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## After Inclusion

### Intellectual Disability as Biopolitics

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After Inclusion



# After Inclusion

## Intellectual Disability as Biopolitics

Niklas Altermark



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DOCTORAL DISSERTATION

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Sweden.

To be defended at Edens hörsal. Date 2016-05-20 and time 10.00.

*Faculty opponent*

Professor Dan Goodley

The University of Sheffield

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| <p>This dissertation examines contemporary politics targeting people with intellectual disabilities. Since this group first emerged, under labels such as 'idiocy' and 'mental deficiency', around the turn of the 20<sup>th</sup> century, its members have been seen as lacking the capacities necessary for citizenship and full societal belonging. For the last forty years, however, liberal democracies and international organizations have set out to include the group through policies promoting citizenship, emphasising 'self-determination', 'independence', and 'autonomous decision-making' as key ambitions. As a result, institutional care has been downscaled and replaced by socially integrated living arrangements. This is often described as a shift of paradigms in disability politics. I argue that this shift means that the same ideas of humanity, as characterised by 'reason' and 'rationality', that was once used as a yardstick to define and exclude 'intellectual disability', are now being put to work to include the group. The purpose of the thesis is to provide a theoretical understanding of what happens after the introduction of this kind of politics, in the era that I call 'post-institutionalisation'. I do so by approaching the government of this group as an instance of what Foucault called 'biopolitics', which denotes the efforts of governments to manage human life, and by drawing on Judith Butler's theorising of subjectivity.</p> <p>The dissertation proceeds in three analytical steps. In its first part, by focusing on how 'intellectual disability' is constituted by scientific and classificatory knowledge, I argue that this diagnosis came into being and persists for purposes of government. Rather than being a biologically rooted condition that policies respond to and target, it is a political and normative category that is made to appear as biological and natural. In this way, a firm line between 'normalcy' and 'intellectual disability' is constructed. In the second part, I examine how this group today is targeted by policies aiming for inclusion and citizenship. The result of how intellectual disability is both seen as the opposite of the norm of the 'good citizen' and as the target of citizenship inclusion, is a politics that simultaneously includes and excludes intellectual disability. Thus, rather than discarding the power exercised over people with intellectual disabilities, power has transformed into a biopolitical regime that seeks to mould members of this group to become included citizens, whilst concurrently upholding their exclusion by continued constraints. Lastly, in the third part of the study, I examine the possibilities of contesting the contemporary biopolitical regime. Here, the main argument is that a productive critique of the government of intellectual disability needs to reconsider the notion that humanity is defined by its capacities of 'reason' and 'rationality'.</p> |                         |                                        |
| intellectual disability, disability studies, biopolitics, Foucault, Butler, crip theory, inclusion                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                         |                                        |
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# After Inclusion

## Intellectual Disability as Biopolitics

Niklas Altermark



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*To Sofia*

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# *Introduction*

## Inclusion and After

In September 2010, the local paper *Sydsvenskan* ([sydsvenskan.se](http://sydsvenskan.se), 10-09-01) revealed that a person diagnosed with intellectual disability getting support in a group home in Malmö, Sweden, had lived with his arms tied behind his back for the last 25 years, more than fifteen years after the approval of legislation that granted him the same freedoms and rights of personal integrity as any 'normal' adult person. It had been almost 20 years since deinstitutionalisation had been completed and succeeded by integrated living and disability rights; he should have been a citizen. Still, a sock had been used to tie up this person, it was a measure ordained by several doctors, still, in clear violation of the law. Of course, it was meant to protect him: it was said that he would hurt himself otherwise, although no one had seen him do so apart from occasionally scratching his ears ([norraskane.se](http://norraskane.se) – 10-09-01). To facilitate the arrangement, he only wore long sleeve t-shirts that could be strapped behind his back and tied together with the sock. There was a schedule for the procedure. If you are tied in this way for 25 years, your muscles wither, coercion inscribes itself upon the materiality of your being. The productiveness of power, in a very manifest sense, came to shape his body ([svt.se](http://svt.se) – 10-09-01; [sverigesradio.se](http://sverigesradio.se) 10-09-02).

