituencies as the main drivers of change, while the latter two displays a stronger focus on professionals and policy makers directly. In addition, when the former two approaches address the issue of training of such professionals, they are considerably more critical and suspicious of them, emphasising 'value-proofing' rather than 'know-how', particularly in relation to the health professions. In comparison, the CRPD displays an equally strong focus on professionals and its constituency as delivering the life opportunities envisaged by the CRPD, and as a human rights instrument its primary focus is the State and its function as policy maker and executor of such policy. Statistics and data collection is a further point of at least a diverging focus among these approaches.

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[918] See connections made between Articles 8 and 9 and other provision above under 8.1.2.1. and 8.1.2.2.

It is core to ICF and ICIDH, but is viewed with suspicion by the Social Model of Disability and the Minority Group Model of Disability. However, the CRPD goes some distance towards bridging these differences by proclaiming a strong obligation to collect such data, while simultaneously setting a clear direction towards registering enjoyment of life opportunities and barriers to these, rather than classifying and counting people for the sake of it or for purposes otherwise contrary to the CRPD. In addition, safeguards for privacy and against other forms of abuse are required.

Comparing with the broad range of measures envisaged by the CRPD explored in Chapter 9 above, ICF provides the most comprehensive equivalent, due to its systematic character. Early accounts of the Minority Group Model of Disability display a strong focus on legal and judicial measures, which in later accounts is replaced as a strategy by political measures, particularly, but not limited to, the collective organisation by its constituency. In contrast to the Minority Group Model of Disability and the Social Model of Disability, the CRPD envisages political life as primarily something to be enjoyed by the person, rather than as explicitly instrumental to particular change. A similar observation can be made in relation to the role accorded employment by the Social Model of Disability and its role in Article 27 on Work and employment in the CRPD. Turning to measures on the international level, the Minority Group Model of Disability and the Social Model of Disability were developed in national contexts and do not display a focus on international efforts such as international cooperation and international monitoring of the CRPD, while ICIDH and ICF were created with the aim to aid international cooperative efforts. Tipping the scale back towards the Minority Group Model of Disability in relation to international monitoring is the early focus of this approach on judicial monitoring as a road to change (provided that an adequate understanding of disability underlie such efforts) and tipping the scale further away from the Social Model of Disability is the latter's suspicion towards the "rights industry"[919], particularly if not controlled by collectively organised disabled people. All approaches save ICIDH call (in different words) for universal design and the move away from individualised segregated solutions and services in the realisation of the enjoyment of life opportunities.

ICIDH focuses on medical care and rehabilitation, as measures in their own right as well as instrumental to composite life opportunities. This connects to the main controversy regarding solutions between the approaches to disability explored in Part I, namely the balance between the impairment and the environment as the target for solutions. As noted in Chapter 9 above, the solutions created by the CRPD towards the realisation of valuable life opportunities all but exclusively target the environment as the locus for change. In relation to the creation of *composite life opportunities*, it is only Article 26 which posits solutions targeting the individual (rehabilitation "in the area[…] of health") as instrumental towards such life opportunities ("maximum independence […] and full inclusion and participation in all aspects of life"). All other provisions explicitly aiming at the enjoyment of composite life opportunities

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[919] Oliver and Barnes, 2006, p. 1.

assume impairment as the constant and the environment as the target for solutions. Through, inter alia, law, policy, systems, programmes and services this environment (including the built environment, the organisation and contents of facilities and services and the attitudes and action of others) is to be changed to be conducive to the enjoyment of composite life opportunities. To conclude, the core message flowing from the solutions created by the CRPD is that the environment must change to accommodate human diversity in order to secure the enjoyment of composite life opportunities for all, irrespective of impairment. This focus was the guiding light of the negotiations, as illustrated by the following record of a statement by Costa Rica during the 7th session of the Ad Hoc Committee:

> The most important point was that since this process started there has been a consensus on the fact that the medical model of disability, which looks at disability as a defect or a disease that needs to be cured through medical intervention, has been completely left behind. The model that now prevails is the social model, in which the problem is defined as interaction between the setting in which the person with impairment lives and the person.[920]

This statement is however not entirely representative of the CRPD, irrespective of in which sense it uses "disability" (as signifying impairment *or* restricted composite life opportunities). It does echo the main message of the CRPD in relation to composite life opportunities ("disability" as depicted in Preamble (e)), taken that the CRPD makes very little room for medical intervention as a solution instrumental to composite life opportunities. Still, the solutions in the CRPD targeting composite life opportunities do not *only* focus on the environment after identifying problems in the "interaction" between the person and his or her "setting". It also, through Article 26, creates solutions to composite life opportunities which target impairment.

If the statement above uses "disability" in the sense of levels and modes of functioning of the body and mind, then this statement is even less representative of the CRPD.[921] Articles 25 and 26 call for measures targeting impairment without justifying these (in the case of Article 26, not solely) against the creation of composite life opportunities. As concluded above under 7.1.1.-7.1.3., Article 25 calls for access to solutions amounting to not only 'care' but 'cure' of the impairment by which one qualifies as part of the constituency of the CRPD ("early identification and intervention") as well as "prevent[ion]" of further impairment through health services and through equal access to public health programmes. The end goal of these solutions in Article 25 is conceptualised as "the highest attainable standard of health" and Article 26 (in addition to composite life opportunities) also posits levels and modes of functioning of the body and mind, expressed as "full physical [and] mental [...] ability" as the end of such habilitation and rehabilitation. To close the illustration provided by the statement above, the position described as the "social model" by Costa Rica

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[920] Record of intervention by Costa Rica. Daily Summaries 24 January 2006, 7th Session.

[921] See above under 7. on the dual use of "disability" in the CRPD.

is largely representative of the CRPD as well as of the negotiations. However, it is also unquestionable that in the CRPD, through Articles 25 and 26, the perception of impairment as something "that needs to be cured through medical intervention" has not "been completely left behind". To conclude, Articles 25 and 26 of the CRPD create entitlements to altering levels and modes of functioning of the body and mind for inherent and instrumental purposes for those who so wishes. However, the presumption of the CRPD as a whole remains that any problem in relation to a composite life opportunity primarily and unequivocally implicates the environment.

The question is then the position of the approaches to disability explored in Part I on the CRPD including entitlements to measures targeting the individual as well as the environment and the balance between these. Beginning with the Social Model of Disability, UPIAS recognise the validity and even importance of measures targeting individual levels and modes of functioning of the body and mind through demanding measures such as "medical help" as part of "arrangements […] to participate fully in society"[922] and by demanding interventions to "restore or maintain physical function"[923]. Such measures are thus demanded both as ends in themselves and as instrumental to the enjoyment of composite life opportunities. However, the overwhelming focus of UPIAS is the demand for measures targeting the environment and this includes the endeavour to redirect attention from measures targeting the individual onto measures targeting the environment. The categorical message, notwithstanding the caveats above, is that the political and ideological platform of disability should be used to further such redirection. Michael Oliver continues along the same line, but adds to it an ambivalence towards measures targeting Impairment. He expresses this through reservations to the 'normalising' ideology of interventions targeting the individual (particularly medical ones) and through the call for celebration of Impairment. At the outset, the CRPD, through Articles 25 and 26, forward interventions targeting the individual level and mode of functioning of the body and mind as a politically relevant question to be implemented through law and policy. The lack of a link between Article 25 and the rest of the CRPD however resonates with the mission of the Social Model of Disability, as does the fact that measures targeting individual levels and mode of functioning of the body and mind are compartmentalised in Articles 25 and 26. The link between medical (re)habilitation and the enjoyment of composite life opportunities made in Article 26 does not however rhyme well with the categorical emphasis of the Social Model of Disability on Impairment and Disability as unrelated or on Disability as the proper focus of political and other attention in the public discourse on disability. On balance, however, altering levels and modes of functioning of the body and mind has not by any means been singled out as *the* issue for the constituency of the CRPD. This is just one aspect in an instrument which, like other human rights instruments, is chiefly geared towards changing the environment of the person. In fact, it may be seen as

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[922] UPIAS, 1974, initial paragraph on Aims.

[923] Ibid., para. 14.

doing the same as UPIAS, namely categorically directing the attention to solutions targeting the environment all the while creating certain entitlements targeting individual levels and modes of functioning of the body and mind. In addition, the focus on choice in Articles 25 and 26, recognising that solutions targeting the individual level or mode of functioning of the body and mind are not necessarily acceptable to the person, somewhat addresses concerns put forward by Michael Oliver regarding both the misguided assumption that such measures as a rule are wished for and the imposition of such measures. However, the level of detail in Article 25 and the explicit entitlements to prevent and minimise impairment still remain contrary to the mission of the Social Model of Disability.

Turning to the Minority Group Model of Disability, it likewise questions the desirability and potential of measures targeting levels and modes of functioning of the body and mind drawing towards 'cure' rather than 'care' and emphasises celebration of diversity as a growing and viable alternative. Like the Social Model of Disability, the crucial target for measures is the environment and a major mission is to redirect the focus from measures targeting impairment as intrinsically or instrumentally problematic to measures targeting environmental barriers. The compartmentalisation of measures targeting the individual level or mode of functioning of the body and mind in the CRPD, its overwhelming focus on environmental barriers and the absence of a link to the enjoyment of composite life opportunities in Article 25 thus rhymes well with the Minority Group Model of Disability, as does the emphasis on choice in Articles 25 and 26. In addition, the Minority Group Model of Disability does not press as strongly as the Social Model of Disability that impairment is, or be forwarded as entirely unrelated to the enjoyment of composite life opportunities. Consequently, the former model would have fewer problems than the latter with the linking of these in Article 26. However, the level of detail in Article 25 and the explicit entitlements to prevent and minimise impairment remains contrary to the mission of the Minority Group Model of Disability.

Turning to ICF, it makes a point out of recognising solutions targeting the environment and solutions targeting levels and modes of functioning of the body and mind on par, in the sense that these are of equal urgency and importance. It deliberately avoids taking a position as to if a solution aiming at the enjoyment of composite life opportunities targeting the environment is to be preferred to a solution targeting the individual, giving none of these a prima facie preferential right of interpretation. Instead it is emphasised that both categories of solutions have a valid role to play and that each situation must be evaluated without a priori limiting the acceptable solutions to either the environment or the individual. Compared to the CRPD, based on ICF, the provisions on interventions targeting impairment would arguable have a more prominent place and be more detailed. In addition, based on the focus on the interrelations between the components in ICF, the entitlements in Article 25 would have a clearly expressed instrumental role in relation to composite life opportunities and this role would be strengthened in Article 26. On the issue of choice, while the importance of this is emphasised in ICF, measures targeting the individual level or mode of functioning of the body and mind are also assumed to be largely sought after.

Finally, moving on to ICIDH, it is the approach which is the furthest away from the CRPD, as Articles 25 and 26 all but exhaust the measures ICIDH advocates. In addition, they do so in a manner which largely avoids the main point of ICIDH. This is so due to Article 25 on Health being framed in isolation from composite life opportunities and being quiet on any instrumental value to this end. Consequently, Article 25 ignores the main aim with the concept of Handicap, namely to make the health profession approach their interventions with composite life opportunities in mind.

11.2.4. Who is it about?

Turning to the question *who* the CRPD covers, it was concluded in Chapter 10 that this was an important question to negotiating States, who on the one side wanted to determine in relation to whom they shouldered obligations and on the other side agreed with IDC on the importance of not being unduly exclusive.

An additional and equally central concern in what became the depiction of "[p]ersons with disabilities" in Article 1 on Purpose was the message sent about the common ground of the constituency. Consequently, a person with disabilities is depicted not only through factors about individual "impairments", but through being hindered from participation in society through the interaction with "barriers". As further noted in Chapter 10, the frontline in determining if a particular person is covered or not will predictably hinge upon factors adhesive to "impairments" and not on the existence of barriers or ensuing disadvantage. Such factors include displaying connection to different categorisations of "impairments", the current tangibility of "impairments", temporal aspects of existing "impairments" and 'level' of "impairments". As concluded there, the general bottle-neck is likely to be the requirement that "impairments" be "long-term" and an implicit assumption that "impairments" inherently carries a requirement of a certain 'level' of departure from a norm.

Returning to the approaches to disability explored in Part I, all save the Minority Group Model of Disability explicitly define impairment as the departure from a norm and no approach problematises more than cursory how such a norm is established. In other words, they all treat impairment as an objectively identifiable feature of the person's body or mind, which, alone or in combination with other factors, determines coverage in their respective constituencies. As noted in Chapter 1, impairment as generally understood under the CRPD, the Social Model of Disability and the Minority Group Model of Disability is depicted by additional categories by ICIDH (Impairment and Disability) and ICF (Impairments and Activity limitations). However, the sum of the levels and modes of functioning of the body and mind included under each approach is not altered by the additional level of detail used by ICIDH and ICF (separating restrictions on the level of the body from restrictions on the level of the persons) nor is the range of persons included. ICF stands out from the CRPD as well as from the other approaches explored in Part I by virtue of including not only chronic but also acute levels and modes of functioning of the body and mind, while the others envisage their constituencies as having levels and modes of functioning of the body and mind of a certain chronicity. In addition, the possible limitation of Article 1 of the CRPD regarding coverage of future or falsely assumed "impairments", are explicitly refuted by ICF and, as regards history of "impairments", also by ICIDH. As discussed above under 10.1.7., the inclusion of all these situations rhymes well with the focus on disadvantage as caused by environmental barriers rather than as hinging upon the existence of impairment. This is formative to the Social Model of Disability and the Minority Group Model of Disability and indeed, as noted above under 10.1.5., to the CRPD as well. The upshot is that, apart from the question of the chronicity of impairment and the present existence of an impairment, the constituencies of the CRPD and these approaches seem to overlap well. The only caveat here is the possible ideological requirement stipulated by Michael Oliver, that being a "disabled person" requires a particular ideological position, rather than merely being objectively defined as such (which would omit what he refers to as "persons with impairments" as opposed to "disabled people" from the constituency of the Social Model of Disability).[924] Furthermore, while the Social Model of Disability and the Minority Group Model of Disability both emphasise the central feature of their constituencies as being the target of socially imposed disadvantage, they both assume, in addition, the existence of impairment. Consequently, this focus does not alter the answer to the question who their constituencies encompass, just by virtue of what (assuming that impairment is coupled with such disadvantage). To conclude, the question of who is in and who is out remains closely connected to impairment. The inclusion of disadvantage in social participation and environmental barriers hereto in the depiction of the constituency is part of an ideological message, amounting to that the central feature of the constituency is being hindered from participation in society by interaction with environmental barriers. The inclusion of this message in Article 1 of the CRPD is a strong reflection of the main message of the Social Model of Disability and the Minority Group Model of Disability. This is particularly so as these features are included in a provision aimed at determining inclusion/exclusion while they have little legal significance to this end *and* taken that "disability" is depicted elsewhere (Preamble (e)) as defined, in addition to "impairments", by environmental barriers and social disadvantage.[925] Finally, while the message that a central feature of their constituencies is being the target of socially imposed disadvantage as such similarly resonates with ICF, this is qualified by that ICF also explicitly recognises that Impairment (and Activity limitations),

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[924] Oliver, 1996, p. 5. See above under 3.5. and 10.1.7.

[925] See further below under 12.1.3.

with or without affecting composite life opportunities, is an equally central feature of its constituency.

Moving on to the question of viewing disability through a 'minority' or a 'universality' lens, the CRPD emerges predominantly as the former view. The title refers to "[p]ersons with disabilities" rather than to 'disability' and the characterisation of "[p]ersons with disabilities" in Article 1 serves the purpose of creating a category of those who are prima facie concerned by the CRPD (and whose rights may therefore be violated), distinct from those who are not. It uses a framework departing from the idea of a delineated 'group' and presents the entitlements due and obligations owed to individuals included therein. Furthermore, this framework is not mediated by the creation of entitlements or principled statements recognising impairments or related restrictions of composite life opportunities as phenomena of actual or potential universal relevance. In particular, no recognition of an overlap between the platform of disability and that of aging is recognised. As concluded just above, among the minority approaches explored in Part I of this book, the method employed by the CRPD to designate its minority resonates with the Social Model of Disability and the Minority Group Model of Disability rather than ICIDH, through putting the disadvantage experienced due to social barriers at least on par with levels and modes of functioning of the body and mind as the formative feature of its constituency.

Moving on to the diversity of the constituency of the CRPD in terms other than impairment, the question addressed above under 10.3. was to what extent and how the CRPD addresses that its constituency differs on grounds such as sex, ethnicity or age. As noted there, how to handle such diversity was a prominent theme in the negotiations, particularly in relation to two (themselves intersecting) sub-groups among its constituency, namely women with disabilities and children with disabilities. This resulted in particular provisions addressing the situations of these two groups as well as in references to these in several articles protecting particular areas or aspects of life. Generally, the CRPD is the first UN human rights convention to explicitly address "multiple or aggravated forms of discrimination".[926] A notable lacuna in the final text of the CRPD, reflective of incompatible positions among the negotiators, is the lack of a reference to sexual orientation as a prohibited ground for discrimination.[927] In the enumeration of such grounds, the addition of "age" is notable as a first among prohibited grounds for discrimination in a UN human rights convention.[928] Otherwise, compared to ICIDH and ICF, the lack of attention paid to the connection between old age and the constituency of the CRPD is notable. Compared to the critique of the Social Model of Disability explored above under 3.7.2. the limited connection with ethnicity is notable, as attention to it in the CRPD amounts only to

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[926] Preamble (p).

[927] See generally Daily Summaries 2 February 2006, 7th session. The list of such grounds in Preamble (p) include the catch all phrase "other status". Consequently, this does not mean that sexual orientation is not a prohibited ground for discrimination under the CRPD, only that this was not made explicit. See e.g. intervention to this effect by the Russian Federation during the 7th session. Ibid.

[928] See Preamble (p).

its inclusion in the listing of prohibited grounds for discrimination. As noted above under 10.3.2., ICF systemically provides for recognising the impact of factors other than Impairment (Personal factors) on the enjoyment of life opportunities. The range of these is broadly envisaged but their importance is however not emphasised. In ICIDH, the question what restrictions in relation to life opportunities are recognised as problematic appear to be relative to what is expected of a person based on perceptions about sex, ethnicity and so on. This is a notably different approach from the CRPD, which has the questioning of such perceptions and ensuing disadvantage at its heart.[929] In addition, ICIDH explicitly displays dated perceptions of diversity such as pathologising all but heterosexuality as regards sexual orientation. As noted above, similar perceptions figured in the negotiations, but these were only displayed or endorsed by some.

11.2.5 To conclude

In sum, it is obvious that the approach with which the CRPD resonates the least is ICIDH, primarily due to the latter's failure to implicate the environment as instrumental to the enjoyment of composite life opportunities.

Turning to ICF, the recognition of both individual and environmental factors as causes of and solutions to restricted composite life opportunities (albeit not on par) in the CRPD echoes ICF particularly well, as does the provision of entitlements to the elimination of impairment. Notably the slant in the CRPD towards the environment is in the instrument as a whole and not in Preamble (e) and Article 1 on Purpose as these, like ICF, do not rank the casual factors mentioned. Many accounts assert commonality between ICF and the CRPD in how disability is understood. Nora Ellen Groce and Alana Officer hold these two instruments as evidence of that "[g]reater consensus has now emerged" in relation to "[d]ebates [that] have raged within the fields of philosophy, health, and the social sciences about what constitutes disability and how it should be measured".[930] They assert this commonality in terms both of what is a problem (restricted "social participation") and in terms of what the causes of this problem is ("health conditions" and the "environment"):

> Both the ICF and the Convention view disability as the outcome of complex interactions between health conditions and features of an individual's physical, social, and attitudinal environment that hinder their full and effective participation in society.[931]

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[929] Compare Article 8 (1b) on Awareness-raising which obliges States to take measures to "combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life".

[930] Groce, Nora E., and Officer, Alana, Key Concepts in Disability, The Lancet, Vol. 28, 2009, p. 1795.

[931] Ibid. It is notable that they do not explicitly address the aspect of whether impairment can be a problem in and of itself, i.e. over and above how it affects "participation in society".

In addition, Groce and Officer spell out the common range of solutions flowing from this shared understanding in the CRPD and ICF:

> Interventions to alleviate the disadvantages experienced by people with disabilities need to be appropriate. Responses depend on the disability and on individual choice, and range from medical care through rehabilitation, support services, and psychological interventions, to barrier removal at home, work, school, and in wider society. [...] Because disability arises from the interaction between the person with a health condition and the complete physical, human-built, attitudinal, and social environment, society's responses to disability must take into consideration all aspects of the experience.[932]

Asserting this common value basis, the lack of an explicit link to ICF in the CRPD is put down to the 'political' circumstances of the negotiations. Jerome Bickenbach notes these circumstances, rather than any actual discrepancies between the understanding of disability in ICF and the CRPD, as the reasons for the latter's silence on the former:

> The link between the ICF conception of disability and CRPD is obvious upon inspection […], but the political environment surrounding the drafting of the CRPD made the explicit adoption of the ICF conception politically inexpedient.[933]

Rosemary Kayess and Phillip French are more explicit on the reflex opposition to ICF in the negotiations accounted for above under 11.1.:

> From the IDC's point of view, the ICF was part of the human rights problem faced by persons with disability that the CRPD was to overcome through its exposition of the social model of disability.[934]

Kayess and French hold the lack of mentioning of ICF in the CRPD as noteworthy, taken "its contemporary prominence as a statistical, analytical and planning tool, including within United Nations and other multilateral agencies".[935] They consequently point to the relationship between the CRPD and ICF and the future of ICF itself, as "at this stage [2008] crucial unanswered questions".[936] Doctrine asserts this relationship mainly in relation to monitoring the implementation of the CRPD and the obligation to provide statistics and data stipulated in Article 31 on Statistics and data collection.[937] Making sure to note the compatibility of ICF and the CRPD in

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[932] Ibid., pp. 1795-1796.

[933] Bickenbach, Jerome E., Disability, Culture and the UN Convention, Disability and Rehabilitation, Vol. 31, No. 14, 2009, p. 1112.

[934] Kayess and French, 2008, p. 25.

[935] Ibid.

[936] Ibid.

[937] This potential is asserted by, inter alia, Bickenbach, Jerome E., Monitoring the United Nation's Convention on the Rights of Persons with Disabilities: Data and the International Classification of Functioning, Disability and Health, BioMed Central Public Health, Vol. 11, Suppl. 4, 2011, Madden, Ros et al., Fundamental Questions before Recording or Measuring Functioning and

terms of the different dimensions of the 'problem' meriting addressing, Janet Lord et al. suggest ICF can help "current shortcomings" in relation to the availability and adequacy of data:

> Notably, the statistical standard offered by the ICF would seem to offer a tool by which Article 31 could begin to be realized insofar as it recognizes that disability is a complex phenomenon that is not simply an individualized health-centered condition *or* a social disadvantage.[938]

Finally, to end the account of the compatibility between ICF and the CRPD, the conclusion reached above under 10.2.2. according to which the CRPD, on balance, reflects a minority rather than a universality view, is where it most visibly departs from the ICF.

Taken that the negotiators of the CRPD repeatedly called upon the "social model" of disability[939] as its lodestar, that commentators all but unanimously hail the CRPD as 'social model' and that the CRPD Committee posits the "social model" as central to the implementation of the CRPD[940], the comparison between the CRPD and the approach delineated in this book as the Social Model of Disability is of particular interest. This comparison has yielded that the CRPD, as a platform for social change in the name of disability, departs from the mission of the Social Model of Disability by creating relatively detailed entitlements to the management of as well as to the prevention, minimisation and elimination of impairment and its effects in Article 25 on Health and Article 26 on Habilitation and Rehabilitation. In addition, Preamble (e) and Article 1 on Purpose depict "impairments" as causally related to the enjoyment of composite life opportunities and this instrumental relationship is also recognised in Article 26.

The attention accorded impairment in the CRPD has led one commentator, Aart Hendriks, to note in relation to Article 1 that "[t]his description of the term disability reflects a combination of the medical and social model of disability", as Article 1 mentions "impairments" and not only "barriers" as factors of the "interaction" resulting in "disability".[941] Another commentator, Paul Harpur, notes that while the CRPD "expressly embraces the social model [...] the CRPD, however, goes much

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Disability, Disability & Rehabilitation, Vol. 35, No. 13, 2013, Madans, Jennifer H. et al., Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: The Work of the Washington Group on Disability Statistics, BioMed Central Public Health, Vol. 11, Suppl. 4, 2011 and Griffo, Giampiero et al., Moving Towards ICF Use for Monitoring the UN Convention on the Rights of Persons with Disabilities: The Italian Experience, Disability & Rehabilitation, Vol. 31, 2009.

[938] Lord, Janet E. et al., Lessons from the Experience of U.N. Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance [hereinafter Lord et al., 2010], Journal of Law, Medicine and Ethics, Vol. 38, No. 3, 2010, p. 574. Emphasis added.

[939] See above under 11.1. and below under 12.1.-12.2.

[940] See below under 12.3.2.

[941] Hendriks, Aart, Selected Legislation and Jurisprudence: UN Convention on the Rights of Persons with Disabilities [hereinafter Hendriks, 2007], European Journal of Health Law, Vol. 14, 2007, p. 276.

farther than the social model [through] addressing the problem where persons with impairments could not fully function even if universal design were embraced".[942] The CRPD, or "[t]he human rights paradigm", is thus seen as different from and an improvement on the "social model":

> The social model advances disability rights substantially from the medical model but fails to ensure [that] all persons with disabilities can exercise their human rights. The human rights paradigm takes this next step and creates a governing policy framework that ensures [that] persons with disabilities can exercise all their human rights.[943]

Janet Lord et al. similarly qualify, at least implicitly, the conclusion that the CRPD is "social model". While noting that the CRPD "embraces a social model of disability, concentrating the disability experience not in the individual deficiency, but in the socially constructed environment and the barriers that impede the participation of persons with disabilities in society" they also state that "the tensions between the framing of disability within a medical model and the conceptualization of disability as a social construction are not fully resolved by the Convention".[944] This comment relates to the fact that the CRPD requires access to "population-based public health programmes" in Article 25 (a) on Health, in other words, to measures that prevent health conditions including those considered as "impairments" in the CRPD.[945]

Turning to another feature of the CRPD which creates dissonance with the Social Model of Disability, the terms "disability"/"disabilities" are employed throughout the CRPD to depict both restricted composite life opportunities *and* Impairment, thus not heeding the importance attached by the Social Model of Disability to separate these by bulkhead.[946] Finally, the depiction of the situation of its constituency as one of "oppression" is central to the Social Model of Disability[947], while the CRPD stops at depicting this situation as "profound social disadvantage".[948]

Numerous features of the CRPD however closely resonate with the Social Model of Disability, as delineated for the purpose of this book. This includes the depiction of the constituency in Article 1 through the social disadvantage experienced and the mentioning of barriers as instrumental to this, the corresponding construction of "disability" in Preamble (e), the predominant omission of impairment from the equation as an operative cause of restrictions of composite life opportunities in the CRPD at large, the General principles (a-f) in Article 3, the positive valuation of impairment in particularly Preamble (m), the role carved out for organisations

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[942] Harpur, Paul, Time to Be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change [hereinafter Harpur, 2011], Valparaiso University Law Review, Vol. 45, 2011, p. 1278.

[943] Ibid. Compare the comments made in the negotiations by Australia (referenced in note 896, Part II) and Israel (referenced in note 900, Part II) noted above under 11.1.

[944] Lord et al., 2010, p. 564.

[945] See Ibid., pp. 576-577.

[946] This is noted Rosemary Kayess and Phillip French in Kayess and French, 2008, p. 21.

[947] See e.g. UPIAS, 1975, p. 14 and Oliver, 1983, p. 23.

[948] Preamble (y).

of persons with disabilities in the implementation of the CRPD and the omission of a general entitlement to the prevention of impairment. Such features have led the overwhelming majority of post CRPD scholarship to characterise the CRPD and/or its depictions of "disability"/"[p]ersons with disabilities" as "social model".[949] Returning to the point that the recognition of impairment as a relevant cause of restricted composite life opportunities departs from the social model, this point is habitually skirted in doctrine by making room for the relevance of impairment in the depiction of the "social model", thus enabling the establishment of its correspondence with the CRPD.[950]

The most focused attempt so far to situate the CRPD against the "social model" of disability is by Rannveig Traustadóttir.[951] Traustadóttir's account appears fundamentally as an exercise looking for common ground, both between the "social model" and the CRPD and among what she refers to as "[s]ocial [m]odels of [d]isability", in which she includes: "the British social model of disability, the Nordic relational approach and the North American minority group understanding".[952] Thus, while relating these to each other and noting that "the social model" is most often associated with the first of these three, she addresses their relationship to the "human rights of disabled people" in concert:

> Thus, although "the social model" has been conceptualized and articulated in different ways in different countries, there are also many common characteristics. The debates within the group of those promoting a social-contextual understanding of disability can be confusing. However, those concerned with human rights of disabled people and legal developments to support these rights share an overall common understanding that can unite people across academic and geographical borders.[953]

Traustadóttir refers to the "social understanding of disability" as "one of the cornerstones of the CRPD" by noting that "the attention is on the importance of a social-relational approach with an emphasis on the interaction between the person and the

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[949] To mention but a few, see Lord, Janet E. and Stein, Michael Ashley, Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities, in Arnardóttir, Oddný Mjöll and Quinn, Gerard (Eds.), The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, Martinus Nijhoff Publishers, Leiden, 2009, pp. 25, 32-33, Schulze, 2010, p. 27 and OHCHR, Monitoring the Convention on the Rights of Persons with Disabilities, Guidance for Human Rights Monitors, Professional Training Series No. 17 [hereinafter OHCHR, 2010], United Nations, New York, 2010, pp. 8-10, 13, 15-16.

[950] Janet Lord thus contextualises her conclusion that the CRPD is "social model" with the statement that "[a] social model perspective properly understood does not deny the reality of impairment or its impact on the individual. It does, however, challenge physical and social environments – and legal frameworks – to accommodate impairment as an anticipated incident of human diversity". Lord, 2013, p. 4 (source not paginated). Along the same lines, Carole Petersen puts is that "[t]he treaty embraces the social and human rights models, which view people with impairments as rights holders who are *often more* disabled by physical and attitudinal barriers than by particular impairments". Petersen, 2010, p. 86. Emphasis added.

[951] Traustadóttir, 2009.

[952] Ibid., p. 9.

[953] Ibid., p. 15.

social environment".[954] Like others, she skirts the potential discrepancy between the CRPD and the "social model" by opening up for "a social understanding" as meaning that not all "difficulties" are attributable to external causes:

> The Convention articulates a stronger emphasis on social barriers than the Standard Rules, indicating a firmer commitment to a social understanding which implies that *many, and even most*, of the difficulties experienced by disabled people are caused by social barriers.[955]

Finally, some authors attribute problematic aspects of the CRPD to the understanding of the "social model" in the negotiations:

> Ultimately, the CRPD has been most influenced by an uncritical, populist, understanding of the social model of disability. At times this understanding approaches a radical social constructionist view of disability, in which impairment has no underlying reality. While the central tenet of the social model - disability as social oppression - has not been superseded, it has been heavily nuanced and qualified by the last decade of critical disability studies, which has re-emphasised the realities of impairment as a dimension of the ontological and phenomenological experience of disability.[956]

Kayess and French mention in particular Article 12 on Equal recognition before the law and Article 17 on Protecting the integrity of the person, which, according to them, "border on a complete denial of instrumental limitations associated with cognitive impairments".[957] Peter Bartlett zooms in on the same issue in his critique of the "social model". Thus, while recognising the importance of "characterizing disability in terms of the relationship between the individual and society and in particular the barriers society creates which excludes the person with disabilities", he concludes that it is "fair to ask whether the social model is, on its own, an adequate model of disability".[958] Like Kayess and French, Bartlett calls for the interpretations and implementation of the rights in the CRPD to recognise and pay attention to negative effects of impairment.

In sum, the account above illustrates a general wish to posit the CRPD as "social model" in order for it to join forces with this extremely influential approach to disability and the victories in terms of recognition and realisation of human rights it has produced. Furthermore, as the "social model" is understood differently by commentators who in addition zoom in on different aspects of it, it remains a 'moving target' which makes comparisons difficult. However, the research upon which this book is based has yielded that the assertion that the CRPD is 'social model' is seriously qualified by the fact that the CRPD posits impairment as causally related to the enjoy-

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[954] Ibid., p. 16.