The most convenient response to this is surely to see it as an anomaly, the result of a very grave, yet local, implementation failure and as something that occurs despite the policy goals of inclusion, citizenship, and personal integrity. Sweden, after all, is commonly seen as a role model as regards progressive disability rights and services (see Race, 2007:23-5). Such sentiments also flavoured the responses of public officials. The manager claimed that she had no knowledge of the incident, and the responsible municipal politicians declared that the man had not suffered any harm by the practice ([sverigesradio.se](http://sverigesradio.se) – 10-09-02). Everyone insisted that this would not happen again, and that similar procedures were not occurring in other group homes; it was a rotten apple in an otherwise appealing fruit basket. To a certain extent, this way of understanding mistreatment recurs in the scholarly literature on intellectual disability, where standard responses to shortcomings may go along the lines of: 'we have good policies but implementation lags behind' or 'if everybody just followed the policy template then none of these bad things would happen'. Such statements, however, cannot explain why the ideals of citizenship, self-determination, and independent living seem to fall short more or less everywhere they should be guiding disability politics.

(Mansell, 2010:11): they cannot explain the locked gates outside group homes which house people who have been granted freedom of movement. They cannot explain locked refrigerators owned by people granted the freedom to eat whatever they want, and they cannot explain the every-day practice of staffers deciding how many cups of coffee is appropriate to drink if you are diagnosed with intellectual disability. Indeed, they certainly cannot explain why it only took a month and a few days before a very similar case of a tied up man diagnosed with intellectual disability was revealed (sydsvenskan.se – 10-10-06).

Rather than an anomaly, I argue that this example of decades-long perpetual violence is an expression of a certain mode of institutionalised politics which operates by producing included citizens whilst simultaneously upholding their exclusion, not anomalous, but symptomatic of how people with intellectual disabilities are being governed. The coexistence of technologies which shape citizens and withhold their fundamental citizenship rights is a defining feature of the present management of the condition. Although they do not make the headlines, the daily practices in disability services of deciding what disabled persons should eat, how they should spend their leisure time, whether they should be allowed to have sex, how many cups of coffee their stomachs can handle, and what specific blend of coercion, bribing, and threats should be put to work when they refuse to take their weekly shower, are, in essence, all expressions of the same mechanisms of concurrently doing and undoing inclusion and citizenship. This book attempts to interpret this mode of politics, emerging in the wake of goals of inclusion and citizenship, as the outcome of a transformation of the government of intellectual disability.

To clarify this a bit further, the production of citizens shapes individuals with this condition to behave appropriately, to learn skills of citizenship that staff consider important, and to manage their own lives in accordance with ideals of how 'normal' people live. The undoing of citizenship consists of restricting individuals, by rules, coercion, and paternalism, because people of this group are simultaneously seen as deficient with respect to the presumed capacities of citizens. The rationalities of these two technologies of government are coexistent and recurring – in disability services and policy discourse, and their contours can be seen throughout the history of Western political philosophy. Hence, I will argue that the new politics of participation, individual rights, and self-determination that emerged during the last decades of the 20th century, did not mean that power was moved from public officials to persons with disabilities, or that power somehow vanished to leave room

for an unconstrained individual freely deciding how to live. Rather, the government of intellectual disability became something else; a way of governing that relies on both crafting citizens and continually monitoring and correcting their conduct, sometimes by brute force, in case an appropriate citizen fails to materialise. Understanding this transformation of government means understanding how power operates after inclusion.

### **The Politics of Inclusion and Post-Institutionalisation**

The last three or four decades witnessed fundamental changes to how people with intellectual disabilities were treated and targeted by social policy, changes that were very often tied to ambitions of deinstitutionalising disability care and that were dressed in the terminology of ‘participation’ and ‘independence’ (see Bigby, 2005:118; Clement & Bigby, 2010:159). The overarching goal was to end ‘exclusion’, interpreted as the lack of integration, rights, and autonomy of people with this diagnosis. This reconceptualisation of people with intellectual disabilities as worthy of social and political belonging is what I call ‘the politics of inclusion’. A central constituent of this mode of politics is the concept of ‘citizenship’, which here denotes governmental efforts that seek to heighten the status of disenfranchised and stigmatised groups by granting them the equal rights and status as full members of political communities. Thus, ‘citizenship’ concerns what the demos of democracy is: who has rights worthy of protection and whose living conditions compose the intrinsic aims of governing; who is ‘normal’ enough, competent enough, and human enough, to be a citizen? The politics of inclusion meant that many liberal democracies answered these questions in a new way with regards to people with intellectual disabilities.