[955] Ibid. Emphasis added.

[956] Kayess and French, 2008, pp. 33-34. See also Ibid., p. 7.

[957] Ibid., p. 7, note 31.

[958] Bartlett, 2012, pp. 758-759.

ment of composite life opportunities, holds interventions targeting impairment as instrumental to the enjoyment of composite life opportunities, creates entitlements to the management, prevention, minimisation and elimination of impairment and uses the term “disability” to signify both impairment and restricted composite life opportunities.

Turning to the Minority Group Model of Disability, the discrepancies between the CRPD and the Social Model of Disability largely mirror those between the CRPD and the Minority Group Model of Disability. This must however be somewhat qualified by the fact that the latter approach does not categorically condemn asserting an instrumental relationship between impairment and the enjoyment of composite life opportunities from the ideological, political and legal platform of disability. In addition, the Minority Group Model of Disability does not place the same emphasis as the Social Model of Disability on using terminology which separates impairment and composite life opportunities by bulkhead. However, the Minority Group Model of Disability does display a strong focus on understanding and framing impairment positively, which runs counter to the explicit entitlements in the CRPD to prevent and minimise impairment. Finally, in addition to mirroring the common features between the CRPD and the Social Model of Disability identified above, using equality and non-discrimination as a central standard to depict and measure levels of enjoyment of life opportunities due creates common ground between the CRPD and the Minority Group Model of Disability.

12. Epilogue – The future role of Article 25, Article 26 and Preamble (j) in the work of the CRPD Committee

In this final section I turn to the implementation of the CRPD and particularly to the role of the CRPD Committee. While the Committee is bound by its mandate and the substantive provisions of the CRPD, considerable discretion remains. This includes what questions and segments of the constituency to focus its attention on in directing the implementation efforts of States as well as more or less subtle expressions of values through choice of language used to communicate such direction.

So far, this book has charted the principled points (contentious or not) of the ideological antecedents of the CRPD and accounted for how these points are addressed in the CRPD as well as in the preceding negotiations. Part II of this book has illustrated that a number of diverging core positions and concerns of the approaches to disability explored in Part I come to a point in relation to the right to health (including health-related rehabilitation). Although such positions and concerns influenced the formation of numerous provisions, obligations and entitlements connected to health emerged as central for controversies relating to the target for intervention as the individual or the environment, to the related question of the valuation of impairment, to the role of professionals and to the portrayal of what defines a person with disabilities, the 'prototype' constituent. Article 25 on Health and Article 26 on Habilitation and rehabilitation actualise these interrelated concerns as the interventions they stipulate target the individual impairment and aim to minimise such impairment, thus attaching a negative value to it. This in turn portrays the person implicated as someone with whom there is 'something wrong', as needing 'correcting'. Finally, another concern voiced particularly in relation to these articles was the undue power of professionals, especially regarding efforts to 'correct' impairment. This concern drew on a heavy history of such interventions routinely being not only actively encouraged (without reflecting on the necessity of the intervention, its effect on other aspects of life or if changes should rather focus the environment) but even enforced against the express wishes of the person. Preamble (j), by emphasising the need for support in relation to the constituency of the CRPD, actualises concerns relating to the portrayal of the constituency of the CRPD as, inter alia, capable and independent. The complex web that these concerns create can be approached from different vantage points. Below, the right to health in Article 25, the obligation of states to provide health-related (re)habilitation in Article 26 and the obligation to implement the CRPD for "those who require more intensive support" in Preamble (j) constitute the hub around which such concerns are explored. It is around the implementation of these provisions alone and as they intersect with in particular Preamble (m), Article 1 on Purpose, Article 3 on General principles and Article 8 on Awareness-raising that the final discussion of the Committee's role in directing the implementation efforts of States will centre.

This Epilogue is divided into four sections. In the first section (12.1.), the concerns expressed in the negotiations relating to the dangers of according attention to questions of health, as well as to high requirements of support, are revisited. This account includes both how these concerns played out in the negotiations and their consequences in terms of the text of the CRPD. In the second section (12.2.), the divergence of agendas in relation to questions of health and to high requirements of support is discussed. In the third section, (12.3.) the role of the Committee regarding the implementation of Article 25, Article 26 and Preamble (j) is discussed against the backdrop of the concerns and consequent diverging agendas presented in 12.1. and 12.2. This discussion draws upon the interpretation of the CRPD provided in Part II of this book, the points made by the approaches to disability in Part I and the critique of these explored there. This section of Chapter 12 addresses directly the task of the CRPD Committee to monitor and guide the implementation of the CRPD as it relates to Article 25, Article 26 and Preamble (j). 12.3.1. starts with outlining the balancing act required by the CRPD Committee in implementing these provisions in light of the concerns and consequent diverging agendas presented in 12.1. and 12.2. 12.3.2. follows by gauging how this balancing act has been executed by the Committee in its monitoring efforts to date. 12.3.3. addresses features of post CRPD doctrine pertaining to this balancing act. 12.3.4. situates the work of the CRPD Committee in the context of it being one out of many UN treaty monitoring bodies with overlapping mandates. In the fourth and final section (12.4.), the challenges facing the CRPD Committee relating to Article 25, Article 26 and Preamble (j) and tentative navigation points addressing these challenges are summarised.

12.1. Concerns shaping the entitlements and obligations relating to health and high requirements of support in the CRPD

12.1.1. Concerns regarding the target for interventions as the individual or the environment

As concluded in Chapter 9, the CRPD is unequivocal on the onus of the environment to change *and* simultaneously creates entitlements for the individual to alter his or her level or mode of functioning of the body and mind. Outside of Article 25 on Health and Article 26 on Habilitation and rehabilitation, which contain the latter category of entitlements, the CRPD is visibly the product of a drafting procedure which took great pains to direct as little attention to impairment as possible. Two prime examples of this drive, manifested as a reluctance to use the term 'impairment', have been discussed in Part II. Firstly, the terms "disability"/"disabilities" are employed throughout the CRPD to depict both restricted composite life opportunities *and* impairment, irrespective of the principled differentiation made between these in the depiction of "disability" (Preamble (e)) and "[p]ersons with disabilities" (Article 1 on Purpose).[959] Secondly, as mentioned above under 7. and 7.1.1., Article 3 (d) on General principles read "[r]espect for difference and acceptance of *disability* as part of human diversity and humanity" up until the last minute of the negotiations.[960] The Drafting Committee pointed out that this, due to "disability"/"disabilities" being depicted as restricted composite life opportunities in Preamble (e) and Article 1, logically implicated the *acceptance* of such restrictions. However, the ensuing force towards mentioning that it was diversity in terms of individual levels and modes of functioning of the body and mind (impairment) that merited acceptance was side stepped by inserting "*persons with* disabilities".[961]

The reluctance to draw attention to impairment also came through when provisions needed to explicitly express that impairment should not, as is habitually the case, be used as a justification for restricted life opportunities. For example, WNUSP is recorded during the 5th session as objecting to the phrase "existence of a disability" as something upon which the deprivation of liberty cannot be based, as having "a medical model tone".[962] In addition, unwillingness to explicitly refer to individual diversity during the negotiations came through in rebutting suggestions to make di-

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[959] See above under 7.

[960] Emphasis added.

[961] Emphasis added. The urge not to mention impairment thus resulted in making it more difficult to argue for a positive valuation of impairment and not just of the person with an impairment, based on the CRPD. See above under 7.1.1.

[962] Daily Summaries 3 February 2005. This formulation remained and is part of Article 14 (1b) on Liberty and security of person. Note that the word "disability" is used here in the sense attributed to "impairment" in Preamble (e) and Article 1.

versity of impairment explicit in the text. The rebuttal of calls to pay attention to the requirements of different levels of impairment through explicitly emphasising person with "severe" impairments, with reference to this being an expression of a "medical model" is an example of this.[963] In addition, recommendations to specify that the call to recognise "the diversity of persons with disabilities" in Preamble (i) implied diversity in terms of levels and modes of functioning of the body and mind[964] were rebutted as unduly diverting the "focus" of the CRPD, as here by LSN:

> A proposal (India) during the Ad Hoc Committee Meeting suggested specifying that the word "diversity" refers to the type of impairment, but since the focus of the Convention is on the environmental barriers to full integration of people with disabilities in the society, this was not included. "Diversity" should encompass different social, economic and cultural situations that people with disabilities encounter.[965]

Other examples where the inclusion of general references implicating the importance of according attention to diversity of impairment were suggested and turned down are Article 8 on Awareness-raising[966], Article 26 on Habilitation and rehabilitation[967], Article 31 on Statistics and data collection[968] and Article 34 on the Committee on the rights of persons with disabilities[969]. In some instances, considerations regarding the need to accord attention to diversity of impairment in the implementation of the CRPD tipped the scale in favour of including language to this effect. Consequently, Article 7 (3) on Children with disabilities calls for "disability[...]-appropriate assis-

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963 See quote by Canada above under 10.1.3 referenced in note 732, Part II and generally below under 12.2.1.

964 India is recorded during the 3rd session as proposing to change what where to become Preamble (i) ("*Recognizing* further the diversity of persons with disabilities") to "Recognizing the wide range of abilities, skills, functional competencies and concerns of PWD." Emphasis in original. Daily Summaries 4 June 2004, 3rd Session. This was seconded in the same discussion by Pakistan. See Ibid. Similar proposals were put forward as late as 2006, during the 8th session. See proposal for the Preamble by Egypt, Morocco, Sudan, Syria, Qatar, Kuwait, Bahrain and Saudi Arabia: "Recognizing further the diversity of **kinds of disabilities**.". Emphasis in original.

965 LSN, Legal Analysis of the Modifications Proposed at the 3rd UN Ad Hoc Committee Meeting [hereinafter LSN Legal Analysis, 4th Session], 4th Session, August 2004, p. 6. A similar call was made during the 7th session by China for clarification in the text of if the reference to "respect for [...] human diversity" as the goal of education in what became Article 24 (1a) on Education implied "cultural diversity or biodiversity". This was answered by the Chair noting that ""human diversity" refers to the variety of shapes, sizes, abilities and disabilities found in the human population" and that "the language was a product of extensive deliberation within the AHC". Daily Summaries 24 January 2006, 7th Session.

966 See particularly suggestions by the Philippines and Thailand during the 3rd session amounting to that Draft Article 6 on Promoting positive attitudes to persons with disabilities should specify that awareness-raising must cover the whole spectra of different levels and modes of functioning of the body and mind. Compilation of Proposals before the 4th session, 2004, p. 15.

967 See submission by IDC quoted below under 12.2.2. referenced in note 1114, Part II.

968 This concerned the question whether the provision should require that statistics and data be disaggregated according to different impairments or not. The end result is the requirement in Article 31 (2) that statistics be disaggregated "as appropriate". See above under 9.1.12.

969 See e.g. intervention by South Africa during the 7th session calling for that a CRPD Committee "representing a diverse nature of disability". Daily Summaries 3 February 2006, 7th Session.

tance" in expressing their views and Article 16 (2) on Freedom from exploitation, violence and abuse calls for protection services that are "disability-sensitive".[970] In addition, concerns to make sure that implementation efforts take the needs of everyone into account led to the inclusion of the word "all" in front of "persons with disabilities". The prime example of this is Article 1 on Purpose calling for "the full and equal enjoyment of all human rights and fundamental freedoms by *all* persons with disabilities".[971]

In addition to the reluctance to generally attach explicit importance to the span of levels and modes of functioning of the body and mind implicated by the CRPD, calls for explicitly mentioning specific categories of impairments were controversial. The only place outside the depiction of "[p]ersons with disabilities" in Article 1 where impairment categories are explicitly mentioned is Article 24 on Education. Here, "persons, and in particular children, who are blind, deaf or deafblind" are singled out as an exception to the general presumption of inclusive education.[972] Opposition to the mentioning of particular impairments was voiced from the beginning of the negotiations[973], however it was retained here due to that "many delegates expressed the belief that the specific categories of persons with disabilities mentioned in 23(3) need specific reference to highlight their situation".[974] The enumeration of particular impairment groups, albeit regarded as necessary, continued to be a sore point. To illustrate, IDC suggested during the 7th session that such language be replaced with a phrasing identifying these groups indirectly by way of describing their languages or modes of communication ("language and/or communication methods of their own") in order to "advance the objective of moving away from the medical perspective of disability towards a more social context".[975]

The examples above illustrate general concerns amounting to directing as little attention to impairment as possible. These concerns were sometimes overridden by other concerns but applied prima facie regardless of the function or context of calls for such attention. The right to health and the obligations to provide health-related (re)habilitation inexorably draws attention to levels and modes of functioning of the body and mind and situates these not only as relevant for the shaping of entitlements and implementation efforts that target the environment, but as relevant targets for intervention in themselves. Consequently, there is no way of expressing the entitlements in Article 25 on Health and Article 26 on Habilitation and rehabilitation

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[970] Note that these refer to "disability" in the sense attributed to "impairments" in Preamble (e) and Article 1.

[971] Emphasis added. Others are Article 4 (1) on General obligations, Article 19 on Living independently and being included in the community and Article 23 (1a) on Respect for home and the family.

[972] See above under 7.2.13.

[973] See e.g. recorded statement by Germany in the Working group: "The article [what became Article 24 on Education] should refrain from mentioning specifically deaf and blind children as it could be misinterpreted as representing the medical model of disability.". Daily Summaries 12 January 2004, Working Group Session.

[974] Recorded statement by Chair. Daily Summaries 24 January 2006, 7th Session. Draft Article 23 (3) mentioned here became Article 24 (3c) in the final version of the CRPD.

[975] Ibid.

in a way that accommodates reservations about drawing attention to impairment. Instead, such concerns were reflected in interventions, unlike those concerning other articles, emphasising that entitlements relating to health do not have a greater, or a different, significance for the constituency of the CRPD than they do for others (although such entitlements may well, like other entitlements, be denied based on impairment). The following statement by IDC illustrates this position to the point:

> It is crucial to understand that it is possible to have a disability and to also be healthy. Of course, in this way, it is also possible to have a disability and, because of discrimination or stigma, to receive inadequate care or to face social and environmental barriers that prevent the achievement of the enjoyment of the highest attainable standard of health.[976]

Chile similarly notes the need "to avoid giving any impression of equating disabled people with persons of ill health"[977], Rehabilitation International (RI) emphasises that "the vast bulk of PWD [persons with disabilities] are not sick"[978], WBU states (on behalf of IDC) that "[a] PWD [person with disabilities] can be perfectly healthy"[979] and PCDA states that "[t]he implication that having a disability implies ill-health […] is erroneous"[980]. The gist of the above is that entitlements relating to health are only as relevant and important for persons with disabilities as they are for others, no more and no less. The emphasis put on not exaggerating the relevance of the entitlements relating to health in Articles 25 and 26 differentiates from the negotiations of other articles, the importance and relevance for persons with disabilities of which were habitually underscored rather than intentionally downplayed.

However, the negotiations also contained statements recognising the importance of health-related interventions, such as Senegal noting during the 7th session "the primacy of health and its inter-dependence with all other aspects of life".[981] References to the importance of medication being affordable also figured, framed by Chile as "an element of interest and very important to large numbers of persons with disabilities".[982] In addition, in the context of the need to separate Articles 25 and 26 (which is also where most of the statements looking to separate the constituency of the CRPD from people who are 'unhealthy' were made), the need to "ensure that the

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[976] IDC, 2nd Information Sheet, Article 21 Health, 6th Session, p. 1 (original not paginated).

[977] Daily Summaries 8 August 2005, 6th Session.

[978] Daily Summaries 12 January 2004, Working Group Session.

[979] Daily Summaries 8 August 2005, 6th Session.

[980] The Physical Disability Council of Australia Ltd (PDCA), Submission on UN Draft Convention on the Rights of People with Disabilities [hereinafter PDCA, Submission on UN Draft Convention, 3rd Session], 3rd Session, 2004, p. 7 (source not paginated).

[981] Daily Summaries 25 January 2006, 7th Session. See also record of interventions by Yemen and Sudan in the same discussion, emphasising a particular importance of the right to health for persons with disabilities. Ibid.

[982] Proposal by Chile on Draft Article 6 on Statistics and data collection, 4th Session, 2004. Chile refers specifically to the existence of "subsidies" of medicine to be recorded in statistics. Senegal makes the point about free or affordable health services in the statement referred to in the previous note.

right to health would not be couched away"[983] as well as the impetus to "make the best use of rehabilitation within the health aspect"[984] was recognised. Thus, the importance of health-related entitlements was noted, albeit these were to be separated by bulkhead from non health-related entitlements. IDC aligned itself with WHO in an unusually explicit statement during the 7th session on the importance of the right to health for the constituency of the CRPD, with reference to "people with chronic illnesses/chronic diseases[/]medical disabilities":

> Finally, we would like to draw attention to the fact that for large groups of people with chronic illnesses/chronic diseases or as it is sometimes called in Europe "medical disabilities", health care is crucial for their survival and well-being. Examples of such groups are people with asthma, diabetes and rheumatism. Thus, the retention of a comprehensive article on the right to health to all people with disabilities is important for a large proportion of the world's population, and we welcome the strong endorsement for this article by the WHO.[985]

On the nature of the relationship between the constituency of the CRPD and health-related entitlements, the dual character of such entitlements was emphasised. Latin American Region Disabled Confederation differentiated between "the various components of the right to health as outlined by WHO that applies to all people, and as they apply to PWD [persons with disabilities] whose healthcare may be linked to their disability".[986]

The account above illustrates ambivalence towards recognising the importance of health interventions for the constituency of the CRPD, particularly as regards any importance disproportionate in numbers or relevance compared to people in general. In the CRPD, the right to health is contained in one article, as it is in other human right treaties, with the addition of the health-related dimension of rehabilitation being covered also in Article 26. Another sign of a distinct relationship between persons with disabilities and the right to health is the separation, in line with the statement above by Latin American Region Disabled Confederation, of health care and programmes "provided to others" in 25 (a) and those "needed by persons with disabilities specifically because of their disabilities" in 25 (b). Furthermore, as discussed in Chapter 9 implementation of the right to health is not instrumentally linked to the enjoyment of composite life opportunities. Statements to this effect were made in the negotiations, but the drive to make sure that health services were conducive to the rest of life arguably ran into concerns that positing health interventions as instrumental to composite life opportunities distorts attention from the

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[983] Recorded statement by Chile. Daily Summaries 8 August 8 2005, 6th Session.

[984] Recorded statement by Thailand. Ibid.

[985] IDC Statement on Article 25 on Health, 7th Session. Compare the seemingly contradictory proposal by IDC submitted at the beginning of the 7th session quoted above under 7.1.1. referenced in note 45, Part II.

[986] Daily Summaries 8 August 2005, 6th Session.

environment as the correct object for change.[987] In addition, such a link carries the connotation that the individual should strive to change as a route to better 'fit' the current infrastructure of enjoyment of composite life opportunities, rather than the other way around.

The fact that the measures targeting the individual in Article 25, as opposed to such measures in Article 26, are not explicitly expressed as instrumental towards the enjoyment of composite life opportunities may influence what measures are demanded towards such life opportunities. The linkage created in Article 26 between health-related (re)habilitation and the enjoyment of "full inclusion and participation in all aspects of life" means that a demand for health-related (re)habilitation can be justified against, and has to be shaped towards, facilitation of participation and inclusion in any area of life. In other words, a claim to (re)habilitation can be based on a need related to education, employment or childrearing. This means both that States must put in place policies and services to this effect and that an individual who has not adequately received such services has a claim vis-à-vis the State based on Article 26.

Concerns about attention to interventions targeting the body and mind diverting attention from environmental barriers was a reoccurring theme in the negotiations. The statement by Canada reproduced here illustrates this concern in relation to health, qualifying as it does "the view that guaranteeing the equal right to the highest attainable standard of physical and mental health without discrimination on the basis of disability is of great importance in this Convention" with the following caveat:

> Canada is also very aware of the fact that there has been a tendency in the past, however, to over-emphasize the health-related aspects of disability and, in doing so, to lose sight of the important human rights dimension of disability that requires societies and their governments to take appropriate measures that go far beyond the medical sphere to promote equality and inclusion.[988]

The slanted focus of intervention towards the individual at the expense of the surrounding environment was a constant backdrop of the negotiations and not only as referred to here, as a feature of the past, but as a tendency still very much alive and well. For this reason, among others, these two targets for interventions were some-

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[987] Statements recognising the instrumental character of health interventions towards the enjoyment of composite life opportunities include the statements by Senegal just above. Compare also the following statements by MDRI during the 6th session in relation to Draft Article 21 on the Right to health and rehabilitation: "Para (c) should therefore provide for a right to health and rehab services, to promote maximum possible social inclusion and individual independence and integrated into mainstream health and rehab services.". Daily Summaries 8 August 2005, 6th Session. See also recorded statement by Federation for and of People with Disabilities (Kenya) below under 12.1.2. referenced in note 999, Part II.

[988] Intervention by Canada, Article 21 – Right to Health and rehabilitation, Talking Points, 6th Session, 8 August 2005.

times juxtaposed as a question of either/or in calling for the latter kind, as here by IDC during the 7th session:

> Deaf people are being urged to have cochlear implants, a type of surgery that only changes but does not eliminate the disability, *rather than* address their needs as a linguistic community through the recognition of sign languages.[989]

The urge to steer the focus away from the individual level in order to make sure that this was not overemphasised at the expense of the environment concerned in particular, in addition to the right to health, the depiction of "disability". The statement reproduced below by PWDA et al. serves as an illustration of this, as well as of this urge being linked to "a social model of disability":

> A few participants indicated that they were concerned that by focussing on the nature of impairment in the definition, the social barriers to full and equal enjoyment of the rights of people with disability may not be achieved. To this end, some argued (in line with current International Disability Caucus debate) that the definition needed to reflect a social model of disability. [...] The social model places the 'problem' of disability in the social environment, rather than in the 'pathology' of the individual. Its action implication is social change rather than personal cure.[990]

To conclude, past as well as current tendencies to turn to interventions targeting the individual rather than to those targeting the environment shaped the negotiations of the CRPD. This resulted in a concerted effort to direct attention towards the environment by paying as little attention as possible to impairment, either as important for the shaping and implementation of interventions targeting the environment or, as in relation to health, as the target of interventions.

12.1.2. Concerns regarding the valuation of impairment

The question what a relevant target for interventions is remains inherently tangled with the question of valuation of impairment. Entitlements to interventions targeting impairment imply a negative valuation of these, lest they would not be posited as appropriate to intervene with. As concluded above in 7.1.3., the CRPD is contradictory on the valuation of impairment. A desire to portray impairment positively resulted in principled statements to this effect, particularly Preamble (m) recognising as it does "the *valued* exiting and potential contributions made by persons with disabilities to the overall well-being and *diversity* of their communities".[991] In contrast to such declaratory statements, Article 25 on Health and Article 26 on Habilitation and

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[989] IDC Intervention on Article 15, 7th Session, p. 1 (source not paginated). Emphasis added. The particular focus of this intervention was the practice of coercion in relation to medical interventions.

[990] PWDA et al., Report on National Consultations, 7th Session, pp. 9-10.

[991] Emphasis added.

rehabilitation create entitlements to the prevention, minimisation and elimination of impairment, solutions which they cannot offer without simultaneously implicating impairment as negative, as something a person can be expected not to want to acquire alternatively want to rid him- or herself of. The general tension discussed in Part I in relation to particularly the Social Model of Disability between promoting impairment as neutral or positive *and* providing entitlements connected to prevention, minimisation and elimination of impairment, is consequently not resolved but rather built into the CRPD.

A further inconsistency is the difference of entitlements created in relation to the impairment by which one is covered by the CRPD (the initial impairment) and any subsequent impairment acquired by persons thusly covered (further impairment). Firstly, entitlements are phrased in stronger, more explicit language in the latter case ("to minimize and prevent"[992]) compared to the former case (to provide "early identification and intervention as appropriate"[993]). As noted above in 7.1.3., it is the same impairments referred to in these cases, the only difference being the order in which they appear. Secondly, these entitlements create a difference in relation to what constitutes a legitimate claim under the CRPD in relation to primary and further impairment. The provisions in the CRPD stipulate what States have to do towards the enjoyment of certain life opportunities in order for these to be enjoyed. If these are not enjoyed, the lack of such proactive measures can amount to a violation which gives an individual a reactive claim for financial or other remedies vis-à-vis the State. In relation to Article 25, the fact that it does not demand prevention generally, means that a person *who becomes part of the constituency of the CRPD* through action or omission which is attributable to a State (either by having a directly instrumental role (e.g. medical malpractice at a state hospital, police violence, nuclear eruption of a State plant) or by not exercising due diligence by providing protecting from others (e.g. hate crimes based on sex or ethnicity, hazardous working conditions with a private employer) do not have a reactive claim under the CRPD. For a person *who already is part of the constituency of the CRPD*, the situation is different. In addition to the demand in Article 25 (a) for access to "the same range, quality and standard of […] population-based health programmes", 25 (b) demands prevention of "further disabilities". This means that a person who is already part of the constituency of the CRPD has a claim towards the State if the existence of an *additional* impairment can be attributed to lacking or malfunctioning "health services" or unequal access to "population-based health programmes".[994] Finally, the demand to provide "persons with disabilities equal and effective legal protection against discrimination on all grounds" in Article 5 (2) on Equality and non-discrimination means that the acquisition of an impairment, which qualifies as such discrimination (note the example of hate crimes above), can give rise to a claim as long as one is *already part of the*

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[992] Article 25 (b) on Health.

[993] Ibid.

[994] The standard is set as the "same" access as others, illustrating that the target is disadvantage in access to general prevention which is linked to one being a person with disabilities.

constituency of the CRPD. This thus extends the protection for those already a part of the constituency of the CRPD against additional impairment outside the realm of "health services" and "population based health programmes" and consequently extends the claims that can be made. Again, if the same impairment, similarly attributable to the State, is the one by which one becomes part of the constituency of the CRPD no such claim can be made.[995] The upshot is that the difference in protection here is not due to these provisions dealing with different impairments or differing State behaviours; instead this difference pivots on whether these provisions concern the impairment by which one became part of the constituency of the CRPD or an additional one.

As illustrated above under 7.1.1. and 8.2., the issue of prevention of impairment was controversial in the negotiations of the CRPD. It was most often opposed with reference to that the CRPD should be "a convention on the rights of PWD [persons with disabilities]"[996], which is not entirely adequate in light of the claims such an entitlement would have created for some persons with disabilities, as discussed above. Arguably, the controversy instead goes to the heart of the negative valuation of impairment it implies, namely as something which is not wanted and should not have happened. This was expressed by New Zealand in the statement quoted above under 7.1.1., arguing that prevention implies that impairment "is not wanted" and that persons with disabilities "are not valued".[997] Consequently, attributing a value to the prevention of impairment and thus a negative valuation to impairment, connected with the perception that this translated into a valuation of the constituency per se, was arguably why it remained "a "strong objection"" throughout the negotiations.[998]

Like entitlements to prevention, entitlements to minimisation or elimination of impairment (popularly addressed in terms of 'cure') implicate a negative valuation of impairment. As concluded above under 7.1.1., the CRPD, while staying clear of the term 'cure', contains such entitlements both concerning the initial as well as any further impairment. As noted there, explicit statements were made in the negotiation on the value of 'cure'. Such value was further the unstated assumption of other interventions, such as this one by the Federation for and of People with Disabilities (Kenya) during the 7th session, the main point of which was that health services must be affordable in countries where resources are scarce:

> It would be expecting too much to ask a person with disability living at US one dollar per day to fund an operation to *correct* his/her disability which may cost, for example,

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[995] In addition to such reactive claims, it poses the question to what extent Article 16 (4) on Freedom from exploitation, violence or abuse creates entitlements to "physical, cognitive and psychological recovery, rehabilitation and social reintegration" not only for "persons with disabilities who become victims of any form of exploitation, violence or abuse" but also for person who become covered by the CRPD through such an instance.

[996] Intervention by IDC quoted above under 7.1.1., referenced in note 36, Part II.

[997] Referenced above in note 38, Part II.

[998] Record of statement by WBU during the Working Group session. Daily Summaries 12 January 2004, Working Group Session.

> US dollars 1,000 to be carried out. Failure to carry out this operation may mean that the person with disability (his degree of disability may worsen) may not be able to enjoy his human rights as he/she could have enjoyed if the operation had been done.[999]

Furthermore, certain statements in the negotiations not addressing minimisation or elimination of impairment, but impairment per se, amount to an implicit and arguably unintentional negative valuation of impairment. For example, while calling attention to crimes against persons with disabilities IDC states the example of a man who has been attacked, noting that he "is recovering from his burns but has been scarred for life".[1000] Similarly, forced psychiatric interventions are opposed based on the possibility that these, among other things, "may create additional impairments".[1001] In contrast, the psychosocial impairments targeted by such interventions are described as "for the most part a "disability" only because of social prejudice and failure to accommodate different ways of being".[…] Madness is not a disease but a disability – a profound expression of our humanity which nevertheless has been met with intolerance and outright discrimination".[1002]

While 'cure' was often referred to in negative terms, it was so in contexts which makes it difficult to determine if the problem was 'cure' as such or rather the understanding of 'disability' (as in restriction of composite life opportunities) as susceptible to 'cure', to 'cure' as an inappropriate substitute for changes to the environment or to 'cure' forced upon persons who do not wish for it. When Costa Rica, as quoted above under 11.2.3., states that "the medical model of disability, which looks at disability as a defect or a disease that needs to be cured through medical intervention, has been completely left behind", this is possibly limited to an expression of how the concept of "disability" should be understood and does not address the relationship between "cure" and *impairment*, but the relationship between "cure" and "disability" only.[1003] Similarly, when IDC calls for the separation of Articles 25 and 26 based on that this was necessary lest the CRPD would be "supporting the outdated medical model of disability in which disability is seen as an illness or health problem that must be cured", this was possibly not a refutation of "cure" as such, but of a structuring of the CRPD which unduly *implicated entitlements to (re)habilitation as intrinsically connected to the area of health*.[1004] Furthermore, when PDCA states that "the definition of disability should reflect the social model of disability within the Convention which views disability as resulting from social barriers to participation as opposed to the medical model which views disability largely as medical issues that need to

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[999] Federation of and for People with Disabilities Kenya, Article 25-Health, 7th session, 24 January 2006, p. 1. Emphasis added.

[1000] IDC Information Sheet on Article 12: Freedom from Violence and Abuse [hereinafter IDC Information Sheet on Article 12, 5th Session], 5th session, 2005.

[1001] Minkowitz, Tina, Supplementary Paper, Advocacy Note: Forced Interventions Meet International Definition of Torture Standards, 5th session, 2005.

[1002] IDC, Intervention on Article 15, 7th Session, p. 2 (source not paginated).

[1003] Record of statement by Costa Rica quoted above under 11.2.3. referenced in note 920, Part II.

[1004] See record of statement by IDC quoted above under 7.1.2. referenced in note 69, Part II.

be 'cured'", the problem is perhaps not "cure" as such, but "cure" *as a substitute for addressing the environment* (as in "social barriers to participation").[1005] Similarly, the requirement that "States Parties shall protect persons with disabilities from forced interventions or forced institutionalization aimed at correcting, improving or alleviating any actual or perceived impairment" present in the draft of the CRPD up until the 8th session, arguably does not denounce minimisation or elimination of impairment as such, but minimisation or elimination of impairment *enforced against the wishes of a person*.[1006] In addition to negative statements on 'cure', the same openness to different interpretations regarding valuation of impairment is adhesive to statements such as that "disability" is not "individual pathology", as such statements say nothing about how *impairment* should be regarded. The following suggestion for the Preamble by PWDA et al. during the 4th session serves as an illustration:

> Recognising a profound shift away from an understanding of disability as an individual pathology towards one that recognises the disabling impact of inaccessible social structures and processes on persons with impairment.[1007]

As discussed in Chapter 7 in relation to Article 10 on Right to life and Article 25 on Health, the link between a negative valuation of impairment, a negative valuation of the life of the person implicated and the consequent denial of such life was a theme in the negotiations which resulted in 25 (f) with its requirement to "[p]revent discriminatory denial of health care or health services or food and fluids on the basis of disability".[1008] The perception of impairment as neutral, positive or negative has had, and still has, huge implications for the life opportunities of the constituency of the CRPD including the opportunity to exist at all. One historic instance where these implications played out was present in the negotiations: the systematic elimination of persons with disabilities during the Holocaust. Here, the elimination of *the person* became the outcome of a focus on prevention, minimisation and elimination of impairment, denying not only any value of human diversity but any human worth to persons sporting the 'wrong' facet of such diversity.[1009] Such instances brought forward in the negotiation were not limited to history, but illustrated that individual as well as structural decisions about the living or dying of the constituency of the CRPD, often heavily influenced by the narrative of tragedy are taken every day.[1010] While not reducing the calls for avoiding attention to impairment as negative to matters of strategy, the above remains the backdrop against which the tendency to downplay negative sides to impairment, including efforts made to avoid references to

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[1005] PDCA, Submission on UN Draft Convention, 3rd Session, p. 8 (source not paginated).

[1006] See Draft Article 17 (2) on Protecting the integrity of the person in CRPD Working Text after the 7th Session, 2006, p. 15.

[1007] PWDA, AFDO and NACLC, Intervention on the Preamble, 3rd Session, 2004.

[1008] See further above under 7.1.1. and 7.2.1.

[1009] See e.g. recorded statement by Thailand during the Working Group session. Daily Summaries 15 January 2004, Working Group Session.

[1010] See further above under 7.2.1.

any implicit recognition of the value of not having an impairment (the case in point being prevention and 'cure'), must be placed.

To conclude, concerns regarding the valuation of impairment, the connection of such valuation with valuations of life with impairment and even with the valuation of the constituency of the CRPD, coloured the negotiations. Such concerns were instrumental to the shaping and outcome of the entitlements covered under the right to health. They resulted in the omission of entitlements relating to the general prevention of impairment as well as in inconsistencies in how the impairment by which one becomes a member of the constituency of the CRPD and additional impairments are approached.

12.1.3. Concerns regarding the portrayal of disability/persons with disabilities

Any approach to disability as an ideological, political or legal platform inevitably produces a portrait of who 'a person with disabilities' is. This portrait emerges through what is forwarded as the requirements, wishes and demands of the constituency as well as through the general choice of language used to describe the constituency and its life situation. In addition to *producing* such a portrait, each approach transmits explicit as well as implicit signals as to how persons with disabilities should be portrayed *in other contexts*.

While the immediate goal of a human rights convention is to codify entitlements and obligations which correspond to the requirements of the people it covers, a parallel and arguably equally central aim to the negotiating parties of the CRPD was that this convention "communic[ates] a paradigm shift in how society views PWD [persons with disabilities]".[1011] This concern permeated the drafting of the entire CRPD and resulted in principled statements on how person with disabilities should be regarded; Preamble (m) and Article 3 (d) on General principles are cases in point.[1012] It also resulted in a definition of persons with disabilities which focuses on restricted participation and environmental barriers, albeit these aspects have little to do with the *legal* purpose of Article 1 which remains determining who is and who is not covered by the CRPD. The strongest sign of this endeavour is Article 8 on Awareness-raising. Article 8 of the CRPD mirrors the importance accorded to the portrayal of persons with disabilities throughout its deliberation, simultaneously amplifying the message it *sends* about persons with disabilities and securing its transmission by requiring States to *spread* such messages: to "*promote* awareness of the capabilities and contributions of persons with disabilities[, to] *promote* positive perceptions and greater social awareness towards persons with disabilities [and to]

[1011] Recorded statement by IDC during the 7th session. Daily Summaries 30 January 2006, 7th Session.

[1012] See further above under 7.1.3.

promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labourmarket".[1013]

The core function of the portrayal of the constituency was asserted in the negotiations as such portrayal being instrumental to the realisation of life opportunities, through the creation of "the fundamental shift in attitudes *that are necessary for this Convention to be effective*".[1014] The following contribution from ARCC to the Working Group on how to define "disability" illustrates that the function of portrayal was seen as such realisation, here expressed in terms of "equity":

> The definition of disability in the Convention must not focus on the inabilities of people with disabilities as this inadvertently leads to stigmatisation and categorisation and does not ogre well for equity. The definition should be premised on an understanding that disability is a social construct and most of its effects are inflicted upon people with disabilities by their social environments. Defining disability as such allows that we collectively contribute to changing this social construct.[1015]

Inside Article 8 on Awareness-raising the function of portrayal in terms of the realisation of life opportunities is expressed as the obligation "to foster respect for the rights and dignity of persons with disabilities".[1016] The core function of portrayal (in the CRPD as well as through the workings of Article 8) is to affect the general perception by surrounding society of the legitimacy and urgency in realising the demands made by the CRPD, in turn leading to such realisation. The main target of concerns about how the constituency was portrayed in and through the CRPD was thus the effect of such portrayals on the susceptibility of the social context to environmental change. An additional target of portrayal was discussed in relation to Article 8, namely the self-regard of persons identifying as part of the constituency of the CRPD or being attributed such affiliation by others. However, this did not leave any marks on the text and was not an explicit theme in the negotiations outside of Article 8.[1017]

The quote by ARCC above illustrates the kind of portrayal which was seen as conducive to the realisation of life opportunities, namely one which focuses on the social environment and does *not* focus on problems associated with levels and modes of functioning of the body and mind, i.e. "inabilities". The following quote by LSN is another example of the perceived necessity to portray that which defies the constituency, "disability", as being all about environmental barriers and not about "impairment" in order to "shift perceptions" in a way conducive to the realisation of the entitlements in the CRPD:

[1013] Article 8 (1c) and (2aii-aiii). Emphasis added. This chain is extended further by asking the state to influence actors only partly in its control, to "encourag[e] all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention". Article 8 (2c).

[1014] LSN, Legal Analysis, 4th Session, p. 3. Emphasis added.

[1015] ARCC, Compilation of Proposals before the Working Group, 2004, p. 39.

[1016] Article 8 (1a).

[1017] See above under 8.1.2.1.

> In order to more comprehensively describe the fundamental shift in attitudes that are necessary for this Convention to be effective, the Preamble should contain language expressing the shift in the perception of disability from one focusing on the individual impairment, to one focusing on the barriers associated with any form of impairment, which result in deprivation of human rights of people with disabilities.[1018]

The following proposal for the Preamble contained in the Chair's Draft for the Working Group illustrates not only the importance attached to how persons with disabilities are "perceived" ("a principal purpose") but also how problematic current perceptions were regarded as well as how closely connected to the denial of human rights:

> *Recognizing* that the continued denial of the human rights of persons with disabilities reflects deep-seated, persistent and invidious prejudice and stereotypes that persons with disabilities are incapable and unworthy of participating in and contributing to society and that a principal purpose of this Convention is to ensure that persons with disabilities are perceived as individuals worthy of respect who are full participants in and members of their societies[.][1019]

This language was strongly objected to in the Working Group, as a "deeply negative message" about persons with disabilities.[1020] In effect, it is rather deeply negative about those holding such prejudice and stereotypes. What the objections illustrate is perhaps that stating a degrading view, nota bene as erroneous, does not entirely neutralise its offensiveness and can even contribute to its reproduction. The power of terminology and the centrality of portrayal to the CRPD are likewise apparent in the call for acceptable labels for categories of persons with disabilities. One such example is the following reprimand from Canada in the 5th session, objecting to terms used to depict persons with intellectual disabilities:

> Canada asked delegations to use respectful language when discussing this Convention. Use of negative language may perpetuate negative stereotypes that this Convention addresses. For example, terms such as intellectual disabilities are preferable.[1021]

Turning to Articles 25 and 26, the urge in the negotiations to ring fence entitlements amounting to interventions targeting the individual level or mode of functioning of the body and mind (i.e. entitlements related to health) was intimately connected to the implications of such entitlements for the portrayal of what defines the constituency of the CRPD. As noted above under 12.1.1., the negotiations were coloured by an urge for the CRPD not to portray its constituency in a way that linked it to question of health: as 'unhealthy' or 'sick. In addition to the habitual use of the ex-

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[1018] LSN, Legal Analysis, 4th Session, p. 3.

[1019] Chairman of the Ad Hoc Committee, Draft Preamble (f), Compilation of Proposals before the Working Group, 2004, p. 8.

[1020] Recorded statement by Sweden. Daily Summaries 13 January 2004, Working Group Session.

[1021] Daily Summaries 25 January 2005, 7th Session.

pression 'the medical model' as a term of abuse, references to "medical treatment" were used as indicative of a "view" of persons with disabilities which the CRPD and the negotiations rightly departed from, as here by Louise Arbour at the adoption of the CRPD by the Ad Hoc Committee:

> Chairperson, time is limited, but allow me to make some short comments on the future. In particular, I would like to highlight the importance of the Convention as a catalyst for change. We have often heard that the Convention enshrines a "paradigm shift" in attitudes that moves from a view of persons with disabilities as objects of charity, *medical treatment* and social protection to subjects of rights, able to claim those rights as active members of society. Nowhere has this been so much in evidence as in this Ad Hoc Committee.[1022]

Concerns about the view of persons with disabilities forwarded by choice of language was ever-present in the negotiations. Language proposed was objected to as e.g. "paternalistic"[1023], "condescending"[1024], "stereotyp[ing]"[1025], "negative"[1026], or "pejorative"[1027]. Some examples are provided here for illustration. The reference to "health care" in Draft Article 25 was objected to as it "gives the perception that people with disabilities needs to be taken care of"[1028] and "will add a paternalistic tone that is not helpful"[1029]. Instead the term "health services" was preferred as "more in line with rights-based language of the 21st century".[1030] In relation to equality and non-discrimination, the habitual reference to "special measures"[1031] in Draft Article 5 on Equality and non-discrimination was omitted due to concerns that "in the disability context, "special" has sometimes had a derogatory meaning"[1032] and "connotes discrimination of some sort, which this Convention must avoid"[1033]. Also, in relation to what was to become the definition of "[r]easonable accommodation" in Article 2 on Definitions, the term "burden" was objected to as it "perpetuates a very negative portrayal of persons with disability as "burdens on society" and is inconsistent with a rights-based approach".[1034] Other expression with which quarrels were had due to

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[1022] Statement by Arbour, Louise, UN High Commissioner for Human Rights to the Resumed 8th Session of the Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities, 8th Session, 5 December 2006. Emphasis added.

[1023] See quote referenced in note 1029, Part II, below.

[1024] See quote in note 1036, Part II, below.

[1025] See quote referenced in note 1040, Part II, below.

[1026] See quote referenced in note 1034, Part II, below.

[1027] See quote in note 1035, Part II, below.

[1028] IDC Statement on Article 25 on Health, 7th Session.

[1029] Recorded statement by IDC during the 7th session. Daily Summaries 25 January 2006, 7th Session.

[1030] IDC Statement on Article 25 on Health, 7th Session.

[1031] Draft Article 7 (5) on Equality and non-discrimination, Working Group Draft, 2004, p. 14.

[1032] LSN, Legal Analysis, 4th Session, p. 16. See also Working Group Draft, 2004, p. 14, note 28 to the same effect.

[1033] Recorded statement by Ghana, speaking on behalf of the African Group. Daily Summaries 24 January 2005, 5th Session.

[1034] PWDA and NACLC, Intervention on Article 2: Definitions, 7th Session, 2006, p. 2.

their connotations include "alternative"[1035], "needs"[1036], "assistance"[1037], "enable"[1038] and "facilitate"[1039].

A reoccurring theme concerning how persons with disabilities were to be portrayed in the CRPD was objections to the portrayal as "vulnerable". This was underscored in particular in relation to the drafting of Article 16 on Freedom from exploitation, violence and abuse and Article 11 on Situations of risk and humanitarian emergencies. In relation to the former article Japan emphasised during the 4th session that "[c]aution should be taken in drafting to not stereotype PWD [persons with disabilities] as vulnerable and necessarily targets of abuse".[1040] In relation to Article 11, IDC noted that "[t]he terminology "vulnerable" has negative implications, especially when referring to persons with disabilities".[1041] The point was made that the text should rather reflect the group as "forgotten or left behind", by using the term "NEGLECTED".[1042] This point, that disadvantage not be explained as a consequence of something inherent in or attributable to the individual, was noted by the Chair during the 7th session as important to the drafting of the CRPD:

> The Chair informed the committee that the Office of High Commissioner for Human Rights has an increasing tendency to change the term "vulnerable groups" to "groups in vulnerable circumstances." This indicates that vulnerability is acknowledged as inherent to the situation and not to the members of the group. The Chair encouraged delegates to reflect on this possibility, noting that this is an important matter of nuance that does affect the underlying theme of the convention.[1043]

[1035] New Zealand is recorded in the 3rd session as "suggest[ing] that "alternative," which may have a pejorative connotation, be replaced in all instances with "a variety of."". This statement was made in relation to how to qualify "communication" in Draft Article 13 on Freedom of expression and opinion, and access to information. Daily Summaries 27 May 2004, 3rd Session.

[1036] The EU is recorded during the 4th session as noting that it "does not support references to "needs" of PWD [persons with disabilities] and is hesitant to include any proposals that "could be seen as being of a condescending nature."". Daily Summaries 31 August 2004, 4th Session. This statement was made in relation to Draft Article 5 on Promotion of positive attitudes to persons with disabilities.

[1037] The Chair is recorded during the 6th session as noting that "[t]here is opposition to "assistance," especially as used in 17.5, due to its negative connotations, and suggestions from many delegations call for replacing this word with "support". Daily Summaries 4 August 2005, 6th Session. This statement was made in relation to Draft Article 17 on Education.

[1038] New Zealand is recorded during the 7th session as proposing "to use "assisting" instead of "enabling" so that the article would not seem patronizing". Daily Summaries 24 January 2006, 7th Session. This statement was made in relation to Draft Article 24 on Education.

[1039] MDRI is recorded during the 7th session as "support[ing] New Zealand's proposal to replace "facilitate" in 24(3) with less paternalistic language that emphasizes assistance and access to means to learn life and development skills". Daily Summaries 24 January 2006, 7th Session. This statement was made in relation to Draft Article 24 on Education.

[1040] Daily Summaries 26 August 2004, 4th Session.

[1041] IDC Amendments to Chair's Draft, 7th Session, p. 26 (source not paginated).

[1042] Ibid. Emphasis in original.

[1043] Daily Summaries 17 January 2006, 7th Session. In addition to such nuance of language the ICD, in this exchange, seemed to down play the particular relevance of such *situations*: "All people are vulnerable in situations of risk and PWD are often in no greater position of vulnerability than everyone else.". Ibid.

The urge to call for attention to a problematic situation while not letting the problem 'taint' the perception of the group led to some inconsistencies in the position of those contributing to the negotiations of the CRPD. For example, IDC, in contrast to the points made in relation to Article 11, stated in relation to Article 16 that it "is essential that this Convention recognize the *disproportionate vulnerability* of persons with disabilities to violence and abuse and take adequate and appropriate steps to protect persons with disabilities from such acts".[1044]

Many of the quotes employed above in order to illustrate different dimensions of the importance attached by the negotiators of the CRPD to how its constituency was portrayed are statements about defining, or amounting to a definition of, 'disability' or 'persons with disabilities'. What became of these statements, Preamble (e) and Article 1 on Purpose, is testament to the fact that portrayal, "guiding disability awareness"[1045], is a core function of these articles. Perhaps the clearest indication of this is the inclusion of Preamble (e) in addition to Article 1, as the former adds little to the legal purpose of the latter which was expressed in the negotiations as making sure that no one was unduly omitted from the protection of the CRPD.[1046] In addition, even Article 1 by itself indicates that its mission extends that of deciding who is eligible for its entitlements. Firstly, the inclusion of a reference to environmental barriers and disadvantage does not answer to the main concern regarding coverage as it came through in the negotiations, namely that nobody be unduly excluded.[1047] Secondly, the call for the depiction of 'disability'/'persons with disabilities' to direct attention to environmental barriers rather than to levels and modes of functioning of the body and mind as a cause of disadvantage in relation to composite life opportunities had little legal necessity. When the negotiations on a depiction of 'disability'/'persons with disabilities' commenced in earnest this was already contained as a fundamental aspect of the entitlements and obligations in the CRPD, in the sense that the overwhelming majority of its provisions stipulated obligations of the State to realise composite life opportunities by addressing environmental barriers.[1048] Only Article 25 on Health and Article 26 on Habilitation and rehabilitation create entitlements amounting to interventions targeting impairment and only Article 26 links these to the realisation of composite life opportunities. The direction of the CRPD in this regard was thus set before the drafting of Preamble (e) and Article 1 took place. Thirdly, illustrating that the focus in drafting these articles was not primarily the range of entitlements

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[1044] IDC Information Sheet on Article 12, 5th Session. Emphasis added.

[1045] Recorded statement by National Human Rights Institutions. Daily Summaries 23 August 2004, 4th Session.

[1046] See above under 10.

[1047] See above under 10.1.6.

[1048] This was noted by PWDA et al. before the 7th session in relation to the need for the definition to reflect "a social model of disability", which was juxtaposed with "incorporat[ing] a clear relationship with impairment": "Further, it was argued in line with the 2004 Australian consultation findings, that it should be recognised that all of the substantive articles of the convention identify and respond to the social and environmental barriers encountered by people with disability, so the convention has achieved its objective of being based in a social model of disability.". PWDA et al., Report on National Consultations, 7th Session, p. 10.

they cover, is that they, presumably without intention, forward a conception of life opportunities which is potentially more limited than “discrimination”[1049] and “violations of […] human rights”[1050], namely “social participation”. “[S]ocial” can be interpreted widely and these three expressions are parallel, which means that this potential limitation will have no legal import. However, the inclusion of “social participation” is not an addition which rings of being included by virtue of it extending the range of life opportunities covered in the CRPD, but rather for purposes of staying close to the “social model” of disability.[1051] Instead of affecting which entitlements can be demanded by whom under the CRPD, the attention paid to environmental barriers and ensuing disadvantage in Preamble (e) and Article 1 is there primarily for reasons of portrayal. It is a principled recognition that the core problem definitive of the constituency of the CRPD is restricted composite life opportunities and that the genesis of such lost opportunities implicates the environment.

In line with the aim of the CRPD to focus on the restricted composite life opportunities of its constituency rather than on impairment, the constituency of the CRPD is thus defined in Article 1 in terms of ”disabilities” rather than “impairments”. The depiction of “[p]ersons with disabilities” in the CRPD differs from the depiction of other groups in previous UN human rights instruments serving as inspiration in the negotiations, such as CEDAW (women) and CRC (children). Even though the latter two groups are protected due to the fact that they were seen as facing undue disadvantage not justifiable by reference to their ‘group marker’, unlike persons with disabilities, *they are not depicted by reference to such disadvantage*. CEDAW refers to ‘women’, not ‘persons subjected to sexism’ and CRC refers to ‘children’, not ‘persons subjected to ageism’. Children, like the constituency of the CRPD, were deemed as needing to be depicted for inclusion/exclusion purposes. However, the definition of a “child” in the CRC stays on the individual level: “every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier”.[1052] The purpose of all these instruments is to target disadvantage and even the adoption of the instruments per se is a rebuttal of the group marker as a prima facie explanation or excuse for disadvantage. Depicting the group through the social disadvantage experienced, as is done in the CRPD, fits well within this tradition as it works as a device for pulling the attention in the direction of how society responds to a person rather than in the direction of the perceived ‘difference’ of that person. In this way, habitual tendencies to abuse such ‘difference’ as an excuse or explanation for disadvantage as ‘natural’ or ‘inevitable’ are counteracted. The depiction of the group through its social disadvantage and implicating the environment as instrumental towards such disadvantage as is done in the CRPD is thus in line with the direction of earlier instruments. The amplification of this direction in the CRPD is a clear ex-

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[1049] Article 2 on Definitions.

[1050] Preamble (k).

[1051] See above under 10.1.6. and 11.1.

[1052] CRC, Article 1.

ample of the "social model" of disability making its mark on the human rights legal framework.[1053]

To conclude, how the constituency of the CRPD was portrayed was central to the negotiators of the CRPD, resulting in this constituency being depicted through experiences of environmental barriers and social disadvantage. Concerns about portrayal permeated choices of language and included forwarding a picture of capacity and contributions rather than inability, vulnerability and requirements for care, particularly health-related care. Finally, the importance accorded portrayal lay chiefly in the creation of a social context generally susceptible to the realisation of the entitlements in the CRPD.

12.1.4. Concerns regarding undue professional influence and interventions

As noted above under 9.1.6., the medical profession was the epicentre of the concerns about undue professional influence and interventions expressed in the negotiations of the CRPD. It was in relation to interventions in the area of health that the question of the relationship between the professional and the consumer in terms of power (including the right to say no to professional intervention) as well as the question of the quality of such intervention was discussed most fervently. This is evident from the end result, as both Article 25 on Health and Article 26 on Habilitation and rehabilitation emphasise voluntariness and as Article 25 is the only provision which contains a situated requirement of States to address the values of professionals.

While Articles 25 and 26 emphasise the role of choice as a mechanism for protection in relation to professional services (an aspect of life opportunities further underscored in general terms in Article 3 on General principles, Article 12 on Equal recognition before the law, Article 15 on Freedom from torture or cruel, inhuman or degrading treatment or punishment and Article 17 on Protecting the integrity of the person), this barrier against harmful treatment is however only partial. Firstly, while the issue of choice emerge as a key feature in counterbalancing the power of professionals as well as is central to whether a form of 'treatment' is to be seen as beneficial or not, the reach of individual choice remains to be seen as the final balance between individual choice and State overdrive is still in need of thorough interpretation.[1054] Secondly, irrespective of the outcome of interpretation in this respect the issue of protection against undue treatment is larger than the question of choice. This is so as certain contested forms of medical treatment are questioned *per se*, which makes it problematic that these remain recommended or even urged by the medical profession. The relevance of this emerges against the backdrop of history, with former practice such as e.g. lobotomy illustrating that yesterday's 'care' is today's abuse. Furthermore, even if the choice remains with the individual, service

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[1053] See above under 11.1. See further Arnardóttir, 2009, pp. 58-59.

[1054] See further above under 7.1.1., 7.2.3.-7.2.5., 7.2.7. and 7.3.2.

providers remain likely to influence the choice of the individual, if nothing else so by which alternatives are presented to the individual, how these are presented and to what extent change is presented as desirable. Thirdly, the provision of choice does not protect persons whose choices the outside world is unable to detect or children who remain at the collective mercy of professionals and parents. The latter question was discussed in the negotiations in relation to when and if sterilisation of children is therapeutically called for and the risk that parents make such choices on behalf of children for the former's own benefit.[1055]

> In many countries in the world, parents arrange for girls with disabilities to be sterilised in order to avoid the risk of pregnancy and even to avoid the inconvenience of dealing with menstruation. Sterilisation of girls with disabilities represents a fundamental violation of their physical integrity. It exposes them to major medical intervention for no clinical benefit. It denies them the right to found a family. It is an intervention, in most instances, serving the interests of the parents rather than the child.[1056]

The issue at heart here is that if parents have the right to consent to the treatment of a minor, leaving only a limited right for the child to influence such decisions, the only avenue for protection against certain forms of intervention presents itself as a blanket prohibition of the intervention. Parents make decisions for their children within the realm of what is professionally sanctioned. This accords professionals a key role both in determining this spectrum and in influencing navigation within it. This role of professionals is recognised generally in Article 23 (3) on Respect for the home and the family which calls for the provision of information to parents. While the explicit aim of "early and comprehensive information" here is to "prevent concealment, abandonment, neglect and segregation of children with disabilities", such information clearly also affects the kind of interventions performed.[1057]

While professionals, as well as parents in relation to children, can withhold (or be unable to provide) beneficial treatment just as well as mistreat or 'over-treat', the ever present fear in the negotiation was the latter problem. In relation to medicine and rehabilitation, it was the choice to say 'no' to unwanted treatment which received the lion's share of attention, rather than the power to demand wanted treatment. In the negotiations, the medical profession was placed at the centre of a misconceived vision of 'human perfection'.[1058] Here, the suggestion by Namibia during the 3rd session to add "respect for diversity" to the aspects of 'value-proofing' for medical pro-

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[1055] See e.g. Daily Summaries 1 February 2006, 7th Session.

[1056] IDC Response to the Facilitator's Proposal on Children, 7th Session, p. 7 (source not paginated). In view of this, IDC proposed an additional paragraph to Draft Article 25 on Health: "States Parties shall protect children from sterilisation on the basis of disability.". As mentioned above under 7.2.12., Article 23 (1c) calls for measures to ensure that "[p]ersons with disabilities, including children, retain their fertility on an equal basis with others", thus emphasising the position of children in this context.

[1057] This also relates to the issue of prenatal screening as discussed above under 7.2.1.

[1058] Compare Draft Article 21 (k) on Right to health and rehabilitation in the Working Group Draft which expressly obliged States to "[p]revent unwanted medical and related interventions and fessionals in what became Article 25 (d) is telling.[1059] Provisions stemming from such concerns include the (less explicit) final language of 25 (d) but also Article 3 (d) on General principles and Preamble (m). In addition, as noted above under 12.1.1., a focus on medical intervention was portrayed as being in opposition to accommodation of diversity in the sense that it diverts society's attention and efforts away from opening up the life world to *all* persons.

Finally, another way in which medical service provision was targeted in a negative light concerned the slanted relationship in terms of power between professional and consumer. This was seen as part and parcel of the medical field: "the "doctor knows best" attitude".[1060] This aspect of the medical context led to a wish to ring fence the area of health in order for this relationship not to 'spill over' to other areas of service. Such concerns manifested themselves in particular through the call for the removal of aspects of (re)habilitation other than those related to health from Draft Article 21 on Right to health and rehabilitation and into a separate article. The separation of (re)habilitation from health was thus seen as merited against the backdrop of the power imbalance between medical professionals and the constituency of the CRPD, expressed here by RI during the 3rd session:

> [R]ightly or wrongly, to depict rehabilitation against the backdrop of health will only serve to heighten the fear of persons with disabilities that those who exercise authority will impose rehabilitation and might now be able to claim the imprimatur of international law. This fear is wholly understandable given the experiences of many persons with disabilities to date throughout the world. The so-called medical model of disability may well be a parody of the true medical mission which is of course to honour and serve human beings. But we cannot ignore the legacy of the past. It would therefore be wiser to separate out habilitation and rehabilitation in order to underscore the primacy of the person as against the power of the expert over the process. This, after all, is what the shift to the rights-based perspective on disability is supposed to be about.[1061]

To this end IDC suggested during the 7th session that Article 26 be explicit on that (re)habilitation plans "assist individuals to meet their actual life goals and personal aspirations".[1062] Another effort to bridge the perceived gap between professional and consumer in terms of power was contained in Draft Article 21 (g) on Right to health and rehabilitation, calling as it does for States to "encourage the development of sufficient numbers of health and rehabilitation professional, including persons who have disabilities".[1063] This language did not make it to the final version of the CRPD.[1064]

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corrective surgeries from being imposed on persons with disabilities". Working Group Draft, 2004, p. 27.

[1059] Daily Summaries 1 June 2004, 3rd Session.

[1060] IDC Working Group on Legal Capacity, Integrity and Related Issues, 8th Session.

[1061] RI Intervention on Article 21 on Health and rehabilitation, 3rd Session, 2004.

[1062] IDC Amendments to Chair's Draft, 7th Session, p. 53 (source not paginated).

[1063] Working Group Draft, Draft Article 21 (g), p. 27, 2004.

[1064] One article in the final version of the CRPD recognises that being part of the constituency of the CRPD and being a professional tasked with the implementation of the CRPD are not mutually

To conclude, concerns about undue professional influence and interventions centred on the right to health and led to a focus on the ability to deny rather than to demand health interventions.

12.2. Diverging agendas among the constituency of the CRPD

The fundamental point of departure in the implementation of the CRPD, as a human rights instrument, is to accord equal concern to the requirements of those persons it covers. Taken the heterogeneity of the constituency of the CRPD regarding not only additional factors but also the factor which is part of the asserted commonality of the constituency in Article 1 on Purpose, "impairments", this is truly challenging. As discussed above under 12.1.1., many proposals reflecting the importance of according attention to the diversity of the constituency in terms of impairment were left out of the final text of the CRPD due to concerns regarding drawing attention to factors adhesive to the individual as opposed to the environment. However, as noted there, the fact that requirements differ according to impairment and the importance of not unduly excluding someone, or the requirement of someone, from protection was also a central concern. The following statement by EDF addresses this as a question of the "equal relevance and value" of the CRPD to its entire constituency:

> A Convention must respect the broad diversity of the population of persons with disabilities, so that it is of equal relevance and value, irrespective of impairment type and geographic location.[1065]

This reference to diversity covers geography and "impairment type", to which many others could be added, including those enumerated in Preamble (p): "race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth [and] age".

Staying with heterogeneity in terms of impairment, concerns regarding making sure that the CRPD be implemented with everyone, and the requirements of everyone, in mind thus clashed with concerns not to draw attention to impairment or its importance. This resulted in general language aimed at appeasing both concerns. As noted above under 12.1.1., the prime example of this is the inclusion of the word "all" in front of "persons with disabilities" in Article 1 on Purpose. Preamble (i)

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exclusive positions. Article 24 (4) on Education calls for the intersection between these positions as it obliges the State "to take all appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille". The Working Group draft put this question on the table in the form of a footnote, but it was not part of Draft Article 17 on Education. Working Group Draft, p. 22, note 59.

[1065] EDF, Compilation of Proposals before the Working Group, 2004, p. 26.

furthermore calls for the recognition of "the diversity of persons with disabilities", which was intended to cover diversity in terms of impairment.[1066] In addition, certain provisions call for measures to be "disability[...]-appropriate"[1067] or "disability-sensitive"[1068].

The impetus to equally address the requirements of everyone poses the question of whom 'everyone' consists; who is the constituency that the CRPD Committee is tasked to represent and what are the requirements and wishes of the persons covered? As discussed in Chapter 10, the depiction of "[p]ersons with disabilities" in Article 1 mentions a number of general categorisations of "impairments" ("physical, mental, intellectual or sensory") but does not, except for the depiction of these as "long-term", specify "impairments" further. As visible from the exchange on the question whether or not to define 'disability' and/or 'persons with disabilities' accounted for above in Chapter 10, States did not necessarily come to the negotiating table with the same constituency in mind. It seems that, albeit repeatedly depicting the constituency in set numbers (600 or 650 million), it was not obvious whom, outside an undisputed core consisting in high levels of permanent impairment immediately associated with the categories above, the CRPD is about.[1069] More importantly, this was not systematically discussed as an aspect of what entitlements and obligations the CRPD was to cover in relation to each of its provisions. Thus, much like in the disability discourse in general, the negotiations proceeded to discuss which life opportunities and threats to such were central to 'persons with disabilities' without an explicit shared view on the outer limits of who the constituency intended to benefit from the CRPD was.

IDC spoke for the constituency of the CRPD, calling for the acceptance of its proposals by stating that "[t]hese are very important issues for persons with disabilities".[1070] It asserted to represent all persons with disabilities, as in the following statement from the 4th session by WBU representing IDC:

> The Caucus has drafted an alternative text for the Committee during the last eleven weeks, the result of more than 700 emails. The Caucus would like to submit this amended text as it is generated, as it is a work in progress. The target group for the convention is 600 [million] PWD [persons with disabilities] around the world and there are DPOs reflecting that.[1071]

WNUSP furthermore recognised the importance of diversity in order for the interest of all to be represented:

[1066] See above under 12.1.1.

[1067] Article 7 (3) on Children with disabilities.

[1068] Article 16 (2) on Freedom from exploitation, violence and abuse.

[1069] See note 726, Part II, above under 10.1.3.

[1070] IDC, List of Key Issues Related to Non Bracketed Text, 8th Session, 18 August 2006.

[1071] Daily Summaries 24 August 2004, 4th Session.