As I will soon discuss further, the new direction of intellectual disability politics is designed to protect the liberty of the individual against a state apparatus which has, throughout history, treated members of this group as lesser beings who are unable to make choices about their own lives. Although there are, of course, differences between national contexts in this respect (we shall return to the extent of these later in the Introduction as well as in Chapter 6), I claim that the concurrent featuring of inclusion by means of citizenship and the construction of intellectual disability as a biologically anchored diagnosis of lacking intellectual capacities is recurrent and characteristic of present disability policies. Hence, we see processes of deinstitutionalisation, socially integrated living arrangements, legal

frameworks granting individual rights, and commitments to ‘independent living’ and ‘self-determination’, across national borders and in the work of influential international organizations such as the UN and the WHO. At the same time, however, the results of inclusion are far less rosy than the stated ambitions: it seems that people with intellectual disabilities are far from the self-determined citizens, participating and fully included, that the new policies postulate (see Bigby, 2005:117; Johnson & Traustadóttir, 2005:14; Tøssebro, 2005:197). First, in the sense that institutionalisation prevails in some places and that many countries fail to live by their own commitments to citizenship rights. But more importantly, I believe, in the sense that the new services and legislations continue to restrain people with this diagnosis. This is the starting point of the investigation I will undertake: on the one hand we have the aspirations of citizenship inclusion, and on the other hand we have the repeated failures to meet these goals.

In this way, contemporary intellectual disability politics is both embedded in promises of liberation and disappointments of bleak outcomes. This is the predicament of the era that I will call ‘post-institutionalisation’ throughout, where oppression has supposedly given way to emancipation and freedom, but where power still lingers and there is a widespread perception that emancipation has failed. The allusion to ‘post-colonialism’ is, of course, intentional: drawing on Spivak’s (1995 in Kapoor, 2004:639) analysis of ‘post-colonialism’ as the failure of de-colonisation, we may ask what the failure of deinstitutionalisation is; what kind of political situation are we facing and how can it be made sense of theoretically? This is the main ambition of this book: to interpret what has happened after inclusion.

To do this, I believe that it is absolutely necessary to reconsider two central issues concerning intellectual disability. The first one is what this condition is. Today, the common understanding is that we are dealing with a biologically anchored diagnosis which is characterised by cognitive deficits. On the contrary, and for reasons I will develop soon enough, I believe that post-institutionalisation can only be made sense of if we understand ‘intellectual disability’ as a social phenomenon, constituted by certain discourses and knowledge techniques and ultimately existing for government purposes. The second thing to reconsider is how we see the politics of citizenship and inclusion as such. Inclusive politics are often depicted in contrast to a history of oppression – of confinement, paternalism, and dehumanisation which have repressed people with this diagnosis – where the new policies are a relief, emancipatory in nature, and depicted as an outcome of the admirable political struggles of the disability movement. I agree with

this. Yet, underlying this picture is often, I believe, a crude and problematic understanding of ‘power’ and ‘citizenship’ as determinate opposites; citizens have power over their own lives and the government restrains citizenship in their exercising of power. In order to understand present intellectual disability politics, I contend that we instead need to understand ‘citizenship inclusion’ as a new way of governing that operates by constituting intellectually disabled *citizen-subjects* (Cruikshank, 1999). In other words, we need to approach politics of inclusion by resisting to take its emancipatory connotations for granted. Reconsidering these two aspects – of what intellectual disability is seen as, and how we should understand the government of the group – is a way of understanding how this particular segment of the population is ruled. This is what Michel Foucault (1990:part 5) termed ‘biopolitics’ – the central theoretical term I will make use of to understand the politics of intellectual disability.

Thus, my contention is that the social constitution of intellectual disability and the politics targeting this group need to be analysed together. Central to what will follow in this book is a theoretical link: between how intellectual disability is constituted and how the governmental efforts targeting the condition are designed. This relationship – between the allegedly neutral scientific knowledge of people with this condition and the technologies of their management – is central to Foucault’s understanding of biopolitics. To further establish this linkage, consider Rose’s (2007:133) argument that projects of citizenship during the past two hundred years produced citizens who came to understand their status as full members of society in biological terms. As we understand the capacities necessary for citizenship to be linked to the materiality of the body – and in recent times to the grey and white matter inside our skulls – the inclusion of non-whites and females implied rethinking the biological basis of their cognition; citizenship status for these groups was premised on dislodging ‘sex’ and ‘skin colour’ from notions of cognitive capacities. The reason why the label of ‘intellectual disability’ cannot be dislodged from lacking capacities in similar ways is that the diagnosis is defined by ‘deficient intelligence’. Indeed, as I will elaborate on in Chapter 1, the reason why the characteristic of ‘deficient intelligence’ was consolidated into a specific category and label was the need to segment individuals who were thought of as lacking the capacities necessary for citizenship.

Ultimately, this relates to the way we understand the defining characteristics of humanity. Capabilities such as ‘reason’, ‘autonomy’, and ‘independence’, are central to a conception of subjectivity that emerged with

Enlightenment philosophy, a conception that has since influenced our thinking about what it means to be human. The condition we understand today as ‘intellectual disability’ consist in the failure to meet these ideals; intellectual disability is their ‘otherness’. Claiming access to this kind of subjectivity, to the dream of a self-ruling and rational individual steering their course through life, has been integral to the disability movement’s fight for citizenship rights and underpins the politics of inclusion more generally (Clifford Simpican, 2015:10-1). This means that when citizenship inclusion became the main political project of liberating people with this condition, this group were to be embraced by the same normativity that produced their exclusion in the first place. What intellectually disabled people share is the fact that their brains and capacities are perceived as different in a similar way. Simultaneously, the goal of inclusion is that they should be able to ‘live as others’, that is, as ‘normal’ people. Indeed, to be eligible for special services that should produce independence, one has to be considered as someone in need of help. As we shall see, post-institutionalisation is frequently haunted by such contradictions and conflicts between designations of otherness and dreams of inclusion. These emerge as the border between exclusion and inclusion is renegotiated, that is, when a group which has served as the outside mirror of humanist reason, autonomy, and independence is to be included by what seems to be precisely these ideals.

### **Not Just another Case of Exclusion**

Before presenting the research questions that guide this book, I want to say a few things about how I believe that understanding the government of intellectual disability can contribute to political analysis, in general. First, it is important to recognise that ‘intellectual disability’ does not entail falling short of just any ideal, but of the very important ideal of humanity as characterised by reason and rationality. I will elaborate on this in the first and fourth chapters of this book, but for now I want to stress that our cognitive abilities often appear to compose a quintessential characteristic of humanity: possessing the capacity of rational reasoning is fundamental to how human beings are differentiated from other living things and it is repeatedly stressed in Western philosophy as our defining characteristic. This particular kind of humanism has also been central to projects of emancipation, where previously excluded groups are included by being embraced by the prevailing ideals of what all humans share. The diagnosis of intellectual disability, on

the other hand, is defined by deficits in precisely these capacities. Hence, it is necessary to engage with the politics of intellectual disability in order to understand the premises and functioning of emancipation in our times; this particular group exposes the limits of a politics that is fuelled by a will to include, inherent to modernity, humanism, and liberal democracy.

As a contribution to political theory, thus, I argue that intellectual disability is a crucial case since it is constituted as the outside mirror of ideals of reason and independence. This means that the study of 'intellectual disability' provides a privileged epistemological position from which the inner workings of a model of emancipation founded on ideas of self-determination, self-sufficiency, and autonomy, can be critically assessed (Clifford Simpican, 2015:3). As a contribution to disability studies, on the other hand, my analysis provides the first book length examination of intellectual disability as the outcome of biopolitics. Carlson (2010:12) argues that attempts by critical disability scholars to destabilise notions of 'impairment' and 'disability' have tended to overlook cognitive impairments. In response to this, I would argue that 'intellectual disability' is pivotal to understanding the mechanisms of a disabling society more generally, precisely because this particular condition is placed at the heart of subjectivity: in the brain of the individual. 'Intellectual disability' is not just another category whose inclusion deserves recognition; it is, arguably *the* group that exposes how the ideals of the humanist subject operate in politics that are geared to include (Erevelles, 2002:22); the group in which the governmental rationalities of citizenship are most clearly crystalized and in which the stigma directed against numerous others is implied (see Goodley, 2014:13). Therefore, this book provides new and better answers as to why practices of restriction and force persist, why the ideals of citizenship are themselves expressions of power, and how this is related to why people are constituted as 'intellectually disabled' for the purposes of government.