> [WNUSP] noted that NGOs come with experience in specific disability issues that may or may not represent the concerns of all PWD [persons with disabilities], and for this reason all of their expertise needs to be heard.[1072]

Statements to the effect that the requirements of persons with particular impairments were neglected in the negotiation were not a common feature, but did figure. One particular group which was repeatedly mentioned as not receiving enough attention was people who are deaf or hard of hearing and who do not use sign language:

> The second point I would like to make is the information needs of people who are hard of hearing. The barriers faced by hard of hearing people, people who do not hear well but do not know sign languages, have been under-represented, to say the least, in the discussions and negotiations of this Convention.[1073]

In the following, two aspects of diverging agendas among the constituency of the CRPD will be drawn out: differing levels of support requirements (12.2.1.) and differing health-related requirements (12.2.2.).

12.2.1. Divergence of agendas depending on differing levels of support requirements

Generally, as discussed above under 10.1.3., the question how to make sure that the CRPD caters equally for the needs of its entire constituency relating to 'levels' of impairment was addressed in the negotiations in terms of "severity" of impairment. As discussed there, proposals calling attention to the requirements of segments of the constituency of the CRPD in such terms were rejected for a number of reasons,

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[1072] Daily Summaries 5 January 2004.Working Group Session.

[1073] JDF, Statement on Article 19 on Accessibility, 6th Session, 5 August 2005. To remedy this, JDF proposed during the 7th session to explicitly include the provision of "display of text" and "speech-to-text interpreters" in Draft Article 9 on Accessibility. JDF Comment on the Chairman's Text, 7th Session, 2006, pp. 6-7. Similarly, IDC proposed during the 6th session to include in Draft Article 19 on Accessibility a requirement for "effective methods of making oral communication available to people hard of hearing", IDC Draft on Accessibility (Draft Article 19), 6th Session, 3 August 2005, p. 3. No such additions were made to these articles, however "display of text" was added to the definition of "[c]ommunication" in Article 2 on Definitions during the 7th session. See CRPD Working Text after the 7th session, 2006, p. 8. Further on this issue, in the 5th session Japan called for that "the various modes and means of communication need to be treated equally [and] [p]rivileging sign language and/or Braille over other means of communication or over one another would be strange". Here, they emphasised the situation of "those members of the deaf community who have lost their hearing over the course of their life [who] would then face the additional burden of not being "native speakers" of sign language". Daily Summaries 1 February 2005, 5th Session. Calls for attention to person who are deaf but who do not use sign language were also made by Ontario Human Rights Commission in the 3rd session in relation to Draft Article 13 on Freedom of expression and opinion, and access to information and Draft Article 24 on Participation in cultural life, recreation, leisure and sport. Ontario Human Rights Commission, Comment on the Draft Convention, 3rd Session, pp. 10, 19.

including that it was "negative labeling", reflected the "medical model" as opposed to the "social model" and created a "hierarchy" among persons with disabilities. The outcome of this debate is that the final version of the CRPD does not contain any reference to the particular situation or demands of persons with 'severe' impairment in its provisions covering particular areas or aspects of life. Instead, Preamble (j) recognises, in general terms, "the need to promote and protect the human rights of *all* persons with disabilities, *including those who require more intensive support*".[1074] Compared to the original formulation in Draft Preamble (m) this provision avoids the expression "severe" as well as any reference to levels and modes of functioning of the body and mind.[1075] Instead it focuses on the difference in the obligations of States flowing from the different requirements among the constituency. As an interpretative provision, it reminds of that higher support needs require *more* support as opposed to being a legitimate excuse for lack of efforts to realise the life opportunities protected in the CRPD. In addition to the discussion whether to explicitly call attention to the situation or demands of this segment of the constituency, positions taken on particular issues were justified by reference to its situation. Two examples of such issues are the role that the CRPD should accord to the families of its constituency and the question of legal capacity.

In relation to family, the desire to put the person in the driver seat of his or her own life[1076] as well as the recognition of the abuse at the hands of families[1077] engendered caution towards recognising family as a source of support in the CRPD.[1078] In the words of one commentator, "in its simplest form, the debate was between advocates of families of persons who have [...] intellectual disabilities – especially those with the greatest need for support – who argued that families need to be there to represent those who do not speak for themselves, and persons with disabilities whose experiences have been that their families had tried to make decisions for them, often against their will".[1079] In the final version of the CRPD, Preamble (x) contains

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[1074] Emphasis added.

[1075] Working Group Draft, 2004, p. 8.

[1076] See e.g. intervention by Japan during the 4th session in relation to a proposal to include the family as a stake holder in the right to participate in decision-making about policies and programs recognised in Draft Preamble (l): "Japan still has "some difficulties" with referencing families in (l), even when qualified with "as appropriate" and called for its deletion. Although Japan supports family values, it pointed out that families often suppress the free decision-making of persons with disabilities.". Daily Summaries 23 August 2004, 4th Session. WNUSP echoed the position of Japan, referring to such proposals as "paternalism". Ibid. Draft Preamble (l) read "*Considering* that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, especially those directly concerning them". Working Group Draft, p. 8. Emphasis in original.

[1077] For an exchange on the dual role of family as potential support and abuse, see e.g. the deliberations on Article 16 on Freedom from exploitation, violence and abuse during the 7th session. Daily Summaries 19 January 2006, 7th Session. See also above under 10.3.1.1.

[1078] In addition, as illustrated above under 7.3.3., there was a North-South divide on the proper constellation of living arrangements as with or without the larger family.

[1079] Richler, Diane, The Meaning of the CRPD and the Role of the Family in the Lives and Future of Children and Youth with Disabilities, in Rehabilitation International (RI)/United Nations a general recognition of the role of the families of persons with disabilities. While (x) notes that "the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance", the goal of such assistance is "to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities". In other words, the end beneficiary and rationale for the assistance is the person with disabilities and this assistance is to work towards not just any idea of what is best for the person but what the CRPD says it is, including its requirements of individual autonomy, independence and choice.[1080]

Calls for recognition of the role of the family were made from the perspective of persons discussed in terms of "severe" impairments. For example, Article 28 (2c) on Adequate standard of living and social protection which obliges the State to take measures "[t]o ensure access by persons with disabilities *and their families* living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care" was originally phrased as applying only to "persons with severe and multiple disabilities".[1081] Calls for recognition of the role of the family against the backdrop of this particular segment of the constituency were the strongest in relation to the obligations of States to consult with stakeholders on the development of legislation and policies and in decision-making on issues relating to persons with disabilities (what eventually became Article 4 (3) on General obligations).[1082] The clear focus of this provision and the discussions preceding it was that the parts of the constituency which were not politically active would be represented by organisations made up by the constituency of the CRPD. As part of the debate on the increasing importance of family correlative to level and kind of impairment it was argued by some States that the obligations to consult families should be explicitly recognised in what became 4 (3).[1083] This was opposed with the argument that a person is best represented by other persons with disabilities and with reference to the tradition to disregard the

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Children's Fund (UNICEF), One in Ten : What Does the CRPD Mean to the Lives and Future of Children and Youth with Disabilities?, Vol. 26, 2008, p. 18.

[1080] Preamble (x) was added during the 7th session after a proposal from the US. See Daily Summaries 2 February 2006, 7th Session. This proposal was further developed during the 8th session. It should be noted here that the first half of this paragraph is not organic to the CRPD but is taken verbatim from Article 16 (3) of UDHR.

[1081] Emphasis added. See Working Group Draft, 2004, p. 102. Calling for the retention of the reference to "severe and multiple" during the 6th session in (what was then) Draft Article 23 (1c) on Social security and an adequate standard of living, Thailand is recorded as "ask[ing] for "empathy and understanding" from the Committee with regards to people with severe and multiple disabilities in para (c), because they need special attention". Daily Summaries 8 August 2005, 6th Session.

[1082] See generally on Article 4 (3) above under 9.1.7.

[1083] See e.g. intervention by Trinidad and Tobago during the 3rd session (Daily Summaries 25 May 2004, 3rd Session) and by numerous States, in particular by India, during the 4th session (Daily Summaries 30 August 2004, 4th Session).

position of members of the constituency of the CRPD and instead listen to others such as family members.[1084] In the end, the reference to "their representative organizations" in 4 (3) potentially includes organisations made up of parents or other family members.[1085]

It remains that those with whom the world (peers, families, professionals as well as others) do not easily communicate, those who were not present in the negotiations, can only give limited guidance as to their preference on particular issues. This includes who they prefer to advocate for law, policy, services and care as well as who they prefer to provide such services and care. It also remains that, irrespective of the availability of services from the State for everyone, different levels and modes of functioning of the body and mind will leave diametrically different gaps to be filled by priming families as 'champions' to secure entitlements for person with disabilities through interaction particularly with the State apparatus. As noted in the following quote by EDF, implementation of the CRPD must balance efforts to maximise the potential of families for those "who cannot represent themselves" with making sure that self-representation remains the rule:

> The UN Convention is to protect the rights of persons with disabilities as individuals. However, it is obvious that the family of children and of adults with disabilities who can't represent themselves plays a key role in the process to ensure the protection and promotion of the rights of persons with disabilities.[1086]

Turning to the issue of legal capacity, as discussed above under 7.2.1., 7.2.3.-7.2.5., 7.2.7. and 7.3.2., the question of systems determining the decision-making capacity of a person and, if found wanting, transferring the power to make legally effective decisions to another person was one of the most controversial issues in the negotiations of the CRPD. Like the issue of the role of family, proponents of the need for what was generally referred to as 'substituted' rather than merely 'supported' decision-making based their arguments on the requirement of those with "serious" or "major"

[1084] See generally the exchange of views on this issue during the 4th session. Daily Summaries 30 August 2004, 4th Session.

[1085] India noted this formulation as open to such interpretation during the 7th session. Daily Summaries 31 January 2006, 7th Session. This interpretation had earlier been acknowledged by the Coordinator during the 4th session. Daily Summaries 30 August 2004, 4th Session.

[1086] EDF Position Paper on Working Group Draft, 3rd Session, p. 2. The importance attached to level of disability in relation to advocacy is evident in the literature on the implementation of this aspect of the CRPD. The learning of "self- advocacy skills", here in the area of health, is explored for persons with "mild and moderate" intellectual disabilities. Feldman, Maurice A. et al., Health Self-Advocacy Training for Persons with Intellectual Disabilities, Journal of Intellectual Disability Research, Vol. 56, Part 2, 2012, p. 1119. Meanwhile, for reasons of level of impairment, among others, it is held that "while self-advocacy may be considered preferable, many people with ID [intellectual disability] require supportive advocacy to have their voices heard and their health needs met" and the role and potential of advocacy on behalf of "[f]amily and disability support worker" in the implementation of the CRPD is explored and confirmed. Brolan, Claire E. et al., Health Advocacy: A Vital Step in Attaining Human Rights for Adults with Intellectual Disability, Journal of Intellectual Disability Research, Vol. 56, Part 2, 2012, p. 1088.

impairments, here referring to some persons among those with intellectual and psychosocial disabilities. Two sides emerged as champions of the "serious" or "severe" cases in relation to whom substituted decision-making was proposed by some.

Proponents emphasised that without such arrangements, which would be an exception to the rule, this segment of the constituency of the CRPD would not be adequately protected. Norway is recorded during the 5th session as stating that "there are certain disabilities, for example serious learning disabilities, developmental disabilities, and major mental illness, which may prevent the person from representing his own interests and may create a need for protection" and as noting the need to "take into account the great diversity of disabilities and the need to assist or protect certain groups".[1087] Along the same lines, the African Group is recorded during the 7th session as making the following statement in relation to what became Article 12 on Equal recognition before the law:

> This article must explicitly protect the rights of those persons [who require somebody else to make decisions on their behalf], who are particularly vulnerable. It is not sufficient to stop at the point of supported decision making. Neglecting to ensure the rights of those whose disabilities are so severe that they cannot express their preferences would represent a critical failure of the convention. As we draft this convention, the rights of all persons with disabilities must be the key focus, including the most vulnerable.[1088]

The most vociferous opponent of substituted decision-making in the negotiations was WNUSP, speaking on behalf of IDC. They questioned any gain by arrangements for substituted decision-making for the segment of the constituency relied upon by its proponents. In addition, they legitimised their opposition through the negative effect the existence of such arrangements would have on the remainder of the constituency, under the heading "Substituted Decision Making will apply to *all* persons with psychosocial disability":[1089]

> A further argument by proponents of some form of substituted decision-making is that as a rule all persons with disability have legal capacity but there are a very small percentage of persons with severe disability for whom supported decision-making will not be sufficient and for whom guardianship will need to be provided. […] It therefore becomes necessary to ask by what procedure this small percentage of persons will be identified. Evidently this will be done from case to case. This process of identification will render the capacity of all persons with psychosocial disability open to question. *This would give rise to a situation where for questionable advantages to a small group of persons all persons with psychosocial disability shall be disadvantaged*. The contention of questionable advantage is being made because studies evaluating the functioning of

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[1087] Daily Summaries 25 January 2005, 5th Session.

[1088] Daily Summaries 3 February 2006, 7th Session. For the same reasons, PWDA et al. similarly called for recognition of "the need for formal supported decision-making and financial management arrangements for some people in some circumstances". PWDA et al., Contributions Articles 1 to 15, 4th Session, p. 16.

[1089] Emphasis in original.

> guardianship have found abuse isn't in fact prevented with guardianship, it is facilitated. Further these arrangements once made cause the guardian to take all decisions on behalf of and without consultation with the ward. This ouster makes for the civil death of the persons subjected to guardianship.[1090]

The example of the "severity" debate points to impairment as determining requirements as well as to the recognition of the requirements of some as potentially counterproductive to the interests of others.[1091] Some of the concerns about explicitly recognising particular solutions in the name of "those who require more intensive support"[1092] seem to have included (in addition to concerns about what is de facto beneficial for this segment of the constituency) fear of these solutions 'spilling over' to others. In relation to substituted decision-making in particular, concerns included that if an inch was given from outright prohibition, even that which was intended as an exception (substituted decision-making) would remain the rule that it presently is for parts of the constituency of the CRPD. In addition, such spilling over relates to the image of the constituency of the CRPD. As WNUSP is recorded as cautioning during the 3rd session, "there is a linkage between a psychiatric diagnosis and the stereotype of being incapacitated and in need of special assistance and aid".[1093] Infringements of the legal capacity of some easily taint perceptions of the actual capacity of others. It is undeniable that changing the way its constituency is viewed is a central project of the CRPD, both as an end in itself and as instrumental to the realisation of life opportunities generally. Here, pulling attention to inability to make decisions or represent oneself, even as an exception, blurs the message targeting current attitudes. Thus, the requirements asserted on behalf of one segment of the constituency can clash with efforts to dispose of prejudice affecting other segments, by implicating that what is true about the former is true about everyone.

12.2.2. Divergence of agendas depending on differing health-related requirements

The above illustrates generally that all persons intended by the CRPD do not have the same requirements or agendas and that these sometimes clash. The protection

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[1090] Dhanda, Amita, WNUSP, Advocacy Note on Legal Capacity, 5th session, 2005. Emphasis added.

[1091] Another example of such a conflict is in relation to the exception from inclusive education for particular impairment groups created by Article 24 (3c) on Education. This was opposed not only in the interest of those covered but for concerns of spilling over on both ideas about and the realisation of the inclusion of others. See e.g. the following contribution by CSIE: "Article 17 should fully reflect the **social model of disability**, focusing government obligations on removing the barriers to full participation in education by persons with disabilities. Education of some learners in separate settings because of their disabilities or impairments reflects and *perpetuates a view of disability premised on the medical and charity models of disability*.". First emphasis in original, second emphasis added. CSIE, Paper on Inclusive Education, 5th Session, p. 1.

[1092] Preamble (j).

[1093] Daily Summaries 27 May 2004, 3rd Session.

of certain entitlements, or the use of particular language, can do justice to some while doing injustice to others. However, from the standpoint that each individual matters, and matters equally, all requirements and agendas, as long as they have a basis in the CRPD, oblige the same concern. In light of the controversial relationship between disability and health, the question poses itself how the health-related entitlements in Article 25 on Health and Article 26 on Habilitation and rehabilitation should be approached in order for the CRPD to "promote, protect and ensure the full and equal enjoyment of *all* human rights and fundamental freedoms of *all* persons with disabilities"[1094] or in the words of EDF, to be of "equal relevance and value"[1095] to its entire constituency.

The constituency of the CRPD covers persons who have little or no need for health interventions "specifically because of their disabilities"[1096] or otherwise, as well as persons for whom such interventions are crucial. When WBU stated in the negotiations that "[h]ealthcare is a temporary intervention for PWD [person with disabilities]" while noting that a person with disability "can be perfectly healthy", this is true for some.[1097] However, as noted by IDC, it is not true for others, including "persons with chronic illness/chronic diseases or as it is sometimes called in Europe "medical disabilities"".[1098] An illustrative example of someone for whom it is not true is the person who launched the first successful complaint under the CRPD complaints procedure, calling for medical rehabilitation based on the following description of her health situation:

> The author has a chronic connective tissue disorder, Ehlers-Danlos Syndrome (EDS), which has led to hypermobility (excessive over-flexibility of joints), severe luxations and sub-luxations (dislocation of joints), fragile and easily damaged blood vessels, weak muscles and severe chronic neuralgia. She has not been able to walk or stand for the last eight years, and she has difficulty sitting and lying down. Her impairment has resulted in her being bedridden for the last two years, which has weakened her even further.[1099]

So, the relevance of health entitlements concerning impairment can, and does, differ dramatically among the constituency of the CRPD. This becomes a potential issue of relative injustice against the backdrop of the strong concerns voiced in the negotiations pointing to the peril of attracting attention to questions of health, concerns which contributed to the shaping of Articles 25 and 26.[1100] These concerns have been explored above and include the detraction from efforts to alter the environment, connotations of impairment as not only relevant but also problematic (with con-

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[1094] Article 1 on Purpose. Emphasis added.

[1095] See quote by EDF above under 12.2. referenced in note 1065, Part II.

[1096] Article 25 (b).

[1097] See quote by WBU above under 12.1.1. referenced in note 979, Part II.

[1098] See quote by IDC above under 12.1.1. referenced in note 985, Part II.

[1099] H.M. v. Sweden, 2012, para. 2.1.

[1100] On the unevenly distributed consequences of the avoidance of health issues see Patricia de Wolfe and Susan Wendell above under 3.7.1.4.

nected assumptions about a low value of life in turn leading to abuse) and the reproduction or spread of a skewed balance of power in the health professional-consumer relationship. In addition, focusing on persons with disabilities as in need of health care and as patients runs counter to concerns about portraying the constituency of the CRPD in a way which is conducive to the larger project of creating susceptibility to the realisation of rights. This includes not focusing on "inabilities"[1101], being "incapable"[1102] or as "need[ing] to be taken care of"[1103] and, in the words of Article 8, focusing instead on "capabilities and contributions"[1104] and "skills, merits and abilities"[1105].

As people have different needs for health services the willingness to, against the background of the concerns mentioned, still focus on requirements for such services are bound to differ. The issue will accordingly appear more respectively less urgent and the potential cost in terms of the concerns explored above more respectively less 'worth it'. When pressed to justify the delimitation of the Social Model of Disability in this regards, Michael Oliver plays down a connection between such willingness and who the framers of the approach had in mind when creating it:

> The social model of disability does indeed avoid mentions of such things [impairment], not because it was written by healthy quadraplegics, but because pain, medication and ill-health properly belong within either the individual model of disability or the social model of impairment.[1106]

However, to pertain that the requirements of those one has in mind (as well as the prospects of those in having these requirements fulfilled) and the importance attached to an issue generally is unrelated seems untenable. One's opinion on where these questions belong arguably depends on the requirements on one's mind, and indeed on if these requirements are currently fulfilled. In relation to the former point it appears symptomatic that it is Persons with Pain International (PWPI) who, in negotiations focusing largely on the right to be free from unwanted treatment, "respectfully requests [t]hat across all Articles <u>there shall not be withholding</u> of opportunities or interventions on the basis of disability, where persons with disabilities consent".[1107] In relation to the latter point, it appears likewise symptomatic that the origins of those in the negotiations underscoring the primacy of health intervention

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[1101] See quote by ARCC above under 12.1.3. referenced in note 1015, Part II.

[1102] See quote by Chairman of the Ad Hoc Committee above under 12.1.3. referenced in note 1019, Part II.

[1103] See quote by IDC above under 12.1.3. referenced in note 1028, Part II.

[1104] Article 8 (1c) on Awareness-raising.

[1105] Article 8(2aiii) on Awareness-raising.

[1106] Oliver, 1996, p. 42.

[1107] PWPI, Request, 8th Session, 2006. Emphasis in original. The same actor, under a different affiliation, calls for "the paradigm shift from medical to social, *including medical*". Communications Coordination Committee for the United Nations (CCCUN), 8th Session, 2006. Emphasis added.

were places where such intervention is not readily available.[1108] Masha Mirza, who has explored unmet health needs of persons with disabilities in displacement camps, notes, with links to the "social model" as developed by Oliver[1109] that "[m]uch academic and advocacy work on disability issues tends to be dominated by norms that have emerged from the Global North and is being increasingly called out for ignoring important issues affecting the majority world".[1110] She continues that "[o]ne of these important yet ignored issues includes access to appropriate health care, which is taken for granted in affluent societies but threatens the basic survival of people with disabilities in resource-constrained settings (Meekosha, 2008; Miles, 2011)".[1111] In the context of displacement camps, Mirza identifies a number of health-related needs as currently largely ignored and as requiring addressing: "curative, preventive and maintenance-based rehabilitation services, technical aids and devices, corrective surgeries, and medical treatment for chronic health conditions".[1112]

Another related point pertinent to the "equal relevance and value"[1113] of the implementation of Articles 25 and 26 concerns the fact that access to health interventions, like other interventions, will not be equally accessibly to all who need and want them even within a national context. Forms of diversity (other than levels and modes of functioning of the body and mind) coupled with disadvantage will be decisive for access and implicated persons will be disproportionately affected by lacking implementation efforts. This was recognised by IDC during the 7th session in relation to what became Article 26 on Habilitation and rehabilitation, in a call for explicit recognition of rehabilitation as "applying to all persons with disabilities irrespective of gender, culture, age, covering all stages in life, degree, duration and complexity of disability and place of residence".[1114] This proposal was justified with the note that without such recognition "there will be a risk that the programs will favour one group (young men) and not reach out to other groups".[1115]

A particularly controversial category of health services are those amounting to prevention, minimisation and elimination of impairment, i.e. efforts for impairment not to be. As discussed above, such entitlements are created by Articles 25 and 26. Entitlements amounting to minimisation and elimination of impairment are created in relation both to the impairment through which one becomes covered by the CRPD as well as in relation to any further impairment, and the latter category is also subject to entitlements to prevention. As discussed above, health services unrelated

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[1108] See above under 12.1.1.

[1109] Mirza, Masha, New Issues in Refugee Research, Research Paper No. 212, Unmet Needs and Diminished Opportunities: Disability, Displacement and Humanitarian Healthcare [hereinafter Mirza, 2011] UNHCR, 2011, p. 3.

[1110] Ibid., p. 24.

[1111] Ibid.

[1112] Ibid.

[1113] See quote by EDF above under 12.2. referenced in note 1065, Part II.

[1114] IDC Amendments to Chair's draft, 7th Session, p. 54.

[1115] Ibid. On the different experiences of health services among persons with disabilities along lines other than impairment see Nasa Begum above under 3.7.2.

to impairment or amounting to the management of impairment are controversial as they attract attention away from interventions targeting the environment, implicate the person as a client of the medical profession and contribute to the portrayal of persons with disabilities as 'patients' and as 'needing care'. In addition to this, entitlements aiming at the elimination of impairment give rise to additional concerns through implying a negative valuation of these. Furthermore, compared to entitlements to the management of impairment, entitlements to prevention, minimisation and elimination of impairment are even more closely coupled with concerns for a general denial of life opportunities (including the opportunity to live) based to associated perceptions of a lower quality of life. As noted above under 7.1.1., 11.1. and 12.1.2., the terms 'prevention' and 'cure' were used in a negative sense in the negotiations. While the value of the elimination of impairment was taken for granted by many in the negotiations (as evident from Articles 25 and 26), cautioning against a negative valuation of impairment and its consequences shaped the CRPD and led to the omission of entitlements regarding prevention of the impairment by which one becomes covered by the CRPD.

While the omission of a general entitlement to the prevention of impairment in the CRPD was seen as crucial in the negotiations and is celebrated or at least regarded as adequate by most commentators[1116], the divorce of this issue from the CRPD is questioned from a perspective of global justice. This omission has been criticised by scholars focusing on the concept of "emergent disability", who emphasise that the creation of impairment is not neutral to structures of power and subordination and argue that blanking the creation of impairment renders this fact, and the legitimate claims of those concerned, invisible. Beth Ribet argues that "with the elimination of attention to disability prevention, international law has also simultaneously vacated any analysis of disability that acknowledges its social origins or enables recognition that power relations have anything to do with the production of disabilities and not just the treatment of people who are for whatever never-specified reason "impaired."".[1117] In criticising the CRPD, she notes concerns of "people with emergent disabilities" rendered invisible there:

[1116] "Importantly, the Convention does not seek to prevent disability – which is a medical approach – but rather to prevent discrimination on the basis of disability. Campaigns to prevent accidents and promote safe childbirth and motherhood are relevant to public safety and health. However, when such campaigns are promoted in the context of persons with disabilities, disability is perceived in negative terms, shifting attention away from respect for difference and diversity as well as from combating discrimination – the primary focus of the human rights model." OHCHR, 2010, p. 23. See also e.g. Lord et al., 2010, p. 576.

[1117] Ribet, Beth, Emergent Disability and the Limits of Equality: A Critical Reading of the UN Convention on the Rights of Persons with Disabilities, Yale Human Rights & Development Law Journal, Vol. 14, 2011, p. 159. Ribet defines "emergent disability" as "physical, cognitive, and/or psychological conditions which are wholly or partially caused by social inequity". She further specifies that "[t]he basis for inequity may be grounded in class and economics, gender, sexuality, race, ethnicity, immigration status, age, or other disabilities, and often occurs at the intersection of several of these demographics simultaneously. The events which generate disabilities may derive from periods of extreme mass violence, systemic, "ordinary" dynamics of medical,

> The critical point here is that the needs of people with emergent disabilities are not limited to needs, rights, or concerns people have related to the continuing social and legal treatment of existing disability vis-à-vis discrimination or even a broader conception of ongoing ableist subordination. I am instead delineating at least two other concerns: a) the prospects and components of reparation, remedy, or healing individuals (and communities) have while and after being disabled by violence and/or subordination (currently un- or under-realized in other civil rights or welfare models as they exist), and b) a kind of collective or cultural (disability) right that populations subject to subordination have not to be harmed in the first place.[1118]

Other such as Janet Lord et al., while agreeing with the omission of prevention from the CRPD with reference to such issues being "on the whole, conceptually distinct public health issues and not disability rights issues appropriately addressed in a human rights treaty designed to protect disabled persons", none the less note, referring to WPA, that "for those persons living in the least developed countries, preventive measures often reach a small proportion of the people in need and that most developing countries have not established a system for the early detection and prevention of impairment through periodic health examinations".[1119] Lord et al. further note that "there are, however, public health prevention issues that clearly do concern persons with disabilities" and exemplifies this with HIV/AIDS education.[1120] Because of this, they regret the lack of "effective engagement between disability organizations and WHO" in the negotiations of the CRPD, an engagement which could have resulted in a "better forecast [of] the relationship between public health concerns and the rights of persons with disabilities".[1121] While Lord et al. put this down to "the lack of engaged participation by WHO in the drafting process", the negotiation records show that the concerns explored above under 12.1. played an at least equally important role here.[1122]

In relation to 'cure', much like the CRPD covers persons who differ in their requirements for and reception of health services to manage impairment, it also covers persons with diametrically different positions on the wisdom or importance of health services to eliminate or minimise such impairment as well as on the balance between the environment and impairment as the operative causes of restricted composite life opportunities.[1123] The CRPD covers both those who resent the idea of 'cure', those

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nutritional, or housing deprivation, labor exploitation, safety or environmental hazards, criminal or medical institutionalization, or interpersonal or domestic violence". Ibid., p. 161.

[1118] Ibid., p. 179. Critical accounts of the CRPD connected to the notion of emergent disability habitually display a strong focus on North-South relations, addressing "impairment being socially made in the South under geopolitical imperialist violence" and calling for "the claims for redistributive justice at the transnational scale to recognize the production of impairment". Soldatic, Karen, The Transnational Sphere of Justice: Disability Praxis and the Politics of Impairment, Disability & Society, Vol. 28, No. 6, 3013, p. 745.

[1119] Lord et al., 2010, p. 576.

[1120] Ibid.

[1121] Ibid., pp. 576-577.

[1122] Ibid., p. 577. See also above under 11.1. and 11.2.5.

[1123] Compare Patricia de Wolfe and Susan Wendell above under 3.7.1.3.

who live for it and those who are ambivalent or not really concerned. It appears inevitable that responses by the surrounding society, as well as the effects of particular impairments, are bound to influence the position taken:

> Failure to appreciate the impairment continuum contributes to some of the sterile arguments about the nature of disability. It appears to me that some of those who see disability as a tragedy which should be prevented at all costs are seeing only the most severe end of the continuum. And some of those who deny that impairment can be problematic, and see disability as just another difference, are seeing only the milder end of the continuum. In other words, the two camps are talking at cross purposes: because they think of different cases when they discuss disability, they are unable to come to agreement about how disability should be understood or defined.[1124]

Because of the onus to give equal recognition to the entire constituency of the CRPD, such "sterile arguments" as referred to here by Tom Shakespeare have no role to play in the implementation of the CRPD. It suffices to note that both positions are represented among the constituency and that neither, less categorically phrased, is contradicting the CRPD, in order for them to prima facie merit consideration. In addition to displaying different attitudes towards the minimisation or elimination of impairment, the constituency of the CRPD will differ as regards the material as well as scientific prospect of such minimisation or elimination. On a global scale, this also actualises the currently largely unrealised potential for, inter alia, minimisation and elimination of impairment in the South, as noted above by Mirza.[1125] For these reasons and others, positions on if a focus on minimisation and elimination of impairment is worthwhile even in the light of strategic concerns (taken that these concerns are considered relevant) are bound to differ.[1126]

Policies amounting to the minimisation and elimination of impairment will appear utterly misguided and degrading to the part of the constituency of the CRPD who not only finds their levels and modes of functioning of the body and mind unproblematic but experiences these as a source of pride, as something to be embraced and celebrated rather than pathologised and deplored.[1127] Consequently, as noted here by Tom Shakespeare, to this segment of the constituency entitlements for prevention and 'cure', even as flanking entitlements to an altered environment, are not only misguided and strategically counterproductive but also personally provocative:

> Underlying these critiques [of the pursuit of cure] is the prevailing disability rights unwillingness to engage with the question of impairment. Whereas the narrative of cure sees disabled people as people with impairments, the social model approach sees disabled people as victims of social oppression and exclusion. To focus on curing im-

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[1124] Shakespeare, 2006, p. 60.

[1125] Mirza, 2011, p. 24.

[1126] See Hahn, 2002, p. 174 and Hahn, 1985, pp. 88-89.

[1127] See Oliver, 1996, p. 89 on "the politics of personal identity" and the position of "the affirmative model of disability" explored above under 3.7.1.6. See also Hahn, 1987, p. 14 (source not paginated), Hahn, 2001, p. 60, Hahn, 2001a, p. 41 and Hahn and Belt, 2004, p. 453.

> pairment is to challenge the whole basis of the social model story of disability, and therefore it becomes unacceptable (Oliver, 1989). It often appears that what is at stake in these bitterly fought arguments about medical cures are competing identity narratives.[1128]

It can be argued that the controversy attached to the different targets for interventions forwarded by the entitlements in the CRPD (the environment and the individual) are successfully mediated by the element of choice built into Articles 25 and 26. As discussed in Chapter 7 above, Article 25 (d) requires interventions to be "on the basis of free and informed consent" and Article 26 (1b) requires intervention to be "voluntary". If one finds that the operational restrictions to one's access to life opportunities reside in one's impairment, one will make claims based on the entitlements in Articles 25 and 26. If instead, or as well, one finds that the operative causes lie in the attitudinal or physical environment, the other articles in the CRPD will be utilised. Thus, to some extent, it can be argued that the CRPD provides a 'buffet' from which each person with disabilities can claim the solutions he or she prefers (with the limitations noted above inherent in that no general right to prevention is recognised by the CRPD as well as any limitation which may be interpreted as formally limiting individual choice).[1129] However, the freedom to say 'yes' or 'no' to health interventions is not immune to general policy and attitudes. The current social context in which the 'choices' provided by the CRPD do their work is not neutral, but one which largely sees impairment as a tragedy.[1130] The question remains how much 'free choice' there is left if one is met with pervasive expectations that one should want to change, as well as how the alternatives one is given in terms of accommodations of diversity are affected not only by the availability of minimisation or elimination of impairment but consequent to one's refusal of such measures.

Furthermore, general policy is directed by choices and prioritisations made above the head of the individual. Thus, the balance between efforts made to provide the health interventions mandated by Articles 25 and 26 and efforts made to alter the environment as envisaged in the remainder of the CRPD is not a choice available to the individual. It is also undeniable that broad policy decisions to provide programmes and services aimed at preventing, minimising or eliminating an impair-

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[1128] Shakespeare, 2006, p. 105. See also Susan Wendell: "Disability pride has come into conflict with medical efforts to prevent disability, especially by selective abortion of potentially disabled foetuses, and with medical efforts to "cure" certain disabilities, especially deafness in children.". Wendell, 2001, p. 31. See also Hahn, 1999, p. 5: "[A]n almost exclusive focus on prevention, or the eradication of disabling conditions [...] may be interpreted by persons who have already acquired these disabilities as threatening or as an indication of neglect of their problems.".

[1129] For the former aspect, see above under 12.1.2. For the latter aspect, see above under 7.1.1., 7.2.3.-7.2.5., 7.2.7. and 7.3.2.

[1130] Janet Lord notes this in relation to abortion and the information offered parents after prenatal screening revealing potential for impairment in their child to be. Lord, 2013, pp. 2, 13-14 (source not paginated). See also Harnett, Alison et al., Convention of Hope- Communicating Positive, Realistic Messages to Families at the Time of a Child's Diagnosis with Disabilities [Hereinafter Harnett et al., 2009], British Journal of Learning Disabilities, Vol. 37, 2009.

ment implicated by the CRPD is likely to negatively affect general attitudes to that impairment as well as the state of mind of an implicated individual (this potentially includes both raging against the devaluation implied and such devaluation affecting one's own valuation of one's impairment and/or oneself).[1131] This does not mean that such policies, or general assumption about valuation connected with these, *necessarily* affect a person's attitude to his or her impairment. However, it remains that how one views oneself is not established in isolation from surrounding society. For people in general, the device 'sticks and stones can hurt my bones but words will never hurt me' is hard to live up to as the way we are mirrored by society easily affects how we view ourselves. While it can be argued that each individual can choose according to his or her own mind not to avail of entitlements implicating ones level and mode of functioning of the body and mind as negative, one does not have the choice to escape the attitudes created, broadcasted or reinforced by general policy. Not having the eradication of one's impairment socially sanctioned is not included in the 'choice' provided. Broad policy thus affects the choices available to an individual in numerous ways, making the freedom to say 'yes' or 'no' to an intervention only a partial aspect of choice.

Consequently, while the notion of 'entitlements' carries positive connotations, especially flanked by the safeguard of choice, entitlements targeting minimisation and elimination of impairment will be perceived by segments of the constituency of the CRPD as misconceived, deeply devaluing and (in line with the concerns described above), strategically counterproductive to the point of being dangerous. As a consequence, persons who could if they so wanted call upon the CRPD and the entitlements to environmental change it contains, are thus likely to reject it due to the negative valuation of levels and modes of functioning of the body and mind inherent in Articles 25 and 26 and implied through the use of the term "impairments" in Preamble (e) and Article 1.[1132]

Against this background, the question poses itself at what point policies granting entitlements to prevention, minimisation and elimination of impairment amount to a breach of an obligation to "foster respect for the rights and dignity of persons with disabilities" and to "combat stereotypes, prejudices and harmful practices relating to persons with disabilities" as expressed in Article 8 (1a-b) on Awareness-raising. To what extent does Article 8 include an obligation not to deprive a person of the "social [...]

[1131] See e.g. UPIAS, 1974, para. 7, Oliver, 1990, p. 122 and Hahn, 2000, p. 272. See also Lord, 2013, pp. 2, 13 (source not paginated). Smitha Nizar expresses the former point as that "[d]isability-linked abortions need a re-examination because they impede the social acceptance of persons with disabilities". Nizar, Smitha, Impact of UNCRPD on the Status of Persons with Disabilities, Indian Journal of Medical Ethics, Vol. 8, No. 4, 2011, p. 229. Compare also the following submission by II during the negotiations of the CRPD: "Given the current general perception of the value of a person with an intellectual disability (they are amongst the most marginalised people in society) the implication [of genetic engineering] for them is obvious. If society accepts that the characteristics of a child not yet born should be changed, then what does that say about the value of the life of all people with an intellectual disability?". II Proposal for the 3rd Session, p. 4 (source not paginated).

[1132] See above under 10.1.2.

bases of self-respect" as in the means to establish and keep a favourable self-regard?[1133] The focus in Article 8 is the person and the question is consequently to what extent a negative valuation of impairment amounting to a "stereotype" is equated with a stereotype *about the person*. While it is unequivocal that a message amounting to a devaluation of the person or the life of a person is in violation of the CRPD, it is less apparent if a devaluation of impairment per se amounts to such a violation. As discussed above under 7.1.3. and 7.3.1., the mere recognition of entitlements to prevention, minimisation and elimination of impairment in Articles 25 and 26 speak against such an interpretation, as a negative valuation of impairment is consequently implied by the entitlements created by the CRPD. Speaking for an entitlement not to have ones impairment portrayed as a relevant object for elimination is the recognition of "the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities" in Preamble (m) and to some extent the principle of "[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity" in General principles 3 (d).

This question may best be conceived as a question of what "dignity" amounts to in the CRPD. Article 8 (1a) contains the obligation to "foster respect" for dignity and Article 1 on Purpose expresses the purpose of the CRPD as "to promote respect for their [persons with disabilities] inherent dignity". "Respect for inherent dignity" is similarly one of the General principles in Article 3. While both the terms "respect" and "dignity" have many dimensions to their meaning in human rights law, they clearly recognise the effects of the treatment by others on a person's self-regard.[1134] The entitlements created by the CRPD to prevention, minimisation and elimination of impairment through Articles 25 and 26 mean that policies to this effect cannot, per se, be regarded as an affront to dignity in the sense attributed to this concept in the CRPD. However, there is surely a line where such policies, particularly the manner in which they are forwarded and carried out, amount to an affront to dignity and thus a potential violation of the provisions just mentioned.

[1133] Rawls, John, A Theory of Justice, Oxford University Press, Oxford, 1971, p. 62. I am borrowing this expression from Rawls while not purporting to stay true to the details of his particular understanding of it.

[1134] So far, doctrine has addressed this issue predominately in relation to antenatal screening and selective abortion. In this context, dignity, as protected in Article 1 on Purpose and Article 3 (a) on General principles dominate among the aspects of the CRPD called upon in challenging (some forms of and circumstances surrounding) such practice (Lord, 2013, pp. 8-9 (source not paginated), Petersen, 2010, p. 108 and Harnett et al., 2009, pp. 262-263). Lord makes this point in relation to health policies generally: "Dignitarian interest are […] at stake when health policies – such as disability-selective antenatal screening policies – characterize , whether explicitly or implicitly, disabling conditions, such as Down syndrome, as burdensome, lacking in quality and the like.". Lord, 2013, p. 9 (source not paginated). Other articles of the CRPD relied upon include Article 8 on Awareness-raising (Lord, 2013, p. 12 (source not paginated) and Harnett et al., 2009, pp. 262-263), Article 3 (d) on General Principles (Lord, 2013, p. 10 (source not paginated), Harnett et al., 2009, pp. 258, 262 and Scully, Jackie Leach, Disability, Human Rights and Contemporary Genetics, in eLS, John Wiley & Sons Ltd, Chichester, p. 3), Article 25 on Health (Lord, 2013, p. 12 (source not paginated) and Harnett et al., p. 263), Article 5 on Equality and on-discrimination (Lord, 2013, pp. 11-12) and Preamble (m) (Harnett et al., p. 258).

12.3. The mandate of the CRPD Committee concerning the implementation of Article 25, Article 26 and Preamble (j)

The accounts above in 12.1. and 12.2. illustrate that the right to health came to the drafting process of the CRPD with heavy baggage. The "human rights" approach to disability was juxtaposed to "a medical model" of disability.[1135] This denounced "medical model" was in turn attributed efforts for "cure" as its hallmark.[1136] Importance was attached to not depicting health concerns as central to the constituency of the CRPD as well as to not depicting this constituency as 'unhealthy'.[1137] Finally, aspects of the right to health such as prevention of impairment were asserted as foreign to a human rights approach to disability issues.[1138] At the same time the right to health, including prevention, holds a central position in the larger human rights framework and a human rights convention aiming to holistically cover the life opportunities of any constituency cannot steer clear of it. In the drafting of the CRPD great pains were consequently taken not to reproduce the negative legacy of health in relation to the constituency of the CRPD while at the same time protect entitlements which were seen as valuable to the same constituency. Concerns regarding the unwanted aspects of health presented above (directing attention away from environmental barriers, an implied negative valuation of impairment, the portrait of person with disabilities as 'patients' and as needing 'correcting' and the slanted relationship in terms of power between medical professionals and consumers) were general themes in the negotiations which were all actualised by the right to health. On balance, they outweighed, at least in terms of airtime, appeals that the drafting of Article 25 on Health and Article 26 on Habilitation and rehabilitation optimise the right to health for the constituency of the CRPD.

Similarly, these accounts have illustrated that paying attention to the segment of the constituency depicted in Preamble (j) as "those who require more intensive support" runs the risk of being regarded as counterproductive to the realisation of the CRPD for others. It does so through drawing attention towards situations of inability and vulnerability rather than towards capability and socially caused injustice remediable by the eradication of social barriers.

[1135] See recorded statement by the Republic of Korea during the Working Group in relation to what became Draft Article 21 on Health and rehabilitation in the Working Group Draft: "The Republic of Korea, noting the general evolution from a medical model to one based in human rights, expressed concern about the Article as a whole. Prevention, health and rehabilitation are core aspects of medical model.". Daily Summaries, 16 January 2004, Working Group Session.

[1136] See e.g. quote by IDC above under 7.1.2. referenced in note 69, Part II and quote by Costa Rica above under 11.2.3. referenced in note 920, Part II.

[1137] See above under 12.1.1.

[1138] See e.g. recorded statement by Serbia and Montenegro during the Working Group session: "Inclusion of prevention should be avoided [...] because this is a medical approach to disability and not a social one and the Convention is a HR [human rights] approach to disability issues.". Daily Summaries 5 January 2004, Working Group Session.

In the following, in light of the diverging concerns and agendas these provisions actualise, attention is turned to their role in the work of the CRPD Committee,

12.3.1. How to walk a tightrope – Outlining the balancing act ahead

The negotiations are completed, the CRPD is adopted and the CRPD Committee now has the mandate to monitor and guide the implementation of the CRPD, including Article 25 on Health, Article 26 on Habilitation and rehabilitation and Preamble (j)[1139]. The Committee does so primarily through the consideration of reports and the subsequent issuing of Concluding Observations, the consideration of communications, the issuing of General Comments and the instigation of inquiries into grave or systematic violations of the CRPD.[1140] As mentioned in the introduction to this chapter, the CRPD Committee is limited by its mandate and a legal interpretation of the obligations and entitlements as contained in the CRPD, but still retains considerable room to manoeuvre. Apart from communications, the balance of attention paid to different issues is largely at the disposal of the Committee: what to choose as the subject of a General Comment, what aspects of a report (or missing from a report) to bring out in Concluding Observations and what violations merit an inquiry.

The historical and current state of affairs reflected in the experiences and perceptions that shaped the CRPD have not changed notably since these negotiations took place. This raises the question how the CRPD Committee will handle the concerns discussed hitherto in this chapter: the urge to steer the attention of States towards barriers external to the person and the composite life opportunities aimed at by targeting such barriers, the urge not to attach a negative valuation to levels and modes of functioning of the body and mind, the urge to forward a portrayal of the constituency seen as generally conducive to the realisation of life opportunities and the urge to reform the relationship between professional and consumer. In light of these concerns, chances are that the Committee perceives its task as one of deflecting attention from impairment and particularly from problematic aspects of impairment. Plainly speaking, tradition in terms of the negotiations (as well as the ideological backdrop called upon in the negotiations, the 'social model' of disability) calls for the Committee to pay as little attention as possible to anything implicating impairment. If this be the case, then scarce attention to entitlements to interventions in the area of health as provided by Articles 25 and 26 is an expected result. Instead, this tradition suggests that attention should be firmly on interventions targeting the environment and their effect on composite life opportunities. As relates to interventions targeting impairment, the focus should be on the right to say no to such interventions, should they be on offer, rather than on their provision. In addition, concerns about

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[1139] It should be note here that Preamble (j), by virtue of not being part of the operative part of the CRPD should strictly speaking 'guide implementation', rather than 'be implemented'.

[1140] See above under 9.1.14.

the portrayal of the constituency indicate that attention should be steered away from the situation of and requirements of “those [persons] who require more intensive support” rather than as called for by Preamble (j), the other way around.

If the Committee perceives its task thusly, this is problematic on numerous accounts. For segments of the constituency, including many of those referred to by IDC as person with “medical disabilities”/“chronic illness”, the entitlement to health services is central.[1141] It is important to note here that this does not make other entitlements, such as education or employment, less central. Furthermore, a global perspective reveals that in many places health services are not readily available; there is no ‘army’ of willing health professionals with the knowledge and resources to provide “health services needed by persons with disabilities because of their disabilities” as demanded by Article 25. In addition, health services unrelated to impairment are routinely denied based on considerations linked to such impairment, as is access to “population-based public health programmes”. In relation to the segment of the constituency intended by Preamble (j), it goes without saying that a high requirement of support indicates that a person is highly dependent upon receiving such support lest the enjoyment of rights generally will suffer, as well as that ‘alternative’ ways of accessing life opportunities without such support are not likely to be readily available.

The above relates to the *need* for attention to the entitlements created by Articles 25 and 26 and Preamble (j). However, as provisions of the CRPD these also create *rights*; legally sanctioned claims. Legally, all the entitlements in Articles 25 and 26 have the same status as other entitlements in the CRPD and merit the same amount of attention on behalf of the Committee. Consequently, “early identification and intervention” and “services designed to minimize and prevent further disabilities” aimed at “the highest attainable standard of health” in Article 25 merit the same concern as e.g. the removal of environmental barriers to education and employment. In addition, the purpose of the CRPD expressed in Article 1 on Purpose is explicit on the obligations to realise the entitlements in the CRPD for “*all* persons with disabilities” which calls for equal concern to different requirements, not only for the universal implementation of the requirements particularly central for some segments of the constituency.[1142] Furthermore, Preamble (i) recognises “the diversity of persons with disabilities”.[1143]

While this underscores the legal obligations to furnish the health interventions provided by Articles 25 and 26, other legal obligations have bearing on how this is to be done. As discussed above under 12.2.2., such obligations flow from the provisions in the CRPD recognising and calling for the valuing of diversity (Preamble (m), Article 3 (d) on General principles and Article 8 on Awareness-raising) as well as from the notion of dignity (Article 1, Article 3 (a) and Article 8). On the level of policy, these articles make demands particularly on general policies aimed at the pre-

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[1141] Quote by IDC above under 12.1.1. referenced in note 985, Part II.

[1142] Emphasis added.

[1143] As elaborated above under 12.1.1. “diversity” here equals impairment. See also Schulze, 2010, p. 28 for the same conclusion.

vention, minimisation or elimination of impairment. It is undeniable that the social sanctioning of such interventions sends a message about the value of impairment, a message from which neither implicated individuals nor the general public can escape. Providing and facilitating 'cure' and prevention contributes to perceptions of impairment as a problem, even if not enforced or unduly encouraged. While such policies are not only allowed but called for by Articles 25 and 26 of the CRPD, other provisions, as well as 25 (d), simultaneously make demands upon the content and packaging of such policies. With regards to content, these provisions call for close scrutiny of the assumptions and values upon which such policies are based, including to what extent these assumptions are echoed by the implicated constituency.[1144] What is a problem, why is it a problem, is intervention targeting the individual the most appropriate solution and what personal cost is attached to such interventions? As regards the 'packaging' of such policies, they must not be justified to the general public by categorical depictions of impairment as tragedy. It remains that such policies do rest on the perception of impairment as potentially negative, lest such policies would not exist. For example, without a negative valuation of Spina Bifida, pregnant women would not be told to eat folic acid. Also, such a policy may not be effective without stating its purpose and implicated women may also be entitled to know why they are encouraged to take folic acid. However, there is a point where such negative valuation becomes unnecessarily exaggerated or exploited in an effort to create fear that will be conducive to compliance. Hitherto, the interest of persons with an impairment which is subject to policies of prevention or 'cure' has not been taken into account in shaping these and this is what the CRPD requires. Again, under the CRPD, this does not amount to a denial of the value of such policies per se, as it is accepted that some impairments are reasonably perceived by some persons as negative. What is required on a policy level is a scrutiny of the current pervasive negativity, while not discrediting all negative valuation of impairment or entitlements amounting to such valuation. Additionally, and crucially, Article 4 (3) on General obligations demands the involvement of the constituency of the CRPD in the creation and evaluation of law and policy, including in the area of health.

While it is essential that health services are available to individuals, provisions in the CRPD create crucial entitlements pertaining to which these services are to be as well as to how they are to be delivered. Article 25 (d) remains central here, with its requirement that States ensure that health professionals "provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care". As concluded above under 12.2.2. choice is only a partial barrier to undue health interventions and so the work of weeding out certain forms of intervention remains paramount. In addition to em-

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[1144] In relation to management and 'cure' the relevant constituency is that of the CRPD while general prevention concerns everyone.

phasising the right to say no to treatment, the professional culture determining the reception of the person is to be subjected to scrutiny, including the valuation of not only the consumer, but the valuation of the impairment of that consumer. It is here argued that the professional encounter must resist the transmission of assumptions about the valuation by an individual of his or her impairment or life with impairment. This is arguably a challenge, both as general policy (calling for the provision of a certain treatment) already has made such a valuation and as part of the task of a health professional is not only to suggest and provide interventions, but to identify problems meriting such intervention in order make suggestions. However, individuals differ and it appears particularly important not to make assumptions about how a person relates to his or her impairment as the current societal default approach is to assume and communicate that anything which diverts from a norm merits interventions, and sometimes at any or at least disproportionate personal cost. Not only is this offensive to persons who find their level or mode of functioning of the body and mind positive or neutral, it also constitutes undue influence on a person irrespective of such positions. The relevance of these considerations are heightened when an intervention comes closer to the minimisation or elimination rather than the management of impairment. Indeed, the health professional may learn a lot on these matters by listening to the consumer with as little preconceived assumptions as possible. On the individual level, the obligations of health professionals not to impose a negative valuation also works in the opposite direction, albeit the risk of this appears rather in circles which make a point of forwarding a positive valuation of levels and modes of functioning of the body and mind. In any event, this entails that a person looking to minimise or eliminate his or her impairment is not to be regarded and mirrored as misguided or as a ‘traitor to the cause’ for subverting the message of neutral or positive diversity.[1145]

It is undeniable that the CRPD Committee represents a diverse constituency with sometimes divergent concerns and agendas. While the immediate goal of a human rights convention is to codify entitlements and obligations which correspond to the requirements of *all* the people it covers, a parallel and equally central aim to the negotiating parties of the CRPD was that the latter “communic[ate] a paradigm shift in how society views PWD [persons with disabilities]”.[1146] The ‘showcase’ constituent of the CRPD is autonomous, independent, capable of all but for environmental barriers, not in need of or wishing for interventions targeting his or her impairment and strong in energy and resolution. This is of course as true as it is false, depending on whom among the constituency one chooses to focus on. The point that each individual matters and that no one is a means to an end but an end in oneself is central to human rights law. From this perspective the purpose of the CRPD and the ultimate measure of its success is not only if it throws its net of protection wide enough (who is in and who is out?) or its systemic impact on national disability law and policy

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1145 See Liz Crow and Karen Beauchamp-Pryor above under 3.7.1.3.

1146 Quote by IDC above under 7.3.6. referenced in note 420, Part II.

generally, but how well it caters for the requirements and wishes of *each and every person* falling within its ambit of protection.

The provisions of the CRPD do not land in a 'neutral' context; instead they take on a life of their own when released into a social context with its current preconceptions, a social context where impairments often are categorically perceived as tragic and as diminishing the value a person can find in his or her life. It can be argued that just as the CRPD emphasises that which is deemphasised in the world at large, so should the Committee in implementation. Conversely, it can also be argued that now that the CRPD is here it is safer to allow the picture to nuance itself by acknowledging diverging concerns and agendas. The CRPD unequivocally implicates the environment as the central target for change and only implicates the individual as the target for change in a circumscribed manner, with little linkage to the enjoyment of composite life opportunities. It contains a principled valuation of impairment and it portrays the 'prototype' constituent as an independent and autonomous person, capable of all but for external barriers. It emphasises choice in relation to professionals as well as, albeit indirectly, problematises the current value basis of the health profession.

Irrespective of the merit of these two viewpoints however, and here lies the thrust, all the provisions mentioned above equally create legal obligations which the Committee must strive to ensure. This can only be done by a careful balancing act explicit on the importance of all provisions, where efforts towards the realisation of some provisions (and the concerns they protect) are carefully crafted so as not to threaten the realisation of others.

12.3.2 The balancing act so far by the CRPD Committee

Turning to the practice of the CRPD Committee so far I will address three dimensions of the work of the Committee in turn: the evaluation of State reports, the issuing of General Comments and the consideration of communications.

In the consideration of State Party reports as mandated by Article 36, the Committee has so far adopted nine Concluding Observations.[1147] Four of these

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[1147] These are the concluding observations issued before the end of August 2013:
Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Tunisia [Hereinafter Concluding Observations Tunisia], 13 May 2011, UN doc: CRPD/C/TUN/CO/1.
Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Spain [Hereinafter Concluding Observations Spain], 19 October 2011, UN doc: CRPD/C/ESP/CO/1.
Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Peru [Hereinafter Concluding Observations Peru], 16 May 2012, UN doc: CRPD/C/PER/CO/1.
Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Argentina [Hereinafter Concluding Observations Argentina], 8 October 2012, UN doc: CRPD/C/ARG/CO/1.

do not include Article 25 as a heading and seven of these do not include Article 26 as a heading.[1148] While I recognise that everything cannot be covered in each Concluding Observations, it is notable that for example Article 24 on Education and Article 27 on Work and employment are included as headings in all nine Concluding Observations.[1149] In the four Concluding Observations which do not address Articles 25 as a heading, three of these address aspects of health interventions under other provisions. This includes (with different degrees of explicitness) both the provision of interventions and the entitlement to make informed decisions for or against interventions offered.[1150] One of these does not address either aspect.[1151] Among the five Concluding Observations which include Article 25 as a heading, two address both the provision of interventions and the entitlement to make informed decisions for or against interventions offered under this heading.[1152] Two others address the entitlement to be provided treatment only under this heading[1153], but address the entitlement to decide for or against treatments on offer under other provisions.[1154] Finally, one Concluding Observations covers only the provision of interventions under the

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Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of China , 15 October 2012, UN doc: CRPD/C/CHN/CO/1. The Concluding Observations on the Initial Report of China contain three sections: China [hereinafter Concluding Observations China], Macau (China) [hereinafter Concluding Observations Macau (China)] and Hong Kong (China) [hereinafter Concluding Observations Hong Kong (China). I count these as three separate Concluding Observations, hence the reference to nine Concluding Observations.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Hungary [Hereinafter Concluding Observations Hungary], 22 October 2012, UN doc: CRPD/C/HUN/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Paraguay [Hereinafter Concluding Observations Paraguay], 15 May 2013, UN doc: CRPD/C/PRY/CO/1.

[1148] Article 25 is not included in Concluding Observations Hungary, Concluding Observations Tunisia, Concluding Observations Spain and Concluding Observations Macau (China). Article 26 is included only in Concluding Observations China, paras. 39-40 and Concluding Observations Paraguay, paras. 61-62.

[1149] Concluding Observations Tunisia, paras. 30-34. Concluding Observations Spain, paras. 43-46. Concluding Observations Peru, paras. 36-37, 40-43. Concluding Observations Argentina, paras. 37-38, 43-44. Concluding Observations China, paras. 35-36, 41-42. Concluding Observations Macau (China), paras. 94-97. Concluding Observations Hong Kong (China), paras. 73-74, 77-78. Concluding Observations Hungary, paras. 39-44. Concluding Observations Paraguay, paras. 57-58, 63-66.

[1150] Concluding Observations Hungary, paras. 22-23, 26-28, 38. Concluding Observations Tunisia, paras. 13, 15, 28-29. Concluding Observations Spain, paras 22-24, 29-30, 36-38.

[1151] Concluding Observations Macau (China).

[1152] Concluding Observations Argentina, paras. 39-42. Concluding Observations China, paras. 37-38.

[1153] Concluding Observations Peru, paras. 38-39. Concluding Observations Hong Kong (China), paras. 75-76.

[1154] Concluding Observations Peru, paras. 30-31, 34-35. Concluding Observations Hong Kong (China), para. 64.

heading of Article 25[1155], but addresses the entitlement to decide for or against treatments on offer under other provisions.[1156]

Turning to Article 26, one of the two Concluding Observations including this article as a heading covers only the right to make informed decisions for or against provided interventions[1157] while the other only addresses health in as much as it deplores the fact that (re)habilitation measures currently address only health and ignores other aspects.[1158] The upshot of the above is that health-related interventions are not addressed in a concerted or comprehensive manner in the Concluding Observations hitherto issued by the CRPD Committee.

In one Concluding Observations, the Committee addresses the prevention of further impairment. In the Concluding Observations to Peru, the Committee thus states that it "regrets the lack of early detection programmes of deafness for children in order to minimize and prevent further disabilities"[1159] and recommends that Peru "[p]rovide services of early identification of disabilities, in particular deafness, designed to minimize and prevent further disabilities, including among children".[1160] The clash between the negative valuation of impairment implicit in this call for prevention of deafness and principled statements on the celebration of diversity becomes particularly visible as Deaf persons constitute the segment of the constituency of the CRPD who on a collective level expresses the strongest position on their mode of functioning as a positive asset, rather than as a problem.[1161] However, that which the Committee asks for remains an entitlement under the CRPD and the call as such is not phrased in an exaggerated or unnecessarily devaluing manner.

In its Concluding Observations to Paraguay the Committee explicitly addresses the provision of "early identification and intervention as appropriate" in relation to the impairment by which one becomes covered by the CRPD, as provided for by Article 25 (b). However, such provision is addressed in ambivalent terms, as the Committee "notes with concern that the National Programme of Comprehensive Care for Children and Adolescents with Disabilities is limited solely to the prevention and early detection of disability *characteristic of the medical model*, and does not take account of the full range of rights recognized to children with disabilities".[1162]

[1155] Concluding Observations Paraguay, paras. 59-60.

[1156] Ibid., paras. 17, 30.

[1157] Concluding Observations China, paras. 39-40.

[1158] Concluding Observations Paraguay, paras. 61-62.

[1159] Concluding Observations Peru, para. 38.

[1160] Ibid., para. 39 (c).

[1161] Compare the recognition of "deaf culture" in Article 30 (4). Testament to this is the reluctance of the Deaf community to use the disability framework, including the CRPD, as a platform for forwarding demands relating to, inter alia, sign language. See e.g. Batterbury, Sarah C. E., Language Justice for Sign Language Peoples: The UN Convention on the Rights of Persons with Disabilities, Language Policy, Vol. 11, 2012. Tellingly, Batterbury holds that the CRPD "offers the best hope for sign language policy *notwithstanding its disability framing*". Ibid., p. 253. Emphasis added.

[1162] Concluding Observations Paraguay, para. 19. Emphasis added. It should be noted here that another Concluding Observation deplores "the lack of early identification, family interventions

This ambivalence towards health interventions flows from the fact that the term "medical model" is as a rule used to emphasise the inappropriateness of measures. For example, in its Concluding Observations to China, the Committee opposes "the medical model of disability" to "the human rights model of disability":

> The Committee takes note of the prevalence of the medical model of disability in both the definition of disability and the enduring terminology and language of the discourse on the status of persons with disabilities. Therefore, the Committee is concerned about the lack of a coherent and comprehensive disability strategy to implement the human rights model of disability that the Convention establishes to achieve the de facto equality of persons with disabilities and implement the rights enshrined in the Convention at all levels.[1163]

In the Concluding Observations to Tunisia the "medical approach" is denounced as the opposite of the required "social approach" in relation to defining disability[1164] and the same distinction is made between "a medical, rather than a social perspective"[1165] in the Concluding Observations to Peru, without further guidance as to what exactly this means. The above shows that while the Committee does make calls for the provision of health-related interventions, it simultaneously uses the epithet 'medical' in a way which casts suspicion on such interventions.

In addition, the CRPD Reporting Guidelines, while referring to "early detection and intervention programmes, as appropriate" calls only for information about such programmes in relation to "secondary disabilities". States Parties are thus asked to report on "[h]ealth services, early detection and intervention programmes, as appropriate, to prevent and minimize the emergence of *secondary disabilities*".[1166] Consequently, measures targeting the initial impairment remain invisible.

Turning from the coverage of Articles 25 and 26 to the attention paid to "those who require more intensive support" as identified in Preamble (j), the nine Concluding Observations adopted so far do not demonstrate a concerted effort to call attention

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and informed support" in relation to children also under the heading of Article 7 on Children with disabilities, however such "early identification" is not explicitly linked to health interventions. Concluding Observations Spain, para. 23.

[1163] Concluding Observations China, para. 9. Similar references are made in other Concluding Observations, such as the following in Concluding Observations Hungary, para. 49: "The Committee recommends that the State party systematize the collection, analysis and dissemination of data, disaggregated by sex, age and disability; enhance capacity-building in this regard; and develop gender- and age-sensitive indicators to support legislative developments, policymaking and institutional strengthening for monitoring and reporting on progress made with regard to the implementation of the various provisions of the Convention, taking into consideration the changes *from the medical to the human rights-based approach to disability.*". Emphasis added.

[1164] Concluding Observation Tunisia, para. 8.

[1165] Concluding Observation Peru, para. 6 (a).