Lastly, inspired by a string of disability scholars influenced by post-structural philosophy, a vital aspect of my analysis will be that intellectual disability contains the norm that it is separated from. Therefore, examining how we construct and govern 'deviancy' also entails that we analyse the unacknowledged norm of appropriate cognitive functioning that disabled people are compared to (see Goodley, 2014:26). This means that this is not a book about 'intellectual disability', but about the dividing line between 'normalcy' and 'deviancy'. It is a division which we are all related to. In this sense, the politics of intellectual disability is also 'the politics of all of us'.

## Research Questions and Structure of the Book

Having previewed the overarching argument of the book and presented some of the most central concepts, it is time to specify what I plan to do and which questions will guide the undertaking. I will engage with the problem of what happens after a previously excluded group is targeted by politics that seek to make them included; what such politics is premised on, how the boundaries marking the sphere of inclusion are monitored and upheld, and how power is maintained and control exercised after inclusion. As the group in question is ‘people with intellectual disabilities’, another way of phrasing this is that I will seek to develop a theoretical understanding of what happens when the constitutive otherness of human reason and ideals of citizenship are to be included in the citizenry. The overriding research question is therefore formulated as follows:

How are people with intellectual disabilities governed in the era of post-institutionalisation?

I believe that any answer to this question requires the tackling of at least three analytical tasks. First, I will examine how questions regarding what intellectual disability is, are answered. This is based on Foucault’s (1990) conception of ‘biopolitics’ which encourages us to understand the fundamental linkage between intellectual disability as an object of knowledge and as a subject of management. Secondly, we need to understand the relationships between inclusion, citizenship, and intellectual disability. This means that I will not start from a certain conception of ‘citizenship’ or use it as a notion with a pre-established content. On the contrary, I believe that we must analyse how citizenship is made, or, more specifically, how citizens are made (see Cruikshank, 1999) – as I will argue, in this case by parallel technologies of ‘inclusion’ and ‘exclusion’. Lastly, we must try to make sense of the possibilities of resistance against the present biopolitical regime and what said resistance may reveal about the possible future of intellectual disability politics. Thus, in the third part I will engage with how the government of intellectual disability faces resistance, and the dangers and possibilities which are thereby opened up.

Each of these analytical tasks can be formulated as a sub-question:

- (i) How is intellectual disability constituted by the production of knowledge?
- (ii) How is the intellectually disabled subject constructed as a citizen and how are such 'citizen-subjects' governed?
- (iii) How can the present government of intellectual disability be resisted?

The general structure of the book follows these questions. This means that the first part deals with constructions of *pathology*, examining classification (Chapter 1), contemporary medical and psychiatric understandings of the condition (Chapter 2), and how these have been challenged by social understandings of disability (Chapter 3). The second part, entitled *Citizenship*, contains an engagement with the history and present of intellectual disability in political theory (Chapter 4), an analysis of the global discourse of citizenship inclusion (Chapter 5), and an examination of how politics of inclusion plays out in supported and integrated living services (Chapter 6). The last part is called *Resistance* and examines how support workers resist ideals of citizenship (Chapter 7), how activists with intellectual disability engage in a politics of representation (Chapter 8), and how discourses surrounding prenatal diagnosis restrain and make possible different forms of contestation of the practice (Chapter 9).