[1166] Committee on the Rights of Persons with Disabilities, Guidelines on Treaty-specific Document to be Submitted by States Parties under Article 35, Paragraph 1, of the Convention on the Rights of Persons with Disabilities [hereinafter CRPD Reporting Guidelines], 18 November 2009, UN doc: CRPD/C/2/3, p. 14. Emphasis added.

to the situation of this segment of the constituency. One Concluding Observations calls for the provision of services to "persons with a high level of support needs" in the context of the provision of services under Article 19 on Living independently and being included in the community.[1167] The same Concluding Observations calls for the allocation of further resources to "persons with intellectual and psychosocial disabilities who require a high level of support, in order to ensure social support and medical treatment outside their own home when necessary".[1168] Another Concluding Observations calls for the State to "[r]each out to vulnerable individuals" in the implementation of the right to vote in Article 29 on Participation in political and public life.[1169] Yet another notes the importance of disaggregation of data on "the situation of specific groups of persons with disabilities in the State party who may be subject to varying degrees of vulnerability" but does not specify if the source of such vulnerability is connected to impairment or to other factors such as sex, ethnicity or age.[1170] The same Concluding Observations calls for the provision of reasonable accommodation under Article 5 on Equality and non-discrimination to apply "regardless of the level of disability".[1171]

Generally, systematic attention to specific groups is accorded only to women with disabilities and children with disabilities, particularly but not only covered under the headings of Article 6 on Women with disabilities and Article 7 on Children with disabilities. Particular Concluding Observations display additional foci, such as "persons who are institutionalized"[1172], "migrant workers with disabilities and disabled children of migrant workers"[1173], "Roma children with disabilities"[1174] and "indigenous and minority persons with disabilities"[1175]. Similarly, different Concluding Observations highlight the situation of different impairment groups, but only rarely highlight inequalities among these. Such examples do exist however, such as the Committee noting in one Concluding Observations that "in practice only students with certain kinds of impairments (physical disabilities and mild visual impairments) are able to attend mainstream education".[1176] The upshot is that while the Committee highlights the particular situation of certain segments of the constituency, there is not a concerted, comprehensive and systematic effort to pay attention to "those who require more intensive support" as identified in Preamble (j). It should be noted here that since the CRPD Reporting Guidelines do not address the Preambular para-

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[1167] Concluding Observations China, para. 32.
[1168] Ibid., para. 26.
[1169] Concluding Observations Peru, para. 45 (b).
[1170] Concluding Observations Spain, para. 49.
[1171] Ibid., para. 20.
[1172] Concluding Observations Argentina, paras. 29-30, 47-49.
[1173] Ibid., paras. 45-46.
[1174] Concluding Observations Hungary, paras. 40, 42, 48, 50.
[1175] Concluding Observations Peru, paras. 12-13, 16, 36-37, 46.
[1176] Concluding Observations China, para. 35.

graphs of the CRPD, no call for attention to this segment of the population is communicated to reporting States Parties.[1177]

Turning to the mandate to issue General Comments as provided for by Articles 36 and 39 of the CRPD, two such General Comments are currently in the process of being drafted. As noted first above under 7.1.1. and 9.1.9. respectively, these deal with Article 12 on Equal recognition before the law[1178] and Article 9 on Accessibility[1179]. Beginning with Draft General Comment on Article 12, as emerged from its exploration in Chapter 7 above, its central theme in relation to Article 25, as well as generally, is the right be protected from unwanted interventions, rather than the right to be provided with wanted interventions. While the right to consent to treatment is relevant both to the opportunity to demand and to reject treatment the connections made with Article 25 only explicitly concern the right to reject treatment, which is indeed the overarching concern of the Draft General Comment. While the general phrasing of the entitlement "to consent to medical treatment"[1180] is able to hold both these concerns, the envisaged problem in relation to the lacking mandate to consent emerges as when this leads to unwanted interventions, rather than when it leads to the non-provision of wanted intervention (or in the case where the position of the receiver cannot be detected, 'required' interventions). The following statement is representative of the former concern as well as of the entire Draft General Comment, and is not flanked by complementary statements addressing the latter concern:

> [F]orced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement upon the rights to personal integrity (Article 17), freedom from torture (Article 15), and freedom from violence, exploitation and abuse (Article 16). This practice denies the right to legal capacity to choose medical treatment and is therefore a violation of Article 12. [...] Policies and legislative provisions that allow or perpetrate forced treatment must be abolished. This is an on-going violation in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness as well as views of people using

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[1177] Such calls are made to take "types of disabilities" into account. See e.g. CRPD Reporting Guidelines, p. 2. In addition, calls are made to pay attention to the situation of person who are described as "vulnerable" by virtue of female sex or low age. See e.g. Ibid., pp. 4, 19. In relation to Article 27 on Work and employment, the Committee calls for the "[i]dentification of the most vulnerable groups among persons with disabilities (including by providing examples) and policies and legislation in place for their inclusion in the labour market". Ibid., p. 16. In relation to the reports by States Parties as such, commentators have made the observation that "little attention is paid to specific vulnerabilities of subgroups of persons with disabilities. Moreover, access to health is understood in a purely physical sense of availability and accessibility of services, while no attention is given to specific expectations and needs of persons with disabilities or to the competence of health staff to work with vulnerable groups". Brehmer-Rinderer, Barbara et al., Promoting Health of Persons with Intellectual Disabilities Using the UN Convention on the Rights of Persons with Disabilities: Early Implementation Assessment in Spain and Hungary, Journal of Policy and Practice in Intellectual Disabilities, Vol. 10, No.1, 2013, pp. 33-34.

[1178] CRPD Draft General Comment on Article 12.

[1179] CRPD Draft General Comment on Article 9.

[1180] CRPD Draft General Comment on Article 12, para. 27.

> mental health systems who have expressed deep pain and trauma as a result of forced treatment.[1181]

Notably, the Committee does not enter into a discussion of the realisation of the rights in Article 12 for "those who require more intensive support" as identified in Preamble (j), except for noting generally that "[a]n individual's level of support needs (especially where these are high), should not be a barrier to obtaining support in decision-making".[1182] There is no explicit refutation or engagement with the discussion in the negotiations accounted for above under 12.2.2. regarding the question if the abolition of substituted decision-making always is to the detriment of the well-being of all, and if not unequivocally so, how to weigh the interests of different segment of the constituency covered by the CRPD. Making this observation here does not amount to a call for substituted decision-making but stops at a strong call for explicit attention to be accorded to how States are to ensure that supported decision-making will best serve those persons identified by Preamble (j) who experience limitations in relation to decision-making.

Turning to Draft General Comment on Article 9 addressing accessibility, it contains a section addressing in general terms the need for accessibility of "[h]ealth care and social protection".[1183] Among the different dimensions of accessibility, it mentions explicitly only the accessibility of "buildings" and "transportation".[1184] Notably, "health" is used in the two places of the General Comment where the Committee exemplifies the life opportunities that accessibility is to make possible.[1185]

The Committee does not enter into a discussion of the realisation of the entitlements in Article 9 for "those who require more intensive support" as identified in Preamble (j). It does however emphasise that accessibility must be realised for *all* persons with disabilities, "regardless of the type of their impairment, legal status, social condition, gender, and age".[1186] On the issue of 'type' of impairment the Committee emphasises that "rare impairment", which may not be accommodated by general accessibility standards, actualises the entitlement to "reasonable accommodation" as provided for by Article 5 on Equality and non-discrimination.[1187] The Committee notes that this means that the accessibility needs of such persons are subject to the caveat "if it is reasonable and not imposing a disproportionate or undue burden" but does not further problematise the categorically lower standard thus potentially set for persons with "rare impairment" compared to others.[1188] The Draft General

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[1181] Ibid., para. 38.

[1182] Ibid., para. 25 (a).

[1183] CRPD Draft General Comment on Article 9, para. 36.

[1184] Ibid.

[1185] In para. 5 the Committee refers to "health and education" and in para. 6 to "the right to seek employment or the right to health care".

[1186] Ibid., para. 10. See also paras. 12, 27-28.

[1187] Ibid., paras. 22-23.

[1188] Ibid., para. 23. See further on the relationship between reasonable accommodation and accessibility above under 9.1.9.

Comment explicitly mentions certain categories of persons as exemplifications of accessibility requirements such as "[a] wheelchair user"[1189], "[a] blind person"[1190], "[a] deaf person"[1191], "[a] person with intellectual disability"[1192] and "those who are facing cognitive fatigue"[1193]. Connecting back to the negotiations and the call for attention to the requirements of persons hard of hearing, the Draft General Comment contains no explicit mention of this group.[1194] In addition, "display of text", as included in the definition of "[c]ommunication" in Article 2 on Definition on account of such persons, is not mentioned in this Draft General Comment while sign-language receives repeated mention.[1195] In relation to diversity factors other than impairment the Committee calls attention, in addition to "legal status, social condition, gender, and age" as noted just above, to the need to ensure accessibility for persons living in urban as well as in rural areas.[1196] In sum, this General Comment displays attention to the importance of life opportunities falling under the right to health, but does not address the position of "those who require more intensive support" as identified in Preamble (j). In addition, the use of different impairment groups as illustrations of the diversity of requirements could be further nuanced to ensure representativeness across the board. Not paying attention to diversity affects segments of the constituency unequally. In terms of categories of impairments, not being explicit about such diversity and related requirements runs the risk of keeping some off the radar. This will be counterproductive to nuancing and broadening the perception of who is included under the CRPD and thus will not direct attention to the requirements and wishes of all. Even furthermore, this results in the requirement of some masquerading as the requirements of all, because no alternative picture is visible.[1197] While this risk is present in relation to all aspects of diversity, it is particularly so in relation to aspects which do not square with the portrayal of persons, situations and requirements the CRPD seeks to forward, such as person thought of in terms of 'chronic illness' or 'medical disabilities'.[1198]

Turning to the mandate to consider communications as provided for by Article 1 of the OP-CRPD, three views have been issued by the Committee so far.[1199] Two of these have been considered on their merits and have been found to disclose a violation of the CRPD and one has been found inadmissible.[1200] These communications

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[1189] CRPD Draft General Comment on Article 9, para. 38.

[1190] Ibid.

[1191] Ibid.

[1192] Ibid.

[1193] Ibid., para. 17.

[1194] See above under 12.2.

[1195] CRPD Draft General Comment on Article 9, paras. 6, 17-18, 27-28, 34-35, 37.

[1196] Ibid., paras. 10, 13.

[1197] See Jill Humphrey above under 3.7.1.4.

[1198] See Patricia de Wolfe and Susan Wendell above under 3.7.1.4.

[1199] Views issued up until September 2013 are included.

[1200] The two cases considered are H.M. v. Sweden, 2012 and Committee on the Rights of Persons with Disabilities, Szilvia Nyusti and Péter Takács v. Hungary [hereinafter Nyusti and Takács v. Hungary, 2013], Communication No. 1/2010, Views adopted by the Committee at its 9th illustrate the diversity of the constituency as well as diverse and sometimes clashing interests. The heart of the inadmissible case, McAlpine v. UK, is a call to oblige the State Party to combat "the stereotypical assumption that diabetes will result in prolonged periods of time off due to illness".[1201] H.M. v. Sweden was the first case decided by the Committee.[1202] The demand is for an exception from planning rules in order for the author to make a construction on her land which will assist in improving her health state. In arguing for the necessity of this in order to ensure "her rights to equal opportunity for rehabilitation and improved health"[1203] and "ensuring her quality of life, including her right to good health"[1204], her health state is described in detail, including expression such as "severe", "fragile", "bedridden", "weakened", "destructive" and "pain and suffering".[1205] She furthermore refers to her "seriously reduced functional ability"[1206] and notes that "she is dependent on her parents, who live nearby"[1207]. This is her reality, but it fits ill with the aim of the UK case, which is targeting the general assumption of impairment as implying illness-related requirements conflicting with ability and contributions, in that case concerning the area of employment. It rhymes less well yet with general statements made by the CRPD Committee in its Concluding Observations. It its Concluding Observations on China the Committee deplores awareness-raising efforts in China in which "the medical model of disability prevails" and which "depict persons with disabilities as helpless and dependent human beings segregated from the rest of society".[1208] It reminds China of "the Convention's human rights model of disability" amounting to a "concept of persons with disabilities as independent and autonomous rights holders" and urges this State Party to "introduce an awareness-raising programme that shows the society positive perceptions of persons with disabilities".[1209] By contrast H.M. refers to her dependency on her parents as strengthening her claim as a 'rights holder' under this "human rights model of disability", thus adding a complexity to the picture lacking in the statement to China. In addition, this aspect of her situation also illustrates her requirements for 'help', which rhymes badly with dismissive depiction of such situations in terms of being "helpless and dependent". Finally, the Hungarian case, Nyusti and Takács v. Hungary, adds another crucial dimension to the picture

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session, 15-19 April 2013, UN doc: CRPD/C/9/D/1/2010, 23 April 2013. The case found inadmissible is Committee on the Rights of Persons with Disabilities, Kenneth McAlpine v. UK, [hereinafter McAlpine v. UK, 2012], Communication No. 6/2011, Views adopted by the Committee at its 8th session, 17-28 September 2012, UN doc: CRPD/C/8/D/6/2011, 13 November 2012.

[1201] McAlpine v. UK, 2012, para. 3.1. The case concerned a person with diabetes who was made redundant from his employment.

[1202] Different aspects of this case are discussed above under 8.1.2.3., 10.1.2. and 10.1.6.

[1203] H.M. v. Sweden, 2012, para. 3.1.

[1204] Ibid., para. 5.4.

[1205] Ibid., paras. 2.1-2.2.

[1206] Ibid., para. 5.8.

[1207] Ibid., para. 4.6.

[1208] Concluding Observations China, para. 15.

[1209] Ibid., para. 16.

of the issues facing the constituency of the CRPD, by targeting environmental barriers to composite life opportunities in society at large through demanding accessible Automated Teller Machines (ATM's) for persons with visual disabilities.[1210]

To sum up, the practice of the Committee so far, and in particular the complaints considered, illustrates the diverse interests of the constituency and the need for the Committee to balance these in the contexts where it is at liberty to set the agenda itself. This practice, as evident from the Concluding Observations and General Comments considered above, illustrates that neither health-related interventions nor the situation of the segment of the constituency identified in Preamble (j) are systematically addressed by the Committee in a comprehensive and (in the case of heath related interventions) unequivocally affirming manner. It is recommended that Articles 25 and 26 are each allocated a heading in every Concluding Observations, which contains, at least, categorical expressions on the entitlements to be provided with interventions, the quality aspect of such interventions and the entitlements to make informed decision for or against such interventions. The quality aspect of interventions must include both 'know-how' and 'value-proofing'. It is also imperative to balance the equally important aspects of providing wanted interventions and protecting against unwanted interventions as well as to avoid references to things 'medical' as somehow in opposition to the CRPD or even to 'human rights'. In addition, the entitlement to be provided with interventions addressing not only further but also the initial impairment as provided for by Article 25 (b) deserves the attention of the Committee. States should also be made aware of the necessity to balance the entitlements in Articles 25 and 26 with the entitlements flowing from the provisions in the CRPD recognising and calling for the respect for dignity and the acceptance and valuation of diversity discussed above (Preamble (m), Article 1 on Purpose, Article 3 on General principles and Article 8 on Awareness-raising) and should receive nuanced guidance in this respect. In relation to "those who require more intensive support" as identified in Preamble (j), it is recommended that this focus permeates each and every aspect brought up by the Committee. To ensure the provision of information by States on this segment of the constituency, a reference should be included in the CRPD Reporting Guidelines. A focus on this group should furthermore permeate General Comments.

12.3.3. The backdrop of this balancing act – Post CRPD doctrine

Although this is by no means a comprehensive analysis of all post CRPD doctrine, a few general, but important tentative conclusions are emphasised here. Firstly, this doctrine hitherto overwhelmingly addresses the entitlement to refuse health interventions, rather than the underlying entitlement to be offered such interventions. Secondly, much like in the negotiations of the CRPD and in the practice of the

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[1210] Nyusti and Takács v. Hungary, 2013.

CRPD Committee, the use of the conceptual pair the 'social model' of disability and the 'medical model' (or sometimes 'charity model') of disability is greatly favoured by doctrine. Furthermore, as in the former two cases, this use at best implicitly but often explicitly casts general suspicion on the relevance and even adequacy of health interventions. This is habitually done through a two step exercise: by emphasising and celebrating the CRPD as 'social model' (and not 'medical model') and by illustrating what the 'social model' is through denouncing health interventions (sometimes explicitly framed as 'medical model'). An illustrative example is when Lord et al. characterise the CRPD as "embrac[ing] a rights-based, social model conceptualization of disability".[1211] This is followed by likening this approach to "human rights" and distancing it from "medical and charity models":

> The tactical reframing of disability as a social construction emphasizes discrimination and affronts to human dignity inherent in the medical and charity models and builds the foundation of disability as a human right issue[.][1212]

Following this, they note that "[t]his issue framing captures the insight that the full participation in society for people with disabilities will be achieved not by "fixing" people, but by breaking down the *barriers* that prevent realization of equal opportunity, full participation and respect for difference".[1213] In order to emphasise the importance of breaking down barriers (in general and in the CRPD), ""fixing" people"", (which is the business of health interventions) is juxtaposed to the "social model", to the CRPD and even to "human rights", thus categorically casting such interventions in a negative light.

Another example of the use of the 'social model' of disability in a way which forwards health interventions as questionable is the account by Rannveig Traustadóttir discussed above under 11.2.5. As noted there, Traustadóttir welcomes the CRPD as "social model". While noting that "this is an oversimplification and does not do justice to the complexity of disability", she employs a table of opposites (attributed to Michael Oliver and Tom Shakespeare) in order to provide "an understanding of the differences" between the "Individual or Medical Model" and the "Social Contextual Model".[1214] The "Social Contextual Model" is then presented as signified by, inter alia, "[e]mphasis on the relationship between the individual and society", "[v]iew[ing] discrimination, exclusion and prejudice as the problem" and the view that "[e]nding discrimination, segregation and removing barriers is the answer".[1215] The "Individual or Medical Model" is then juxtaposed to the former model and presented as signified by, inter alia, "[e]mphasis on clinical and medical diagnosis", "[v]iew[ing] the person as the problem that needs to be fixed or cured" and the view

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[1211] Lord et al., 2010, p. 568.

[1212] Ibid.

[1213] Ibid. Emphasis in original.

[1214] Traustadóttir, 2009, p. 8.

[1215] Ibid.

that "[m]edical, psychological and rehabilitative service are the answers".[1216] By noting that this is an "oversimplification" and by using an expression such as "emphasis", Traustadóttir communicates in general terms that this juxtaposition is not the 'whole picture'. However, by using health interventions to illustrate what the CRPD is not, and indeed should not be, while omitting to explicitly note that part of this 'whole picture' includes recognising the relevance and adequacy of health interventions, this exercise still serves to render such interventions under suspicion.

Other accounts categorically and without qualification divorce the CRPD from all things 'medical'. An example of this is a handbook developed by the OHCHR to guide the monitoring of the CRPD. This handbook celebrates "the social model of disability [...] endorse[d] [by] the CRPD" as opposed to the "medical approach" and the "charity approach".[1217] The "medical approach" is explained as the position that "individuals can be "fixed" through medicine or rehabilitation" and the "charity approach" is explained as the position that "they can be cared for, through charity or welfare programmes".[1218] Furthermore, "[f]ixing the environment" is equated with the "[h]uman rights approach" and "[f]ixing weakness" is equated with the "[c]harity approach".[1219] Monitors are told to focus on "what society has or has not done which is obstructing the full enjoyment of their [constituents of the CRPD] rights", which is juxtaposed with focusing on "how their physical or mental impairment has affected the enjoyment of their rights". [1220] Issues concerning "impairment" are consequently designated as irrelevant or inappropriate in relation to "rights". Finally, the manual notes that "[i]mportantly, the Convention does not seek to prevent disability – which is a medical approach".[1221]

To conclude, post CRPD doctrine generally focuses on the non-intervention side of health interventions at the expense of the provision side. In addition, it uses the juxtaposition of the 'social model' of disability on the one side and the 'medical model' of disability (sometimes flanked by the 'charity model' of disability) on the other to illustrate what is and what is not compatible with the CRPD and 'human rights'. By depicting the latter models by way of health interventions (and sometimes in flippant or derogatory terms such as 'fixing'), such interventions are produced in categorical terms as at best irrelevant and at worst inappropriate. In effect, such interventions are neither, which furthermore is explicitly recognised by the CRPD.

[1216] Ibid.
[1217] OHCHR, 2010, p. 8.
[1218] Ibid.
[1219] Ibid., p. 10.
[1220] Ibid., p. 48.
[1221] Ibid., p. 23.

12.3.4 The backdrop of this balancing act – The overlapping mandates of the CRPD Committee and other UN treaty bodies

The CRPD is a continuation of the legal body created by the sum total of UN human rights conventions and as mentioned above the mandate of the CRPD Committee overlaps with other committees overseeing the implementation of earlier such conventions. This common ground was emphasised in the negotiations of the CRPD; indeed this instrument was negotiated based on an explicit understanding of it as not departing from earlier human rights law on points of principle but merely elaborating its details.[1222] The constituency of the CRPD thus overlaps with that of earlier conventions, as do the rights protected therein. As a consequence, the positions taken by the CRPD Committee and the committees overseeing earlier conventions are likely to be the result of efforts to converge rather than diverge, even if within the limits of interpretative space.[1223] If they do diverge, this will attract additional scrutiny to the interpretation arrived at.

In earlier conventions and their implementation, entitlements related to health are not approached with the suspicion these incurred in the negotiations of the CRPD. Rather than juxtaposing 'medicine' and 'rights' these merge in earlier practice through 'the right to health'. In addition, no equivalents of Preamble (m), Article 3 (d) on General principles or Article 8 on Awareness-raising, questioning the default negative valuation of the levels or modes of functioning of the body and mind implicated as "impairments" by Preamble (e) and Article 1 on Purpose of the CRPD and covered by earlier conventions under the blanket of 'health', are included in those

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[1222] This connects to the discussion on whether such elaboration of detail amounts to "new rights" or not. The reassurance that the CRPD would not create "new rights" was used in the negotiations to appease delegations weary of particular provision (see e.g. quote by the Chair above under 7.1.1. in note 27, Part II). While this statement has been widely taken at face value in doctrine also subsequent to the adoption of the CRPD, others have questioned its accuracy. For such an account of questioning backed up by a detailed analysis of the entitlement in the CRPD, see Mégret, Frédéric, The Disability Convention: Human Rights of Persons with Disabilities or Disability Rights?, Human Rights Quarterly, Vol. 30, No. 2, 2008. CRPD Committee Draft General Comment on Article 9 states that the Committee is divided between using a blanket statement holding that "CRPD does not create any new rights, and indeed accessibility should not be viewed as a new right" and the following, opposite, statement: "Although during the negotiations of the treaty it was said that the intention was not to create new rights, if we read the text of article 9 in accordance with the general guidelines for the interpretation of treatises set forth in article 31 of the Vienna Convention on the Law of Treaties, we can arrive to the conclusion that we are fact in the presence of a new right. If we read the text plainly, in conformity with the ordinary use of language, we can see that it establishes binding obligations for states and consequently rights for persons with disabilities that are not yet included in the other core human rights treatises, although there are important precedents to this effect in ICCPR article 25 (c) and ICERD article 5 (f).". CRPD Committee Draft General Comment on Article 9, para. 11.

[1223] To some extent, working towards convergence is the express duty of the CRPD Committee according to Article 38 (b) on Relationship of the Committee with other bodies: "The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.".

conventions. It is also a fact that explicit attention to the constituency of the CRPD in these instruments as well as in their implementation has been a long time coming, which has inhibited the emergence and expressions of principled positions such as these.[1224] Against this background, and taken the diverging concerns and agendas attached to Article 25 on Health, Article 26 on Habilitation and rehabilitation and Preamble (j) as well as the long history of the right to health in the larger human rights discourse, it becomes apparent that the convergence of the practice by earlier committees and that of the CRPD Committee may require some effort. Here, the CRPD Committee occupies a key position to guide the work of other committees as it relates to the constituency of the CRPD, including the interpretation, monitoring and implementation of the right to health.

At the outset, it should be noted that the mandate of earlier instruments exceeds the CRPD in terms of constituency as they represent both persons with disabilities *and* persons without disabilities. As a consequence, in contrast to the CRPD, these instruments create entitlements to measures to prevent the impairment through which one becomes part of the constituency of the CRPD, measures which were deliberately left out of the CRPD. The focus of all committees is, within the limits of the law, to expand the cluster of entitlements and obligation covered by a specific right. Regarding the right to health, such efforts by the committees preceding the CRPD Committee have focused on emphasising what was referred to in the negotiations as "the underlying determinants of health".[1225] The main point made is that entitlements and obligations inherent in the right to health are not limited to services, but instead include "a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment".[1226] As mentioned above under 7.1.1., such measures overlap with broad policies aimed at the prevention of impairment. As similarly mentioned there, the CRPD deliberately does not call for such efforts but still asks that these, if they exist, are equally accessible to the constituency of the CRPD.

In order to examine the practice of the other committees relating to disability and issues falling under the right to health from the perspective of the entitlements and obligations under the CRPD and the concerns discussed above as shaping these, I will look at the most recent approach to disability, General Comment No. 9 on The Rights of Children with Disabilities from 2006 by the CRC Committee.[1227]

[1224] See Quinn and Degener with Bruce et al., 2002.

[1225] See quote by Paul Hunt above under 7.1.1. referenced in note 32, Part II.

[1226] Committee on Economic, Social and Cultural Rights General Comment No. 14 on the Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights) [hereinafter ICESCR General Comment 14], 2000, UN doc: E/C.12/2000/4, para. 4.

[1227] Committee on the Rights of the Child General Comment No. 9 on the Rights of Children with Disabilities [hereinafter CRC General Comment 9], 2007, UN doc: CRC/C/GC/9. This recent

The focus of the CRC Committee on *all* children is visible from the reoccurring theme of general prevention in its General Comment 9. In the first paragraph, the CRC Committee starts by describing lack of services and education for children with disabilities, going on to note that causes of impairment are preventable and ending with the call that "more should be done to create the necessary political will and real commitment to investigate and put into practice the most effective actions to prevent disabilities with the participation of all levels of society".[1228] Throughout this General Comment there are numerous references to prevention of impairment.[1229]

CRC was the first UN Convention to explicitly mention disability: Article 2 (1) includes disability as a prohibited ground for discrimination among children and Article 23 focuses on children with disabilities. The aim of Article 23 is expressed in 23 (1) as "a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community". 23 (2) recognises a right to "special care" and 23 (3) recognises "the special needs of a disabled child" and the right to assistance relating to education, health care, rehabilitation, recreation and future employment in order to achieve "the fullest possible social integration and individual development, including his or her cultural and spiritual development". 23 (4) then addresses co-operation and exchange of information between States "in the field of preventive health care and of medical, psychological and functional treatment of disabled children". In this field, "methods of rehabilitation, education and vocational services" are included.

In sum, CRC General Comment 9 appears shaped by Article 23 and its focus on the provision of services and prevention. Albeit the General Comment notes that "the barrier [to the full enjoyment of the rights in CRC] is not the disability itself but rather a combination of social, cultural, attitudinal and physical obstacles which children with disabilities encounter in their daily lives", this message does not permeate the addressing of other issues throughout the General Comment.[1230] It uses the vocabulary of Article 23 in that it repeatedly refers to "special care"[1231]. In addition, it refers to children with disabilities as "children who suffer disabilities"[1232] and phrases the goal of information on "causes, management and prognosis" of impairment as "enable[ing] them [children with disabilities] to adjust and live better with their disabilities".[1233] It also emphasises the difficulties in bringing up a child with disabilities and directs the reason for such difficulties to the child without recognition of the

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General Comment from the Committee monitoring CRC contains several references to the CRPD.

[1228] CRC General Comment 9, para. 1.

[1229] In addition to thus dominating the first paragraph of the General comment, this aspect is addressed in a section named prevention (para. VII. B.), as well as in paras. 15, 19, 22, 23, 61 and 79. Like in the CRPD, the term "disabilities" is used to signify imparment.

[1230] CRC General Comment 9, para. 5.

[1231] See Ibid., paras. 12-14. Para. 33 refers to "special services", para. 46 to "special requirements" and para. 65 to "special needs".

[1232] Ibid., para. 78.

[1233] Ibid., para. 37.

attitudinal, built and other environment. It thus states that “children with disabilities often pose a challenge in the extra care they may need and the special requirements in their physical, psychological and mental upbringing”[1234] and the need for support groups for care takers are justified by the need for assisting them in “coping with their [children with disabilities’] disabilities”.[1235] Measured against the CRPD, the identification of the source of difficulties is unbalanced towards the individual diversity rather than the environment and the focus on the challenges posed by children with disabilities is left without recognition of their potential contribution to a family.[1236] In addition, unnecessarily negative expressions such as “suffering” are used with an air of generality.

Outside of General Comment 9, the CRC Committee equates “disability” with “health problems”.[1237] While this is not a comprehensive analysis of the practice by the UN treaty monitoring bodies regarding connections between ‘disability’ and ‘health’, it can be noted that the tendencies above are not limited to the CRC Committee. The Committee on Economic, Social and Cultural Rights (ICESCR Committee) does not separate levels and modes of functioning of the body and mind understood as impairments in the CRPD from health conditions generally. In its General Comment on the right to health the provision of “preventive, curative [and] rehabilitative health services” are addressed in concert regarding “diseases, illnesses, injuries and disabilities”.[1238] Also, according to its General Comment on non-discrimination, “health status” as a ground for discrimination includes “mental illness”.[1239] In relation to entitlements to say yes or no to treatment on offer the ICESCR Committee recognises “the right to be free from torture, non-consensual medical treatment and experimentation”[1240] in its General Comment on the right to health but qualifies the obligation to refrain from “applying coercive medical treatments” with the caveat “unless on an exceptional basis for the treatment of mental

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[1234] Ibid., para. 46.

[1235] Ibid., para. 43 (c).

[1236] Bronagh Byrne reaches similar conclusions in her evaluation of this General Comment, see Byrne, 2012, pp. 424-425.

[1237] See Committee on the Rights of the Child General Comment No. 15 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (Art. 24), 2013, UN doc: CRC/C/GC/15, para. 5. Here the CRC Committee refers to “disease, death and disability” as “new health problems and changing health priorities”. The same General Comment continues by “recogniz[ing] that most mortality, morbidity and disabilities among children could be prevented if there were political commitment and sufficient allocation of resources directed towards the application of available knowledge and technologies for prevention, treatment and care”. Ibid., para. 1.

[1238] ICESCR General Comment 14, para. 17.

[1239] Committee on Economic, Social and Cultural Rights General Comment No. 20 on Non-discrimination in Economic, Social and Cultural Rights (Art. 2, Para. 2, of the International Covenant on Economic, Social and Cultural Rights), 2009, UN doc: E/C.12/GC/20, para. 33. In para. 28, “disability” is also recognised as a prohibited ground for discrimination. The relationship between “health status” and “disability” is not further elaborated.

[1240] ICESCR General Comment 14, para. 8.

illness".[1241] To somewhat counterbalance these examples, it should be noted that the ICESCR Committee in 1993 issued a General Comment focusing solely on persons with disabilities which, in areas such as equating the situation of persons with disabilities with discrimination, was truly ground breaking.[1242]

While the named general comments do not explicitly state impairment as an unwanted consequence of violations of human rights, such statements can be found elsewhere. For example, the CEDAW Committee condemns practices such as female genital mutilation by reference to it causing impairment. In a General Recommendation titled "Article 12: Women and Health" this Committee notes e.g. that "cultural or traditional practices such as female genital mutilation also carry a high risk of death and disability".[1243] The same General Recommendation categorically links "disabling [...] diseases" and "suffer[ing]", by noting that "women often live longer than men and are more likely than men to suffer from disabling and degenerative chronic diseases, such as osteoporosis and dementia". [1244]

The examples above indicate that the CRPD Committee, based on the mandate provided by the contents of the CRPD, carries lessons for the other committees. These committees in turn have the opportunity to implement such lessons in as much as these do not contravene the mandates they have under their respective instruments. The most obvious such lessons deductable from the above relates to not losing sight of how the (attitudinal and otherwise) environment permeates every aspect of the situation of the constituency of the CRPD and avoiding blanket negative valuations of impairment as well as the categorical forwarding of such valuations without concern as to the consequence of this for individual persons as well as for general perceptions.

The position of all instruments, including the CRPD, builds on the same assumption: that it can be assumed that individuals generally want to avoid impairments they do not have. Hence the focus of the ICESCR Committee and the CRC Committee on prevention and the social determinants of health and hence the entitlements to the prevention of further impairments and equal access to public health programmes in the CRPD. What the CRPD adds to this is the questioning of the assumption that all persons who do currently have such impairment deplore this, the drive to moderate this assumption and the aim to illustrate the role of the environment in making impairment a problem. In order for the CRPD Committee to influence other committees in a way which honours the former's entire constituencies, a principled but nuanced message is necessary. This message should call for, and applaud calls for,

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[1241] Ibid., para. 34.

[1242] Committee on Economic, Social and Cultural Rights General Comment No. 5 on Persons with Disabilities, 1994, UN doc: E/1995/22(SUPP).

[1243] Committee on the Elimination of Discrimination against Women General Recommendation No. 24 on Article 12: Women and Health [hereinafter CEDAW General Recommendation 24], 1999, UN doc: A/54/38/Rev.1, chapter I, para. 12. It should be noted that the ICESCR Committee similarly deplores such practices, but depicts their negative consequence as questions of "health". See e.g. ICESCR General Comment 14, paras. 22 and 36.

[1244] CEDAW General Recommendation 24, para. 24.

health interventions for its constituency. However, this cannot be at the expense of forwarding the entire constituency as 'suffering' or needing to 'adjust', of ignoring other interventions (particularly those targeting the environment), of failing to apply an approach targeting all dimensions of life or of failing to question the assumptions and practices of medical policy and professionals and a forced nature of such interventions. The Committee needs to illustrate the lack of representativeness and the cost of unnecessarily negative categorical expressions by making visible the heterogeneity of its constituency and the need to balance different interests. There are indeed persons among this constituency who experience and describe themselves as 'suffering' which is not for anyone to question or much less to attempt to silence. However, to categorically refer to the constituency of the CRPD as 'suffering' is not only misguided but unnecessarily feeds current stereotypes and misconceptions targeted by the CRPD, with no visible gain for anyone. At the other end of the spectrum, categorical dismissal of all things medical or denial that suffering, for a variety of reasons, exist, will not be influential. This is particularly so as the other instruments answer to a larger constituency to which the assumption that people generally do not want impairments they do not currently have applies. In order to bridge the gap to other conventions and committees the CRPD Committee must straightforwardly and holistically address the right to health and the diverse concerns and interests it and the rest of the CRPD builds upon. In order to gain ground, this must be done in a manner which balances and does not shy away from the different situations and legitimate interests represented within, as well as without, its constituency.

12.4. To conclude

What this Epilogue aims to communicate is that the CRPD protects conflicting interests and requirements which are embodied in persons of equal importance and due equal concern. This actuality needs to be carefully navigated by the Committee through which segments of the constituency it chooses to focus on, what requirements it chooses to emphasise (as all requirements are more central to some than to others) and the connotations it transmits through choice of language.

Irrespective of the crucial work still cut out for provisions such as Articles 8 on Awareness-raising, Preamble (m) and General principle 3 (d) in terms of changing general perceptions of the constituency of the CRPD en masse, time is over for simplifications such as addressing 'persons with disabilities' as one in requirements and interests as well as for sweeping and dismissive references to the 'medical model' of disability and all things 'medical'. As argued above under 12.1. and 12.2. these tendencies are fuelled by per se important concerns and agendas regarding, inter alia, the direction of focus towards the environment or the individual, the valuation of impairment, the portrayal of the constituency of the CRPD and the relationship between this constituency and professionals. However, rather than sidelining requirements which run counter to such concerns and agendas, these requirements and interests must be explicitly and unequivocally acknowledged and addressed, *but* addressed as relevant only to *some* persons with disabilities. Through allowing the picture to nuance itself in this way, these requirements and interests will neither be allowed to reinforce stereotypes about the constituency of CRPD en masse *nor* will they need to remain out of focus.

In the CRPD, many of the requirements actualising the concerns and agendas enumerated just above are part of the right to health as protected by Article 25 on Health and Article 26 on Habilitation and rehabilitation. I am here arguing that it is not by less attention to the urgency of the provision, quality and value basis of health interventions and by a one-sided focus on the right to decline these that the concerns enumerated above should be addressed by the CRPD Committee. Different dimensions of health interventions are crucially important to many people, for many different reasons. In addition, the fact that some segments of the constituency are less likely than others to have health requirements fulfilled adds to the onus of the Committee to contribute to the realisation of such entitlements. A slanted focus on the right to say no to services, as opposed to the right to demand these, remains as problematic as its opposite. Instead, these two aspects require balanced attention recognising them as equally crucial *to people*. 'Some persons with disabilities' should be the standing expression of categorical statements. In addition, in order to honour Article 8, requirements and situations amounting to 'negative' stereotypes largely assumed about *all* persons with disabilities should in particular be flanked by explicit recognition that these are not representative of everyone. While this in turn can be seen as stigmatising of those concerned, it appears as a balance of interest in line with the provisions of the CRPD. In addition, great care must be taken with the nuances of language used.

Categorical dismissive references to all things 'medical' or to 'cure', as figured in the negotiations of the CRPD do not reflect the entitlements and obligations in the final text of Articles 25 and 26 nor is it representative of the requirements and wishes of segments of its multifaceted constituency. Statements such as the "comments on the future" delivered by OHCHR at the adoption of the CRPD relegating the view of the constituency of the CRPD as "objects of [...] medical treatment" to the past, without qualifying that the problem lies in the word "object" rather than "medical treatment", runs the risk of hampering the realisation of the right to health.[1245] In the Concluding Observations adopted so far, the CRPD Committee continues the juxtaposition so common in the negotiations between 'the medical model/approach/perspective' on the wrong side and 'the social model/approach/perspective' and 'the human rights model/approach/perspective' on the right side of the CRPD. In this practice, the Committee is largely joined by post CRPD doctrine.

The point I want to make is that this practice serves to cast suspicion on all things medical and does a disservice to the right to health, particularly when these terms are used in a sweeping and imprecise manner. Such use leaves room for the ambiguities

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[1245] See quote by Louise Arbour above under 12.1.3. referenced in note 1022, Part II.

and inconsistencies relating to the value of health interventions purposefully and strategically built into the ideological heritage that constitutes the 'social model' of disability. It will be necessary for the Committee to position itself explicitly and set the record straight in relation to aspects of the 'social model' which serves to side-line or even compromise the right to health if it wishes to harness the potential of the 'social model' of disability *and* contribute to the realisation of the right to health. In addition, from a legal point of view, if references are to be made to the 'social model' of disability its meaning must be clearly derived from, linked to and compatible with all the provisions in the CRPD. Furthermore, if the term "the social model" is crafted to closely reflect the CRPD and an opposite 'villain' is required for illustrative and informative purposes, the term 'the individual model' appears preferable, as it does not immediately compromise any of the rights protected in the CRPD.[1246]

Much like Articles 25 and 26, attention to the segment of the constituency emphasised in Preamble (j): "those who require more intensive support", actualises the concerns and agendas enumerated above. In particular, Preamble (j) actualises concerns about the general perception of the constituency of the CRPD. These concerns in turn rest on the assumption that in order for surrounding society to be receptive to seeing the requirements of this constituency as legitimate claims and fulfilling these, the constituency itself must be related to as somehow 'worthy'. As mentioned above under 12.3.1. the 'showcase' constituent of the CRPD is autonomous, independent, capable of all but for environmental barriers, not in need of or wishing for interventions targeting his or her impairment and strong in energy and resolution. Against this background, it is here strongly suggested that the CRPD Committee makes a rule out of considering each dimension of its work from the perspective of if and how it implicates and caters for the interests of the segment of its constituency emphasised in Preamble (j). This is particularly called for in instances where those interests appear to depart from the interests of the majority.

To conclude, the rhetoric of the negotiations answering to the concerns and agendas enumerated above served to reduce attention to the persons intended by Preamble (j) as well as to downplay the relevance of entitlements falling under the right to health as now protected through Articles 25 and 26. The practice of the CRPD Committee so far indicates that this is likewise a real risk in relation to their guiding of the implementation of the CRPD. Rhetoric, simplifications and generalisation have served well in propelling disability onto the human right agenda and in generating the momentum for the creation of the CRPD. However, it is only by leaving generalisations, simplifications and easy answers behind, especially when these compromise the fulfilment of protected rights, that the entire constituency of the CRPD will enjoy the entitlements provided therein.

[1246] This happens to be the terminology used and preferred by Michael Oliver, albeit not due to concerns connected to safeguarding entitlements relating to health. See e.g. Oliver, 1996, p. 31.

Sources

UN Conventions, Declarations and Resolutions

International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Adopted 21 December 1965. Entered into force 4 January 1969. 660 UNTS 195.

International Covenant on Civil and Political Rights (ICCPR). Adopted 16 December 1966. Entered into force 23 March 1976. 1999 UNTS 171.

International Covenant on Economic, Social and Cultural Rights (ICESCR). Adopted 16 December 1966. Entered into force 3 January 1976. 993 UNTS 3.

Vienna Convention on the Law of Treaties (VCLT). Adopted 23 May 1969. Entered into force 27 January 1980. 1155 UNTS 331.

Convention on the Elimination on All Forms of Discrimination against Women (CEDAW). Adopted 18 December 1979. Entered into force 3 September 1981. 1249 UNTS 13.

Convention on the Rights of the Child (CRC). Adopted 20 November 1989. Entered into force 2 September 1990. 1577 UNTS 3.

Convention on the Rights of Persons with Disabilities (CRPD). Adopted 13 December 2006. Entered into force 3 May 2008. 2515 UNTS 3.

Optional Protocol to the Convention on the Rights of Persons with Disabilities (OP-CRPD). Adopted 13 December 2006. Entered into force 3 May 2008. UN doc: A/RES/61/606.

Universal Declaration of Human Rights (UDHR). Adopted by the UN General Assembly 10 December 1948. UN Doc: A/RES/3/217/A (III).

Declaration on the Rights of Disabled Persons. Adopted by the UN General Assembly 9 December 1975. UN doc: A/RES/3447 (XXX).

World Programme of Action concerning Disabled Persons (WPA). Adopted by the UN General Assembly 3 December 1982. UN doc: A/RES/37/52.

Principles Relating to the Status of National Institutions. Adopted by the UN General Assembly 20 September 1993. UN doc: A/RES/48/134.

Standard Rules on the Equalization of Opportunities for Persons with Disabilities (StR), adopted by the UN General Assembly 20 December 1993, UN doc: A/RES/48/96.

Documents by UN Treaty Bodies

Committee on the Rights of Persons with Disabilities

Committee on the Rights of Persons with Disabilities, H.M. v. Sweden [H.M. v. Sweden, 2012], Communication No. 3/2011, Views adopted by the Committee at its 7th session, 16-27 April 2012, UN doc: CRPD/C/7/D/3/2011, 21 May 2012.

Committee on the Rights of Persons with Disabilities, Kenneth McAlpine v. UK, [McAlpine v. UK, 2012], Communication No. 6/2011, Views adopted by the Committee at its 8th session, 17-28 September 2012, UN doc: CRPD/C/8/D/6/2011, 13 November 2012.

Committee on the Rights of Persons with Disabilities, Szilvia Nyusti and Péter Takács v. Hungary [Nyusti and Takács v. Hungary, 2013], Communication No. 1/2010, Views adopted by the Committee at its 9th session, 15-19 April 2013, UN doc: CRPD/C/9/D/1/2010, 23 April 2013.

Committee on the Rights of Persons with Disabilities Draft General Comment on Article 12 of the Convention – Equal Recognition before the law [CRPD Draft General Comment on Article 12], Advanced Unedited Version, 10th session, 2013.

Committee on the Rights of Persons with Disabilities Draft General Comment on Article 9 of the Convention – Accessibility [CRPD Draft General Comment on Article 9], Advanced Unedited Version, 10th session, 2013.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Tunisia [Concluding Observations Tunisia], 13 May 2011, UN doc: CRPD/C/TUN/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Spain [Concluding Observations Spain], 19 October 2011, UN doc: CRPD/C/ESP/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Peru [Concluding Observations Peru], 16 May 2012, UN doc: CRPD/C/PER/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Argentina [Concluding Observations Argentina], 8 October 2012, UN doc: CRPD/C/ARG/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of China , 15 October 2012, UN doc: CRPD/C/CHN/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Hungary [Concluding Observations Hungary], 22 October 2012, UN doc: CRPD/C/HUN/CO/1.

Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Paraguay [Concluding Observations Paraguay], 15 May 2013, UN doc: CRPD/C/PRY/CO/1.

Committee on the Rights of Persons with Disabilities, Guidelines on Treaty-specific Document to be Submitted by States Parties under Article 35, Paragraph 1, of the Convention on the Rights of Persons with Disabilities [CRPD Reporting Guidelines], 18 November 2009, UN doc: CRPD/C/2/3.

Committee on the Rights of the Child

Committee on the Rights of the Child General Comment No. 5 on General Measures of Implementation of the Convention on the Rights of the Child (Arts. 4, 42 and 44, para. 6), 2003, UN Doc: CRC/GC/2003/5.

Committee on the Rights of the Child General Comment No. 9 on the Rights of Children with Disabilities [CRC General Comment 9], 2007, UN doc: CRC/C/GC/9.

Committee on the Rights of the Child General Comment No. 15 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (Art. 24), 2013, UN doc: CRC/C/GC/15.

Committee on the Elimination of Discrimination against Women

Committee on the Elimination of Discrimination against Women General Recommendation No. 24 on Article 12: Women and Health [CEDAW General Recommendation 24], 1999, UN doc: A/54/38/Rev.1.

Committee on the Elimination of Discrimination against Women General Recommendation No. 25 on Article 4, Paragraph 1, of the Convention on the Elimination of All Forms of Discrimination against Women, on Temporary Special Measures [CEDAW General Recommendation 25] 2004, UN doc: A/59/38.

Committee on the Elimination of Racial Discrimination

Committee on the Elimination of Racial Discrimination General Recommendation No. 32 on the Meaning and Scope of Special Measures in the International Convention on the Elimination of Racial Discrimination, 2009, UN doc: CERD/C/GC/32.

Committee on Economic, Social and Cultural Rights

Committee on Economic, Social and Cultural Rights General Comment No. 5 on Persons with Disabilities, 1994, UN doc: E/1995/22(SUPP).

Committee on Economic, Social and Cultural Rights General Comment No. 14 on the Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights) [ICESCR General Comment 14], 2000, UN doc: E/C.12/2000/4.

Committee on Economic, Social and Cultural Rights General Comment No. 20 on Non-discrimination in Economic, Social and Cultural Rights (Art. 2, Para. 2, of the International Covenant on Economic, Social and Cultural Rights), 2009, UN doc: E/C.12/GC/20.

Official Documents Pertaining to the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities:

UN General Assembly Resolution on a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, 19 December 2001, UN doc: A/RES/56/168. Available through the UN webpage at http://www.un.org/esa/socdev/enable/disA56168e1.htm. Last visited 10 October 2013.

Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [Working Group Draft, 2004], Annex I to Report of the Working Group to the Ad Hoc Committee [Working Group Report, 2004], 27 January 2004, UN doc: A/AC.265/2004/WG/1. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcwgreportax1.htm. Last visited 10 October 2013.

Summary of the Discussions Held Regarding the Issue of International Cooperation to be Considered by the Ad Hoc Committee, Annex II to Report of the Working Group to the Ad Hoc Committee [Working Group Report, 2004], 27 January 2004, UN doc: A/AC.265/2004/WG/1. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcwgreportax1.htm. Last visited 10 October 2013.

Compilation of Proposed Revisions and Amendments Made by the Members of the Ad Hoc Committee to the Draft Text Presented by the Working Group as a Basis for Negotiations by Member States and Observers in the Ad Hoc Committee [Compilation of Proposals before the 4th Session, 2004], Annex II to Report of the Third Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [3rd Session Ad Hoc Committee Report, 2004], 9 June 2004, 3rd Session, UN doc: A/AC.265/2004/5. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3reporte.htm. Last visited 10 October 2013.

Report of the Coordinator to the Fourth Session of the Ad Hoc Committee [4th Session Report by Coordinator, 2004], 2004, Annex III to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Fourth Session [4th Session Ad Hoc Committee Report, 2004], 14 September 2004, UN doc: A/59/360. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc4reporte.htm. Last visited 10 October 2013.

Report of the Coordinator to the Ad Hoc Committee at its Fifth Session [5th Session Report by the Coordinator, 2005], Annex II to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Fifth Session [5th Session Ad Hoc Committee Report, 2005], 23 February 2005, UN doc: A/AC.265/2005/2. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc5reporte.htm. Last visited 10 October 2013.

Status of the Text Following the Discussion Held during the Fifth Session of the Ad Hoc Committee [5th Session Status of the Text, 2005], Annex III to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Fifth Session [5th Session Ad Hoc Committee Report, 2005], 23 February 2005, UN doc: A/AC.265/2005/2. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc5reporte.htm. Last visited 10 October 2013.

Report by the Chairman [6th Session Report by the Chairman, 2005]. Annex II to the Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Sixth Session [6th Session Ad Hoc Committee Report, 2005], 17 August 2005, UN doc: A/60/266. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6reporte.htm. Last visited 10 October 2013.

Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [Chair's Draft, 7th session, 2005], Annex 1 to Letter dated 7 October 2005 from the Chairman to all members of the Committee [Letter from the Chair to the Ad Hoc Committee, dated 7 October 2005, 7th session], 14 October 2005, UN doc: A/AC.265/2006/1. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcchairletter7oct.htm. Last visited 10 October 2013.

International Convention on the Rights of Persons with Disabilities, Working Text [CRPD Working Text after 7th Session, 2006], 7th Session, 2006, Annex II to Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Seventh Session [7th Session Ad Hoc Committee Report, 2006], 13 February 2006, UN doc: A/AC.265/2006/2. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7report-e.htm. Last visited 10 October 2013.

Draft Convention on the Rights of Persons with Disabilities [Interim Draft, 8th Session, 2006], Annex II to Interim Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its Eighth Session [8th Session Ad Hoc Committee Interim Report, 2006], 1 September 2006, UN doc: A/AC.265/2006/4. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8intreporte.htm. Last visited 10 October 2013.

Ad Hoc Committee 8th Session Drafting Committee, First Revised Text [First Revised Drafting Committee Text, 8th Session, 2006], 13 September 2006, 8th Session. Available through the UN webpage at http://www.un.org/esa/socdev/enable/drafting.htm. Last visited 10 October 2013.

Proposals and Comments Submitted to the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities:

The Working Group Session

Various contributors, Compilation of Proposals for Elements of a Convention [Compilation of Proposals before the Working Group, 2004], Working Group Session, 15 January 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/comp-element0.htm. Last visited 10 October 2013.

The 3rd Session

Adaptive Environments, Contextual Bases for Integrating Universal Design into the U.N. Convention on Persons with Disabilities, 3rd Session, May 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3aa.htm. Last visited 10 October 2013.

Asia Pacific Forum of National Human Rights Institutions (APF), Submission for the 3rd Session to the Ad Hoc Committee, 3rd Session, May 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3contrib.htm. Last visited 10 October 2013.

European Disability Forum (EDF), Position Paper on the Draft International Convention Text from the Working Group [EDF Position Paper on Working Group Draft, 3rd Session], 3rd Session, April 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3edf.htm. Last visited 10 October 2013.

European Union (EU), Proposal on Draft Article 16 on Children with disabilities, 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3eu.htm. Last visited 10 October 2013.

Inclusion International (II), Position on the Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities [II Proposal for the 3rd Session], 3rd Session, April 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3ii.htm. Last visited 10 October 2013.

International Labour Organization (ILO), Proposal, 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3ilo.htm. Last visited 10 October 2013.

Japan Disability Forum (JDF), Comments on Important Articles of the Draft Convention Prepared by the Working Group [JDF Comments on Draft Convention, 3rd Session], 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3contrib.htm. Last visited 10 October 2013.

Ontario Human Rights Commission, Comment on the Draft Convention [Ontario Human Rights Commission, Comment on the Draft Convention, 3rd Session], 3rd Session, 15 April 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3ohrc.htm. Last visited 10 October 2013.

Physical Disability Council of Australia Ltd (PDCA), Submission on UN Draft Convention on the Rights of People with Disabilities [PDCA, Submission on UN Draft Convention, 3rd Session], 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3pdca.htm. Last visited 10 October 2013.

People with Disability Australia Incorporated (PWDA), Australian Federation of Disability Organisations (AFDO) and National Association of Community Legal Centres (NACLC), Intervention on the Preamble, 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3comaustrl.htm. Last visited 10 October 2013.

Rehabilitation International (RI), Intervention on Article 21 on Health and rehabilitation, 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3comri.htm. Last visited 10 October 2013.

Republic of Korea, Proposal for Inclusion of a Separate Article on Women with Disabilities, 3rd Session, 27 May 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3korea.htm. Last visited 10 October 2013.

World Health Organization (WHO), Position Statement on Working Group Draft [WHO Position Statement on Working Group Draft, 3rd Session], 3rd session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcunsyscon.htm. Last visited 10 October 2013.

World Network of Users and Survivors of Psychiatry (WNUSP), Position Paper for the 3rd Meeting of the Ad Hoc Committee [WNUSP Position Paper 3rd Session], 3rd Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3wnusp.htm. Last visited 10 October 2013.

The 4th Session

Chile, Proposal, 4th Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc4chile.htm. Last visited 10 October 2013.

Israel, Proposal, 4th Session, 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc4israel.htm. Last visited 10 October 2013.

Landmine Survivors Network (LSN), Legal Analysis of the Modifications Proposed at the 3rd UN Ad Hoc Committee Meeting [LSN Legal Analysis, 4th Session], 4th Session, August 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcngocon.htm. Last visited 10 October 2013.

People with Disability Australia (PWDA), Australian Federation of Disability Organisations and (Australian) National Association of Community Legal Centres (NACLC), Contribution in Relation to Articles 1 to 15 [PWDA et al., Contribution Articles 1 to 15, 4th Session], 4th Session, 24 August 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcngocon.htm. Last visited 10 October 2013.

People with Disability Australia Incorporated (PWDA), Australian Federation of Disability Organisations (AFDO), and National Association of Community Legal Centres (NACLC), Contribution in Relation to Definitions, 4th Session, 23 August 2004. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcngocon.htm. Last visited 10 October 2013.

The 5th Session

Centre for Studies on Inclusive Education (CSIE), Ending Segregation – Enclusive education for All Children [CSIE, Paper on Inclusive Education, 5th Session], 5th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc5contngos.htm. Last visited 10 October 2013.

Dhanda, Amita, WNUSP, Advocacy Note on Legal Capacity, 5th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/art9legal.htm. Last visited 10 October 2013.

Facilitator on Draft Article 7, Proposed Modifications on Draft Article 7 – Equality and non-discrimination, 5th Session, 31 January 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc5facilitator.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Updated Contribution on the Draft Text of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 5th Session, 23 January 2005.

International Disability Caucus (IDC), Information Sheet on Article 12: Freedom from Violence and Abuse [IDC Information Sheet on Article 12, 5th Session], 5th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/art12.htm. Last visited 10 October 2013.

International Disability Caucus (ICD), Information Sheet, Why are Forced Interventions a Form of Torture?, 5th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcstata15fiscomments.htm. Last visited 10 October 2013.

Minkowitz, Tina, Supplementary Paper, Advocacy Note: Forced Interventions Meet International Definition of Torture Standards, 5th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/art11suppl.htm. Last visited 10 October 2013.

United States (US), Proposal for Article 8 on the Right to life, 5th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc5usa.htm. Last visited 10 October 2013.

The 6th Session

Canada, Intervention on Article 21 – Right to Health and rehabilitation, Talking Points, 6th Session, 8 August 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6canada.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Draft on Accessibility (Draft Article 19), 6th Session, 3 August 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Information Sheet on Article 22 Right to work, 6th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Information Sheet on Draft Article 21bis Habilitation and rehabilitation, 6th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), 2nd Information Sheet, Article 21 Health [IDC 2nd Information Sheet, Article 21 Health, 6th Session] 6th Session, 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

Japanese Disability Forum (JDF), Statement on Article 19 on Accessibility, 6th Session, 5 August 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

National Right to Life, Society of Catholic Social Scientists, Statement by Cockfield, Wayne on Article 21**,** 6th Session, 8 August 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

World Federation of the Deaf (WFD), World Blind Union (WBU) and the World Federation of the Deafblind (WFDB), Article 17, Statement on Inclusive Education for Persons Who are Deaf, Blind and Deafblind: The Rationale for Choice in Education, 6th Session, 2 August 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6contngos.htm. Last visited 10 October 2013.

The 7th Session

Arbour, Louise, UN High Commissioner for Human Rights, Statement to the General Assembly Ad Hoc Committee, 7th Session, 27 January 2006. Available through the UN webpage at http://www.un.org/disabilities/default.asp?id=368. Last visited 10 October 2013.

Australian Federation of Disability Organisations (AFDO), People with Disability Australia Incorporated (PWDA) and National Association of Community Legal Centres (NACLC), Report of the National Consultation Project on the Chair's Text of the Proposed Comprehensive and Integral International Convention on the Rights and Dignity of Persons with Disabilities [PWDA et al. Report on National Consultations, 7th Session], 7th Session, November 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

Australia, Proposal for an Article 5bis – Specific Population Groups, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7australia.htm. Last visited 10 October 2013.

Chair of the Ad Hoc Committee, Closing Remarks after the 7th Session [Chair's Closing Remarks, 7th Session], 3 February 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7chairclose.htm. Last visited 10 October 2013.

Chair of the Ad Hoc Committee, Possible Definition of “Disability”: Discussion Text Suggested by the Chair, 7th session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7pddisability.htm. Last visited 10 October 2013.

El Salvador, Proposal for an Article 16 (bis) Older Persons with Disabilities, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7elsalvador.htm. Last visited 10 October 2013.

European Union (EU), Position on Women and Children in Response to the Joint Facilitator’s Proposal, 7th Session, 31 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contgovs.htm. Last visited 10 October 2013.

Facilitators on Women and Children, Proposal on Women and Children [Facilitators Proposal Women and Children, 7th Session], 7th Session, 28 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7facilitator.htm. Last visited 10 October 2013.

Federation of and for People with Disabilities Kenya, Submission on Article 25 - Health, 7th Session, 24 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

Hunt, Paul, United Nations Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Intervention of the Special Rapporteur on Right to Health, A Note on Article 25 (Health), [Submission by Paul Hunt, 7th Session], 7th Session, 24 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7srhealth.htm. Last visited 10 October 2013.

India, Intervention regarding Draft Article 2 on Definitions, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7india.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Chairman’s Text as Amended by the International Disability Caucus [IDC Amendments to Chair’s Draft, 7th Session], 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Intervention on Article 15, Freedom from torture and other cruel, inhuman or degrading treatment or punishment, 7th Session, 19 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Response to the Facilitator’s Proposal on Children [IDC Response to the Facilitator’s Proposal on Children, 7th Session], 7th Session, 22 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Statement on Article 26 on Habilitation and rehabilitation, 7th Session, 25 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Statement on Article on 25 Health [IDC Statement on Article 25 on Health, 7th Session], 7th Session, 25 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

International Labour Organization (ILO), Chair's Text, ILO Technical Advisory Note [ILO Technical Advisory Note on Chair's Text, 7th Session], 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contunagencies.htm. Last visited 10 October 2013.

Israel, Position Paper for the 7th Ad Hoc Committee - First week [Israel Position Paper, 7th Session], 7th Session, 12 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7israel.htm. Last visited 10 October 2013.

Japanese Disability Forum (JDF), Comment on the Chairman's Text, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

Kenya, Position on Article 2 on Definitions, 7th Session, 10 January 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7kenya.htm. Last visited 10 October 2013.

Mental Disability Rights International (MDRI), Intervention by Mental Disability Rights International (MDRI) on Draft Article 25 (Right to health), 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

National Association of Community Legal Centres (NACLC), Comments on the Chair's Text, 7th Session, 19 December 2005. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7naclc.pdf. Last visited 10 October 2013.

National Society for Children and Adults with Learning Disabilities and their Families (RESCARE), through Jackson, Richard S., Letter dated 5 January 2006, 7th Session. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

People with Disability Australia Incorporated (PWDA) and National Association of Community Legal Centres (NACLC), Intervention on Article 2: Definitions, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm. Last visited 10 October 2013.

United States (US), Position on Article 25 on Health, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcstata25sevscomments.htm. Last visited 10 October 2013.

United States (US), Proposal on the Preamble, 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahcstatpreamblesevscomments.htm. Last visited 10 October 2013.

World Health Organization (WHO), Proposal for the Seventh Session of the Ad Hoc Committee on Article 25 on Health [WHO Proposal Article 25, 7th Session], 7th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7contunagencies.htm. Last visited 10 October 2013.

The 8th Session

Arbour, Louise, UN High Commissioner for Human Rights, Statement to the Resumed 8th Session of the Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities, 8th Session, 5 December 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8hrcmsg.htm. Last visited 10 October 2013.

Communications Coordination Committee for the United Nations (CCCUN), Submission, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

Egypt, Morocco, Sudan, Syria, Qatar, Kuwait, Bahrain and Saudi Arabia, Proposal for the Preamble, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8gpcapreamble.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Correction to Compilation, Article 17 on Protecting the integrity of the person, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), List of Key Issues Related to Non Bracketed Text, 8th Session, 18 August 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), News Page 23 August, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), News Page for 24 August, 8th Session, 24 August 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), News Page for Monday 21 August, Reaction the AHC8 Compilation of Proposals in Attachment [IDC News Page 21 August, 8th Session], 8th Session, 21 August 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Proposed Text on Definitions, 8th Session [IDC Proposed Text on Definitions, 8th Session], 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC) Report on First Informal Discussion on a Definition of Disability led by Korea [IDC Report from Informal on Definition of Disability, 8th Session], 8th Session, 17 August 2006. On file with author.

International Disability Caucus (IDC), Working Group 1 on Legal Capacity, Integrity and Related Issues, Forced Interventions [IDC Working Group on Legal Capacity, Integrity and Related Issues, 8th Session], 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Working Text as Amended by the IDC According to the Chair Proposed Program for the 8AHC 1st Week, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

International Disability Caucus (IDC), Working Text as Amended by the International Disability Caucus [IDC Amendments to CRPD Working Text, 8th Session], 8th Session, 18 August 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

Persons with Pain International (PWPI), Request, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contngos.htm. Last visited 10 October 2013.

Qatar on behalf of Bahrain, Kuwait, Oman, Saudi Arabia, Yemen and United Arab Emirates, Proposal on Article 25, 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8gpcart25.htm. Last visited 10 October 2013.

World Health Organization (WHO), Definition of Disability, The International Classification of Functioning, Disability and Health (ICF) [WHO Submission ICF, 8th Session], 8th Session, 2006. Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc8contagency.htm. Last visited 10 October 2013.

Daily Summaries of the Proceedings of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities:

Daily Summaries from the Working Group Session

Available through the Disability Information Resources webpage at http://www.dinf.ne.jp/doc/english/news/index.html. Last visited 10 October 2013.
Daily Summaries 5 January 2004, Working Group Session.
Daily Summaries 6 January 2004, Working Group Session.
Daily Summaries 7 January 2004, Working Group Session.
Daily Summaries 8 January 2004, Working Group Session.
Daily Summaries 9 January 2004, Working Group Session.
Daily Summaries 12 January 2004, Working Group Session.
Daily Summaries 13 January 2004, Working Group Session.
Daily Summaries 14 January 2004, Working Group Session.
Daily Summaries 15 January 2004, Working Group Session.
Daily Summaries 16 January 2004, Working Group Session.

Daily Summaries from the 3rd Session

Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc3summary.htm. Last visited 10 October 2013.
Daily Summaries 24 May 2004, 3rd Session.
Daily Summaries 25 May 2004, 3rd Session.
Daily Summaries 27 May 2004, 3rd Session.
Daily Summaries 1 June 2004, 3rd Session.
Daily Summaries 2 June 2004, 3rd Session.

Daily Summaries 3 June 2004, 3rd Session.
Daily Summaries 4 June 2004, 3rd Session.

Daily Summaries from the 4th Session

Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc4summary.htm. Last visited 10 October 2013.
Daily Summaries 23 August 2004, 4th Session.
Daily Summaries 24 August 2004, 4th Session.
Daily Summaries 25 August 2004, 4th Session.
Daily Summaries 27 August 2004, 4th Session.
Daily Summaries 30 August 2004, 4th Session.
Daily Summaries 31 August 2004, 4th Session.
Daily Summaries 1 September 2004, 4th Session.

Daily Summaries from the 5th Session

Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc5summary.htm. Last visited 10 October 2013.
Daily Summaries 24 January 2005, 5th session.
Daily Summaries 25 January 2005, 5th Session.
Daily Summaries 26 January 2005, 5th Session.
Daily Summaries 27 January 2005, 5th Session.
Daily Summaries 28 January 2005, 5th Session.
Daily Summaries 1 February 2005, 5th Session.
Daily Summaries 2 February 2005, 5th Session.
Daily Summaries 3 February 2005, 5th Session.
Daily Summaries 4 February 2005, 5th Session.

Daily Summaries from the 6th Session

Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc6summary.htm. Last visited 10 October 2013.
Daily Summaries 1 August 2005, 6th Session.
Daily Summaries 2 August 2005, 6th Session.
Daily Summaries 4 August 2005, 6th Session.
Daily Summaries 5 August 2005, 6th Session.
Daily Summaries 8 August 2005, 6th Session.
Daily Summaries 9 August 2005, 6th Session.
Daily Summaries 11 August 2005, 6th Session.