I have already stated that these questions answer a theoretical problem about how the present situation of intellectual disability can be made sense of. I shall soon return to why I do not think that prevailing interpretations are adequate. That this is a theoretical problem, however, does not mean that the concerns are removed from the actual lives of people with and without this condition. In this book, for example, we will encounter people who have been held back in their everyday lives in ways that would be deemed unacceptable had they belonged to any other group; we will meet support workers struggling to implement policy – each and every working day from 7.00 to 16.30 and from 12.00 to 21.00 (or from 21.00 to 07.00 if working the night shift) – and we will discuss in detail how present classificatory criteria are constructed. Along the way, I will analyse interviews and written material, together with philosophical works and disability scholarship. Thus, although this is a work in political theory, this book is constantly seeking to put theory into dialogue with the empirical matters of disability politics. 'Theory' here, is considered to be a tool used to reinterpret the world, to make us question our presumptions concerning how it functions, which, in turn, might pave the way for actually changing it. This means that I will not try to paint a general picture of the government of intellectual disability. I do not claim that my

interpretations are the only possible ones, and I do not think that the merits of this book hinge on its meticulous representation of complicated empirical matters. Indeed, I situate my work within a tradition of critical political theory which is suspicious of such grand knowledge claims. Rather, the merits of this book hinge on its capability to enlighten our understanding of intellectual disability politics, to spur new insights and better questions, and to provide theoretical tools that can help us make better sense of our present.

### **On Scope, Demarcations, and some Possible Misunderstandings**

Before continuing this introduction with a research overview and a theoretical introduction, I first want to leave the reader with a few clarifying statements of intent.

First, as the main topic is politics of inclusion, I believe that my analysis will have something to say about any context where such politics have gained influence. Primarily, I analyse the US and Western Europe, along with a number of international organizations and global institutions that also promote policies of inclusion, but I do think that my theorisations can have bearing on other contexts and other projects of inclusion, as well. However, it is important to remember that disability scholarship and discourse is ethnocentric and largely excluding of non-Western perspectives. I want to make absolutely clear that I am well aware that when I speak of ‘global’ policy tendencies and the like, promoted by ‘global’ institutions such as the UN or the WHO, the substance of the ‘global’ has most often been formed and defined in Western contexts.

Secondly, as will become evident throughout, I see a conceptual link between politics of inclusion and Western liberal political thinking, evident in the emphasis on individualism, independence, choice, and self-determination in policy discourses surrounding intellectual disability (see Tøssebro, 2005:197-8). This is the liberal tradition of political thinking that I have set out to critically engage with. I am well aware that debates on inclusion and citizenship outside of disability politics often involve communitarian, republican, and collectivist notions of inclusion and citizenship, as well. However, considering the content given to ‘inclusion’ within this empirical field, I believe that engaging the liberal-humanist tradition of political thinking need to be the primary concern. Lastly, as concerns the scope of the inquiry, it may seem as that the conclusions of this book primarily pertain to people with ‘mild’ intellectual disability, since this

group occupies the liminal zone between 'normal' and 'deficient'. This is not the case. My arguments concern intellectual disability, in general, although 'mild' intellectual disability is useful to illustrate the tenaciousness of the border separating 'normal' and 'deviant'. I believe that this will become clearer after the first three chapters where I develop a thorough analysis of the social constitution of intellectual disability.

I also want to forestall some possible misunderstandings. This book entails a lot of critical discussions of notions such as 'citizenship', 'independence', and 'inclusion', that is, of concepts that were integral to the abandonment of institutionalisation. This certainly does not imply that I promote 'exclusion', 'dependence', 'paternalism', or any other remnant of institutional disability care (see Simons & Masschelein, 2005:209). I agree with almost everyone else writing on this topic that deinstitutionalisation and policies of inclusion were very much called for and I fully accept that the services emerging after deinstitutionalisation have often meant better lives for people belonging to this group (see Bigby, 2005; Tøssebro, 2005; Clement & Bigby, 2010:25-27). Still, I do not infer from this that the present policies should be immune to criticism or that they, by merit of not being the harsh oppression of institutional confinement, are untouched by power. That deinstitutionalisation and citizenship politics were badly needed at that time does not mean that they marked the end of politics, the end of power, or that they should imply the end of critique.

Lastly, I want to stress again that this is not a book about 'people with intellectual disabilities'. I do not believe that individuals labelled as such have an essence, a set of common and knowable interests, or a unified voice that I shall make heard. I am interested in 'intellectual disability' as a biopolitical categorization and one of the purposes of my analysis is to denaturalise its existence by pointing out the political considerations that underpin it. More importantly, still, is that I will analyse 'normalcy' as a foundation of intellectual disability. This means that the examination can be presented as dealing with how the relationship between the norm of cognitive functioning, reason, and intelligence, and the corresponding constitution of its otherness, characterised by lack, deficiency, and disorder, is governed. Hence, rather than writing about 'intellectual disability', I want to make it a bit harder to write about people labelled this way as a fixed group with a certain essence that can be analytically divorced from the particular social organization that conditions its existence.