Daily Summaries from the 7th Session

Available through the UN webpage at http://www.un.org/esa/socdev/enable/rights/ahc7summary.htm. Last visited 10 October 2013.
Daily Summaries 16 January 2006, 7th Session.
Daily Summaries 17 January 2006, 7th Session.
Daily Summaries 18 January 2006, 7th Session.
Daily summaries 19 January 2006, 7th Session.
Daily Summaries 20 January 2006, 7th Session.
Daily Summaries 23 January 2006, 7th Session.
Daily Summaries 24 January 2006, 7th Session.
Daily Summaries 25 January 2006, 7th Session.
Daily Summaries 26 January 2006, 7th Session.
Daily Summaries 27 January 2006, 7th session.
Daily Summaries 30 January 2006, 7th Session.
Daily Summaries 31 January 2006, 7th Session.
Daily Summaries 1 February 2006, 7th Session.
Daily Summaries 2 February 2006, 7th Session.
Daily Summaries 3 February 2006, 7th Session.

Literature

Altman, Barbara M., Disability Definitions, Models, Classification Schemes, and Applications [Altman, 2001], in Albrecht, Gary L. et al. (Eds.), Handbook of Disability Studies, Sage Publications, London, 2001.

Arnardóttir, Oddný Mjöll, A Future of Multidimensional Disadvantage Equality [Arnardóttir, 2009] in Arnardóttir, Oddný Mjöll and Quinn, Gerard (Eds.), The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, Martinus Nijhoff Publishers, Leiden, 2009.

Arnardóttir, Oddný Mjöll, The Right to Inclusive Education for Children with Disabilities – Innovations in the CRPD, in Eide, Asbjørn et al. (Eds.), Making Peoples Heard: Essays on Human Rights in Honour of Gudmundur Alfredsson, Brill, The Netherlands, 2011.

Australian ICF Disability and Rehabilitation Research Program, ICF: Interaction of Concepts, Available at http://sydney.edu.au/health-sciences/aidarrp/icf/multi_dimensional.shtml. Last visited 10 October 2013.

Barnes, Colin and Mercer, Geof (Eds.), Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996.

Barnes, Colin, Review of Wendell, Susan, The Rejected Body: Feminist Philosophical Reflections on Disability, Disability & Society, Vol. 13, No. 1, 1998.

Barnes, Colin, Rehabilitation for Disabled People: a 'Sick' Joke?, Scandinavian Journal of Disability Research, Vol. 5, No. 1, 2003.

Bartlett, Peter, The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law [Bartlett, 2012], The Modern Law Review, Vol. 75, No. 5, 2012.

Batterbury, Sarah C. E., Language Justice for Sign Language Peoples: The UN Convention on the Rights of Persons with Disabilities, Language Policy, Vol. 11, 2012.

Beauchamp-Pryor, Karen, Impairment, Cure and Identity: 'Where Do I Fit in?' [Beauchamp-Pryor, 2011], Disability & Society, Vol. 26, No. 1, 2011.

Begum, Nasa, Doctor, Doctor…Disabled Women's Experience of General Practitioners, in Morris, Jenny (Ed.), Encounters with Strangers: Feminism and Disability, The Women's Press Ltd, London, 1996.

Bickenbach, Jerome E., Minority Rights or Universal Participation: The Politics of Disablement, in Jones, Melinda and Basser Marks, Lee Ann, Disability, Divers-Ability and Legal Change, Martinus Nijhoff Publishers, The Hague, 1999.

Bickenbach, Jerome E. et al, Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps [Bickenbach et al., 1999], Social Science & Medicine, Vol. 48, 1999.

Bickenbach, Jerome E., Disability Human Rights, Law, and Policy [Bickenbach, 2001], in Handbook of Disability Studies, Albrecht, Gary L. et al. (Eds.), Sage Publications, London, 2001.

Bickenbach, Jerome E., Disability, Culture and the UN Convention, Disability and Rehabilitation, Vol. 31, No. 14, 2009.

Bickenbach, Jerome E., Monitoring the United Nation's Convention on the Rights of Persons with Disabilities: Data and the International Classification of Functioning, Disability and Health, BioMed Central Public Health, Vol. 11, Suppl. 4, 2011.

Blackman, James A., Early Intervention: A Global Perspective, Infants and Young Children, Vol. 15, No. 2, 2002.

Brehmer-Rinderer, Barbara et al., Promoting Health of Persons with Intellectual Disabilities Using the UN Convention on the Rights of Persons with Disabilities: Early Implementation Assessment in Spain and Hungary, Journal of Policy and Practice in Intellectual Disabilities, Vol. 10, No.1, 2013.

Brett, Jane, The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: Is It Time For An Alternative Model of Disability?, Disability & Society, Vol. 17, No. 7, 2002.

Brolan, Claire E. et al., Health Advocacy: A Vital Step in Attaining Human Rights for Adults with Intellectual Disability, Journal of Intellectual Disability Research, Vol. 56, Part 2, 2012.

Bruce, Anna, Negotiating the Monitoring Mechanism for the Convention on the Rights of Persons with Disabilities: Two Steps Forward One Step Back, in Alfredsson, Gudmundur et al. (Eds.), International Human Rights Monitoring Mechanisms: Essays in Honour of Jacob Th. Möller, Martinus Nijhoff Publishers, The Hague, 2009.

Bury, Mike, A Comment to the ICIDH2 [Bury, 2000], Disability & Society, Vol. 15, No. 7, 2000.

Byrne, Bronagh, Minding the Gap? Children with Disabilities and the United Nations Convention on the Rights of Persons with Disabilities [Byrne, 2012], in Freeman, Michael (Ed.), Law and Childhood Studies: Current Legal Issues Vol. 14, Oxford University Press, Oxford, 2012.

Campbell, Jane, Valuing Diversity: The Disability Agenda – We've Only Just Begun [Campbell, 2002], Disability & Society Vol. 17, No. 4, 2002.

Campbell, Jane, Fighting for a Slice, or for a Bigger Cake?, The 6th Annual Disability Lecture, University of Cambridge, St John's College, 29 April 2008. Available at http://www.leeds.ac.uk/disability-studies/archiveuk/Campbell/Fighting%20for%20a%20slice%20of%20the%20cake%20FINAL%20FINAL%2029%2004%2008.pdf. Last visited 10 October 2013.

Carney, Terry and Beaupert, Fleur, Public and Private Bricolage – Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-making, University of New South Wales Law Journal, Vol. 36, No. 1, 2013.

Clements, Luke and Parker, Camilla, The UN Convention on the Rights of Persons with Disabilities: A New Right to Independent Living?, European Human Rights Law Review, Vol. 4, 2008.

Corbett, Jenny, Independent, Proud and Special: Celebrating Our Differences, in Barton, Len and Oliver, Michael (Eds.), Disability Studies: Past, Present and Future, The Disability Press, Leeds, 1997.

Corker, Mairian and Shakespeare, Tom (Eds.), Disability/Postmodernity: Embodying Disability Theory, Continuum, London, 2002.

Crenshaw, Kimberlé, Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics, The University of Chicago Legal Forum, 1989.

Crow, Liz, Including All of Our Lives: Renewing the Social Model of Disability [Crow, 1996], in Barnes, Colin and Mercer, Geof (Eds.) Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996.

Degener, Theresia and Koster-Dreese, Yolan (Eds.), Human Rights and Disabled Persons-Essays and Relevant Human Rights Instruments, Martinus Nijhoff Publishers, Dordrecht, 1995.

Despouy, Leandro, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, Human Rights and Disabled Persons, United Nations Publications, Geneva, 1993. Available through the UN webpage at http://www.un.org/esa/socdev/enable/dispaperdes0.htm. Last visited 10 October 2013.

de Wolfe, Patricia, Private Tragedy in Social Context? Reflections on Disability, Illness and Suffering [de Wolfe, 2002] Disability & Society, Vol. 17, No. 3, 2002.

Dhanda, Amita, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future? [Dhanda, 2007], Syracuse Journal of International Law and Commerce, Vol. 34, 2007.

Donoghue, Christopher, Challenging the Authority of the Medical Definition of Disability: An Analysis of the Resistance to the Social Constructionist Paradigm, Disability & Society, Vol. 18, No. 2, 2003.

Feldman, Maurice A. et al., Health Self-Advocacy Training for Persons with Intellectual Disabilities, Journal of Intellectual Disability Research, Vol. 56, Part 2, 2012.

Ferraina, Sabrina, Analysis of the Legal Meaning of Article 27 of the UN CRPD: Key Challenges for Adapted Work Settings, European Association of Service Providers for Persons with Disabilities (EASPD), Brussels, 2012.

Finkelstein, Victor, Attitudes and Disabled People: Issues for Discussion [Finkelstein, 1980], World Rehabilitation Fund Inc., New York, 1980.

Finkelstein, Victor, The Commonality of Disability [Finkelstein, 1993] in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (1st Ed.), Sage Publications Ltd, London, 1993.

Finkelstein, Victor, The Biodynamics of Disablement? [Finkelstein, 1999], Proceedings of the Workshop on Research Informed Rehabilitation Planning in Southern Africa, Harare (29 June-3 July 1998), Department of Public Health, Leids Hogeschool, Leiden, The Netherlands, 1999.

Finkelstein, Victor, The Social Model of Disability Repossessed [Finkelstein, 2001], originally published in Manchester Coalition of Disabled People, December 2001. Available at http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/soc%20mod%20repossessed.pdf. Last visited 10 October 2013.

Fougeyrollas, Patrick, Documenting Environmental Factors for Preventing the Handicap Creation Process: Quebec Contributions Relating to ICIDH and Social Participation of People with Functional Differences [Fougeyrollas, 1995], Disability & Rehabilitation, Vol. 17, No. 3, 1995.

Fougeyrollas, Patrick and Beauregard, Line, Disability: An Interactive Person-Environment Social Creation [Fougeyrollas et al., 2001], in Handbook of Disability Studies, in Albrecht, Gary L. et al. (Eds.), Sage Publications, London, 2001.

French, Sally, Disability, Impairment or Something in Between? [French, 1993], in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (1st Ed.), Sage Publications Ltd, London, 1993.

French, Sally, The Wind Gets in my Way, in French, Sally and Corker, Mairian (Eds.), Disability Discourse, Open University Press, Buckingham, 1999.

Greater London Action on Disability (GLAD), Reclaiming the Social Model of Disability Conference Report [GLAD, 2000], February 2000. Available through the Disability Archive UK at: http://www.leeds.ac.uk/disability-studies/archiveuk/GLAD/Social%20Model%20of%20Disability%20Conference%20Report.pdf. Last visited 10 October 2013.

Griffo, Giampiero et al., Moving towards ICF Use for Monitoring the UN Convention on the Rights of Persons with Disabilities: The Italian Experience, Disability & Rehabilitation, Vol. 31, 2009.

Groce, Nora E. and Officer, Alana, Key Concepts in Disability, The Lancet, Vol. 28, 2009.

Hahn, Harlan, Towards a Politics of Disability: Definitions, Disciplines, and Policies [Hahn, 1985], The Social Science Journal, Vol. 22, No. 4, 1985.

Hahn, Harlan, Civil Rights FOR Disabled Americans: the Foundation of a Political Agenda [Hahn, 1987], paper for Independent Living Institute, 1987. Available at http://www.independentliving.org/docs4/hahn.html. Last visited 10 October 2013.

Hahn, Harlan, Can Disability Be Beautiful? [Hahn, 1988], Social Policy, Vol. 18, 1988.

Hahn, Harlan, Review of Disabled Policy: America's Programs for the Handicapped by Berkowitz, Edward D., The American Political Science Review, Vol. 82, No. 3, 1988.

Hahn, Harlan, Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective [Hahn, 1996], Behavioral Sciences and the Law, Vol. 14, 1996.

Hahn, Harlan, The Political Implications of Disability Definitions and Data [Hahn, 1999] in Marinelli, Robert P. and Dell Orto, Arthur E. (Eds.), The Psychological and Social Impact of Disability (4th Ed.), Springer Publishing Company, New York, 1999.

Hahn, Harlan, Disputing the Doctrine of Benign Neglect: A Challenge to the Disparate Treatment of Americans with Disabilities [Hahn, 2000], in Pickering Francis, Leslie and Silvers, Anita (Eds.), Americans with Disabilities, Exploring Implications of the Law for Individuals and Institutions, Routledge, New York, 2000.

Hahn, Harlan, Adjudication or Empowerment: Contrasting Experiences with a Social Model of Disability [Hahn, 2001], in Barton, Len, (Ed.), Disability, Politics and the Struggle for Change, David Fulton Publishers Ltd, London, 2001.

Hahn, Harlan, Attitudes towards Disabilities: A Research Note on Activists with Disabilities [Hahn, 2001a], Journal of Disability Policy Studies, Vol. 12, 2001.

Hahn, Harlan, Academic Debates and Political Advocacy: The US Disability Movement [Hahn, 2002], in Barnes, Colin (Ed.), Disability Studies Today, Polity Press, Cambridge, 2002.

Hahn, Harlan, The ICF and the ICIDH: Privacy, Paradigms, and Definitions [Hahn, 2002a], 8th North American Collaborating Centre Conference on ICF, June 2–4, 2002. Despite considerable effort I have not been able to locate a copy with the footnotes intact. Available at http://www.cihi.ca/CIHI-ext-portal/pdf/internet/ICF_JUN02_PAPERS_3A_EN. Last visited 10 October 2013.

Hahn, Harlan D. and Belt, Todd, L., Disability Identity and Attitudes toward Cure in a Sample of Disabled Activists [Hahn and Belt, 2004], Journal of Health and Social Behavior, Vol. 45, 2004.

Harnett, Alison et al., Convention of Hope- Communicating Positive, Realistic Messages to Families at the Time of a Child's Diagnosis with Disabilities [Harnett et al., 2009], British Journal of Learning Disabilities, Vol. 37, 2009.

Harpur, Paul, Time to Be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change [Harpur, 2011], Valparaiso University Law Review, Vol. 45, 2011.

Hasler, Frances, Developments in the Disabled People's Movement, in Swain, John et al. (Eds.), Disabling Barriers – Enabling Environments (1st Ed.), Sage Publications Ltd, London, 1993.

Hendriks, Aart, Selected Legislation and Jurisprudence: UN Convention on the Rights of Persons with Disabilities [Hendriks, 2007], European Journal of Health Law, Vol. 14, 2007.

Hughes, Bill and Paterson, Kevin, The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment, Disability & Society, Vol. 12, No. 3, 1997.

Hughes, Bill, Disability Activisms: Social Model Stalwarts and Biological Citizens, Disability & Society, Vol. 24, No. 6, 2009.

Humphrey, Jill, Researching Disability Politics, Or, Some Problems with the Social Model in Practice [Humphrey, 2000], Disability & Society, Vol. 15, No. 1, 2000.

Hurst, Rachel, Record of Statement, in The Use and Usefulness of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), Proceedings from an International Workshop under the Council of Europe, Strasbourg (France) 25-26 March 1996.

Hurst, Rachel, To Revise or Not to Revise? [Hurst, 2000], Disability & Society, Vol. 15, No. 7, 2000.

Imrie, Rob, Demystifying Disability: A Review of the International Classification of Functioning, Disability and Health, Sociology of Health and Illness [Imrie, 2004], Vol. 26, No. 3, 2004.

Kayess, Rosemary and French, Phillip, Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities [Kayess and French, 2008], Human Rights Law Review, Vol. 8, No. 1, 2008.

Lawson, Anna, The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?, Syracuse Journal of International Law and Commerce, Vol. 34, 2007.

Liggett, Helen, Stars are Not Born: An Interpretative Approach to the Politics of Disability, Disability, Handicap & Society, Vol. 3, No. 3, 1988.

Light, Richard, Social Model or Unsociable Muddle?, Article for Disability Awareness in Action, undated. Available at http://www.daa.org.uk/uploads/pdf/Social%20Model%20or%20Unsociable%20Muddle-1.pdf. Last visited 10 October 2013.

Lord, Janet E. and Stein, Michael Ashley, Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities, in Arnardóttir, Oddný Mjöll and Quinn, Gerard (Eds.), The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, Martinus Nijhoff Publishers, Leiden, 2009.

Lord, Janet E. et al., Lessons from the Experience of U.N. Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance [Lord et al., 2010], Journal of Law, Medicine and Ethics, Vol. 38, No. 3, 2010.

Lord, Janet E., Screened Out of Existence: The Convention on the Rights of Persons with Disabilities and Selective Screening Policies [Lord, 2013], International Journal of Disability, Community & Rehabilitation, Vol. 12, No. 2, 2013.

Madans, Jennifer H. et al., Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: The Work of the Washington Group on Disability Statistics, BioMed Central Public Health, Vol. 11, Suppl. 4, 2011.

Madden, Ros et al., Fundamental Questions before Recording or Measuring Functioning and Disability, Disability & Rehabilitation, Vol. 35, No. 13, 2013.

Matinvesi, Seppo, Perspectives and Applications of the ICIDH, in The Use and Usefulness of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), Proceedings from an International Workshop under the Council of Europe, Council of Europe Publishing, Strasbourg (France) 25-26 March 1996.

Mégret, Frédéric, The Disability Convention: Human Rights of Persons with Disabilities or Disability Rights?, Human Rights Quarterly, Vol. 30, No. 2, 2008.

Mégret, Frédéric, The Disabilities Convention: Towards a Holistic Concept of Rights [Mégret, 2008], The International Journal of Human Rights, Vol. 12, No. 2, 2008.

Miles, M, ICIDH Meets Postmodernism, or 'Incredulity toward Meta-terminology', Disability World, Issue No. 7, March-April 2001. Available at http://www.disabilityworld.org/03-04_01/resources/icidh.shtml. Last visited 10 October 2013.

Minkowitz, Tina, the United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions [Minkowitz, 2007], Syracuse Journal of International Law and Commerce, Vol. 34, 2007.

Mirza, Masha, New Issues in Refugee Research, Research Paper No. 212, Unmet Needs and Diminished Opportunities: Disability, Displacement and Humanitarian Healthcare [Mirza, 2011] UNHCR, 2011.

Morris, Jenny, Pride against Prejudice – Transforming Attitudes to Disability, Women's Press, London 1991. Available at http://disability-studies.leeds.ac.uk/files/library/morris-Pride-and-Prejudice.pdf. Last visited 10 October 2013.

Morris, Jenny, Introduction [Morris, 1996], in Morris, Jenny (Ed.), Encounters with Strangers, The Women's Press Ltd, London, 1996.

Nirje, Bengt, How I Came to Formulate the Normalization Principle, in Flynn, Robert J. and Lemay, Raymond A., (Eds.) A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact, University of Ottawa Press, Ottawa, 1999.

Nizar, Smitha, Impact of UNCRPD on the Status of Persons with Disabilities, Indian Journal of Medical Ethics, Vol. 8, No. 4, 2011.

Oliver, Michael, A New Model of the Social Work Role in Relation to Disability, in Campling, Jo (Ed.), The Handicapped Person: A New Perspective for Social Workers? [Oliver, 1981], Radar, London, 1981.

Oliver, Michael, Social Work with Disabled People (1st Ed.), [Oliver, 1983], The Macmillan Press Ltd, London, 1983.

Oliver, Michael, The Politics of Disablement (1st Ed.), [Oliver, 1990], Macmillan Press Ltd, Basingstoke, 1990.

Oliver, Michael, The Individual and Social Models of Disability [Oliver 1990a], Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospital, 23 July 1990. Available at http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf. Last visited 10 October 2013.

Oliver, Michael and Barnes, Colin, Discrimination, Disability and Welfare: From Needs to Rights [Oliver and Barnes, 1991], in Oliver, Michael et al., Equal Rights for Disabled People: The Case for a New Law, Institute for Public Policy Research, London, 1991. Available at http://disability-studies.leeds.ac.uk/files/library/bynoe-equal-rights-for-disabled-people.pdf. Last visited 10 October 2013.

Oliver, Michael, Understanding Disability [Oliver, 1996], Macmillan Press Ltd, London, 1996.

Oliver, Michael, Defining Impairment and Disability: Issues at Stake, [Oliver 1996a], in Barnes, Colin and Mercer, Geof (Eds.), Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996.

Oliver, Michael and Campbell, Jane, Disability Politics: Understanding Our Past, Changing Our Future [Oliver and Campbell, 1996], Routledge, London, 1996.

Oliver, Michael, Capitalism, Disability and Ideology: A Materialist Critique of the Normalization Principle [Oliver, 1999], in Flynn, Robert J. and Lemay, Raymond A., (Eds.) A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact, University of Ottawa Press, Ottawa, 1999.

Oliver, Michael, Disability Issues in the Postmodern World [Oliver, 2001], in Barton, Len (Ed.) Disability, Politics and the Struggle for Change, David Fulton Publishers Ltd, London, 2001.

Oliver, Michael, The Social Model in Action: If I Had a Hammer [Oliver, 2004], in Barnes, Colin and Mercer, Geof (Eds.), Implementing the Social Model of Disability: Theory and Research, The Disability Press, Leeds, 2004.

Oliver, Michael and Barnes, Colin, Disability Politics and the Disability Movement in Britain: Where Did It All Go Wrong? [Oliver and Barnes, 2006]. Originally published in Manchester Coalition of Disabled People, August 2006, Available at http://disability-studies.leeds.ac.uk/files/library/Barnes-Coalition-disability-politics-paper.pdf. Last visited 10 October 2013.

Oliver, Michael and Barnes, Colin, Back to the Future: the World Report on Disability, Disability & Society, Vol. 27, No. 4, 2012.

Oliver, Michael, The Social Model of Disability: Thirty Years On, Disability & Society, 2013.

Petersen, Carole J., Population Policy and Eugenic Theory: Implications of China's Ratification of the United Nations Convention on the Rights of Persons with Disabilities [Petersen, 2010], China: An International Journal, Vol. 8, No. 1, 2010.

Pfeiffer, David, The ICIDH and the Need for its Revision [Pfeiffer, 1998], Disability and Society, Vol. 13, No. 4, 1998.

Pinder, Ruth, Sick-but-Fit or Fit-but-Sick? Ambiguity and Identity at the Workplace [Pinder, 1996], in Barnes, Colin and Mercer, Geof (Eds.) Exploring the Divide: Illness and Disability, The Disability Press, Leeds, 1996.

Pinder, Ruth, A Reply to Tom Shakespeare and Nicholas Watson [Pinder, 1997], Disability & Society, Vol. 12, No. 2, 1997.

Priestley, Mark, Constructions and Creations: Idealism, Materialism and Disability theory [Priestley, 1998], Disability & Society, Vol. 13, No. 1, 1998.

Quinn, Gerard and Degener, Theresia with Bruce, Anna et al., Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability [Quinn and Degener with Bruce et al., 2002], United Nations Publications, New York, 2002.

Quinn, Gerard, Disability and Human Rights: A New Field in the United Nations [Quinn, 2009], in Krause, Catarina and Scheinin, Martin (Eds.), International Protection of Human Rights: A Textbook, Åbo Academy University Institute for Human Rights, Åbo, 2009.

Quinn, Gerard, The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability, Jacobus tenBroek Disability Law Symposium, April 17, 2009, Texas Journal on Civil Liberties & Civil Rights, Vol. 15, No. 1.

Rae, Anne, Social Model under Attack, originally published in Manchester Coalition of Disabled People, August 1996. Available at http://www.leeds.ac.uk/disability-studies/archiveuk/Rae/social%20model%20under%20attack.pdf. Last visited 10 October 2013.

Ravenek, Michael et al., Perspectives in Rehabilitation: Enhancing the Conceptual Clarity and Utility of the International Classification of Functioning, Disability & Health: The Potential of a New Graphic Representation [Ravenek et al., 2013], Disability and Rehabilitation, Vol. 35, No. 12, 2013.

Rawls, John, A Theory of Justice, Oxford University Press, Oxford, 1971.

Ribet, Beth, Emergent Disability and the Limits of Equality: A Critical Reading of the UN Convention on the Rights of Persons with Disabilities, Yale Human Rights & Development Law Journal, Vol. 14, 2011.

Richler, Diane, The Meaning of the CRPD and the Role of the Family in the Lives and Future of Children and Youth with Disabilities, in Rehabilitation International (RI)/United Nations Children's Fund (UNICEF), One in Ten: What Does the CRPD Mean to the Lives and Future of Children and Youth with Disabilities?, Vol. 26, 2008.

Schulze, Marianne, Understanding the UN Convention on the Rights of Persons with Disabilities: A Handbook on the Human Rights of Persons with Disabilities (3rd Ed.), [Schulze, 2010], Handicap International, New York, 2010.

Scotch, Richard K. and Schriner, Kay, Disability as Human Variation: Implications for Policy, Annals of the American Academy of Political and Social Science, No. 549, 1997.

Scully, Jackie Leach, Disability, Human Rights and Contemporary Genetics, in eLS, John Wiley & Sons Ltd, Chichester. Available at www.els.net. Last visited 10 October 2013.

Shaffer, Bret, The Right to Life, the Convention on the Rights of Persons with Disabilities, and Abortion, Penn State International Law Review, Vol. 28, No. 2, 2009.

Shakespeare, Tom and Watson, Nicholas, The Social Model of Disability: An Outdated Ideology? [Shakespeare and Watson, 2002], Research in Social Science and Disability, Vol. 2, 2002.

Shakespeare, Tom, Disability Rights and Wrongs [Shakespeare, 2006], Routledge, London, 2006.

Shildrick, Margrit, Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity, in Watson, Nick et al. (Eds.), Routledge Handbook of Disability Studies, Routledge, London, 2012.

Soldatic, Karen, The Transnational Sphere of Justice: Disability Praxis and the Politics of Impairment, Disability & Society, Vol. 28, No. 6, 2013.

Strauss, David A., The Illusory Distinction between Equality of Opportunity and Equality of Results, in Devins, Neal and Douglas, Davison. M. (Eds.) Redefining Equality, Oxford University Press, New York, 1998.

Swain, John and French, Sally, Towards an Affirmative Model of Disability [Swain and French, 2000], Disability & Society, Vol. 15, No. 4, 2000.

Swain, John and French, Sally, Whose Tragedy? Towards a Personal Non-tragedy View of Disability [Swain and French, 2004]. Originally published in Swain et al. (Eds.), Disabling Barriers – Enabling Environments (2nd Ed.), Sage Publications Ltd, London, 2004. Available at http://www.leeds.ac.uk/disability-studies/archiveuk/swain/affirmative%20chapter.pdf. Last visited 10 October 2013.

Thomas, Carol, Female Forms: Experiencing and Understanding Disability [Thomas, 1999], Open University Press, Buckingham, 1999.

Thomas, Carol, Defining a Theoretical Agenda for Disability Studies, Paper for Disability Studies Conference: Theory, Policy and Practice, Lancaster, September 2003. Available at http://www.lancs.ac.uk/fass/events/disabilityconference_archive/2003/papers/thomas2003.doc. Last visited 10 October 2013.

Thomas, Carol, How is Disability Understood? An Examination of Sociological Approaches [Thomas, 2004], Disability & Society, Vol. 19, No. 6, October 2004.

Thomas, Carol, Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda, in Barnes, Colin and Mercer, Geof (Eds.), Implementing the Social Model of Disability: Theory and Research, The Disability Press, Leeds, 2004.

Thomas, Carol, Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology [Thomas, 2007], Palgrave Macmillan Ltd, Basingstoke, 2007.

Traustadóttir, Rannveig, Disability Studies, the Social Model and Legal Developments [Traustadóttir, 2009], in Arnardóttir, Oddný Mjöll and Quinn, Gerard (Eds.), The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, Martinus Nijhoff Publishers, Leiden, 2009.

Tregaskis, Claire, Social Model Theory: The Story So Far… [Tregaskis, 2002], Disability & Society, Vol. 17, No. 4, 2002.

Union of the Physically Impaired Against Segregation (UPIAS), Aims and Policy Statement [UPIAS, 1974], 3 December 1974. Available through the Disability Archive UK web page at http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/UPIAS.pdf. Last visited 10 October 2013.

Union of the Physically Impaired Against Segregation (UPIAS), Union of the Physically Impaired Against Segregation and the Disability Alliance Discuss Fundamental Principles of Disability [UPIAS, 1975], 22 November 1975. Available through the Disability Archive UK web page at http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental%20principles.pdf. Last visited 10 October 2013.

Vernon, Ayesha, Multiple Oppression and the Disabled People's Movement, in Shakespeare, Tom (Ed.), The Disability Reader: Social Science Perspectives, Continuum, London, 1998.

Vernon, Ayesha, The Dialectics of Multiple Identities and the Disabled People's Movement [Vernon, 1999], Disability & Society, Vol. 14, No. 3, 1999.

Watson, Nick et al. (Eds.), Routledge Handbook of Disability Studies, Routledge, London, 2012.

Wendell, Susan, Unhealthy Disabled: Treating Chronic Illnesses as Disabilities [Wendell, 2001], Hypatia, Vol. 16, No. 4, 2001.

Whiteneck, Gail, Conceptual Models of Disability: Past, Present, and Future, in Workshop on Disability in America: A New Look, National Academy of Sciences, Washington, 2006, Appendix B.

Williams, Gareth, Theorizing Disability, in Albrecht, Gary L. et al. (Eds.), Handbook of Disability Studies, Sage Publications, London, 2001.

Williams, Simon J., Is Anybody There? Critical Realism, Chronic Illness and the Disability Debate, Sociology of Health and Illness, Vol. 21, No. 6, 1999.

Wilson, Duncan, Human Rights: Promoting Gender Equality in and through Education, Paper Commissioned for the Education for All Global Monitoring Report 2003/4, The Leap to Equality, 2003. Available through the United Nations Educational, Scientific and Cultural Organization (UNESCO) webpage at http://unesdoc.unesco.org/images/0014/001469/146974e.pdf. Last visited 10 October 2013.

World Health Organization (WHO), International Classification of Impairments, Disabilities, and Handicaps – A Manual of Classification Relating to the Consequences of Disease [WHO, 1980], World Health Organization, Geneva, 1980.

World Health Organization (WHO), International Classification of Impairments, Disabilities, and Handicaps – A Manual of Classification Relating to the Consequences of Disease, World Health Organization, Geneva, 1993, Reprint with added foreword.

World Health Organization (WHO), International Classification of Functioning, Disability and Health (ICF) [WHO, 2001], World Health Organization, Geneva, 2001.

World Health Organization (WHO), Towards a Common Language for Functioning, Disability and Health [WHO, 2002], WHO, Geneva, 2002, WHO/EIP/GPE/CAS/01.3. Available through the WHO webpage at http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf. Last visited 10 October 2013.

World Health Organization (WHO), International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY) [WHO, 2007], Geneva, 2007.

Yoshihara, Susan, Lost in Translation: The Failure of the International Reproductive Rights Norm, Ave Maria Law Review, Vol. 11, No. 2, 2013.

Zola, Irving Kenneth, Ageing and Disability: Toward a Unifying Agenda [Zola, 1988], Educational Gerontology, Vol. 14, No. 5, 1988.

Zola, Irving Kenneth, Toward the Necessary Universalizing of a Disability Policy [Zola, 1989], The Milbank Quarterly, Vol. 67, Suppl. 2, 1989.

Zola, Irving Kenneth, Bringing Our Bodies and Ourselves Back In: Reflections on a Past, Present and Future "Medical Sociology", Journal of Health and Social Behaviour, Vol. 32, No. 1, 1991.

Miscellaneous

Beijing Declaration on the Rights of People with Disabilities in the New Century. Adopted 12 March 2000 at the World NGO Summit on Disability. Available through Disability Information Resources at http://www.dinf.ne.jp/doc/english/asia/conf/z00021/z0002101.html. Last visited 10 October 2013.

Office of the High Commissioner for Human Rights (OHCHR), Monitoring the Convention on the Rights of Persons with Disabilities, Guidance for Human Rights Monitors, Professional Training Series No. 17 [OHCHR, 2010], United Nations, New York, 2010.

World Health Organization (WHO), World Health Assembly Resolution 54th Session, 22 May 2001, WHA.54.21. Available through the WHO webpage at http://www.who.int/classifications/icf/wha-en.pdf. Last visited 10 October 2013.