## Emancipation and Disappointment

The problem of this book is set up against the background of a popular history of intellectual disability: the story of grim oppression which hard fought victories transformed into citizenship and inclusion. Although this surely is a caricature of how the politics of intellectual disability is narrated, I do believe that the movement of progression, along with the idea of power as ‘that which we have finally left behind’, characterises a common understanding of intellectual disability politics. My research overview focuses on this specific narrative trait, both in order to explain the misconceptions that I believe my own approach answers to, and to specify the branch of disability research that I situate my own work within. In the coming pages, I will first sketch a short historical introduction of government responses to intellectual disability and, more importantly, discuss some blind spots of disability research that connect to how the history and present of this condition are comprehended. Thereafter, I will situate this book within a field of post-structural disability research.

### **Lyricism of the Cold Monster**

Intellectual disability emerged as a distinct category, in the form we know it today, at the end of the 19<sup>th</sup> and during the first decades of the 20<sup>th</sup> centuries. At the time, psychometric tests, anchored in the belief that human intelligence is a single entity that can be summed up and measured quantitatively, came to be used by governments in order to divide up the population (see Harris, 2006:43). The opportunity to pinpoint people with ‘mental deficits’ provided the basis for the governmental regime that would dominate the 20<sup>th</sup> century. This regime entailed institutionalisation, eugenics, and an on-going search for the biological causes of lesser intelligence. Although, the emerging welfare states came to develop along different trajectories, histories of institutionalisation and classification are surprisingly similar across national borders: institutional confinement developed, to varying degrees and in various forms, in most countries, founded on the dual logics of ameliorating disability and protecting society from the disabled (Walmsley, 2005:51; Carlson, 2010:42-3). It was in contrast to this world, the world of the institution, that intellectual disability policies would be reformed and take aim at citizenship.

The moment of inclusion did not occur over night or precisely at the same time. Rather it consisted of a succession of changing policies, aiming to include the intellectually disabled in the citizenry in a number of western countries and over a time span of at least forty years. The process and ideas of deinstitutionalisation had arguably already begun in the 1960s, at least in the US, the UK, and in the Scandinavia countries (see Parmeter, 2004:9; Nehring & Betz, 2007:82). In successive steps, dormitories decreased in size and were finally replaced by group homes and other models of socially integrated living. At the same time, new policies made individual rights, participation, and an emphasis on self-determination and autonomy, cornerstones of the citizenship status of people with disabilities. Different countries have their own milestones to narrate this story: the 1975 Education of all Handicapped Children Act and the 1990 Americans with Disabilities Act (ADA) in the US; the Swedish Omsorgslag of 1986 and the Law of Support and Service (LSS) of 1994; the 1995 Disability Discrimination Act and the *Valuing People* strategy of 2001 (Department of Health, 2001) in the UK, and so on. A number of cross-national efforts, such as the 1982 UN *World Programme of Action Concerning Disabled Persons* and the 2007 UN *Convention on the Rights of the Disabled* can also be seen as parts of this wave of efforts to include. I will analyse the ideas of citizenship inclusion more thoroughly in the second part of this book, but the most important point right now is that these policies all seemed to cast themselves against a shadow of confinement, discrimination, and paternalism, and instead promoted community living, integration, and independence (see Walmsley, 2005:52; Clifford Simplican, 2015:98).

The story of what has happened since is dual in nature. First, it should be noted that the politics of inclusion is understood as being a clear and important break with the past, often a source of pride which answers to the historical guilt of how people with intellectual disabilities have previously been treated. Simultaneously, as I have already mentioned, there has also been a lot of disappointment with regards to the outcomes. People with intellectual disabilities are still not considered equal or fully integrated citizens. On the contrary, members of this group lag behind in more or less every standard of living or socio-economic measurement scale there is (see Tøssebro, 2005; WHO, 2007:9; Clement & Bigby, 2010:160). Indeed, as Mansell (2010:11) notes, the recognition of a gap between ideals and outcomes of independent and community living has been prevalent more or less since ‘citizenship inclusion’ came to guide disability politics (see Cumella, 2008; Clement & Bigby, 2010; Lewin, 2011).

Now, this history of deinstitutionalisation, liberation, and disappointment is also ingrained in much of the social scientific research on intellectual disability. Obviously, disability studies is a diverse and trans-disciplinary research field, considering theoretical presumptions and empirical focus, which means that I will be guilty of considerable oversimplifications here. Nevertheless, there are some themes that reoccur, concerning what the purpose of research should be and in relation to what emancipation is possible. These themes are important to understand how citizenship inclusion is conceived of. Thus, in order to argue the case of my own theoretical approach, I will not try to give a general overview of disability studies or discuss all of its merits and shortcomings. Instead, I will focus on a common way of understanding politics of inclusion against the backdrop of the historical treatment of people with intellectual disabilities.

‘The lyricism of the cold monster’ is what Foucault (2007:109) calls the tendency to start every discussion about power with the state, pictured as oppressive and reigning over and down on its people. A considerable degree of such lyricism is present in social scientific research about disability. Hence, the perceived enemy is the totalising institution that confines, forces, subjects, and constrains. Therefore the ambition – whether it be stated or implicit – of much disability research has become to guard the freedom of the individual against a vindictive state. In practice, this guarding often consists of measuring disability services against some pre-set standard used to localise failures (see Yates, 2005:75). Often starting from a phase-based and instrumental view of policy processes (Hill & Hupe, 2002:5-8), a lot of disability research takes the smooth following of regulations and rules as an unquestioned descriptive ideal (see Drake, 1999:25-9; Bigby, 2005). Indeed, social scientists and public commissioners regularly conclude that disability service personnel ‘still’ possess power and that people with disabilities are not ‘yet’ independent (Drake, 1999:90-1; Gustavsson, 2004:56; Larsson, 2008). From this perspective, any conceptual complications or discursive implications of these policies are effectively precluded. When it turns out that people with intellectual disabilities are not independent despite the stated ambitions of inclusive policies, it is interpreted as an indicator of disability services suffering from ‘implementation failures’, explained by the persistence of an institutionalisation mentality, lack of resources, or dysfunctional organization of service provision (see Drake, 1999:91; Bigby, 2005:118-9; Clement & Bigby, 2010:32). According to this line of reasoning, if everything had only worked out as it was intended to, then public power would have been dismantled and citizenship granted for the targeted group.

Identifying paternalism and the neglect of legal rights has obvious merits. However, there are also notable perils, the main one being that there is a tendency to uncritically accept the present formulations of policy goals. An instrumental view on policy implementation that takes the link between emancipation and citizenship for granted can never detect if or how power is systematised within present disability services as something else than a residue of practices that our present policies have sworn themselves free from. Hence, there is a predisposition to answer questions formulated from the perspectives of administrators and politicians, where the focus is to facilitate organizational efficiency and goal compliance rather than to examine the wider implication of disability policies (see Mabbett, 2004:32). As a result, stories of the kind that I started this introduction with – of the tied-up man in Malmö, Sweden – are easily recognised as an exercise of power in violation of the law, an anomaly against a backdrop of good intentions. But this perspective will not help us see how this example is an expression of a systematised mode of government. Nor can it help us understand that government also can operate by actively shape people to become citizens *in accordance* with the ideals of the politics of inclusion.

Thus, my argument here is that the dark past has functioned as an imaginary in opposition to which understandings of the present are produced (Drinkwater, 2005:229-230). I believe that this is worth expanding on a bit further. Consider how Spivak (1999:1) warns of the dangers of placing colonialism securely in the past, thereby blinding us to how practices of our present continue to constrain and repress the subaltern. In a similar vein, consider the glum black-and-white pictures which are often used to illustrate books on the history of disability (see Grunewald, 2008 for an illustrating example), the vacuous facial expressions of the disabled and the large institutional buildings in the background. Drinkwater (2005:230) analyses this as manner of visualising power as ‘that dark era which we have left behind’; pictures that serve as mental images of what oppression looks like but which belong to history. The question is to what extent are we prepared to pay attention if power no longer looks like that. Brown (1995:8) poignantly expresses the pitfall of this mode of analysis as a situation where

freedom premised upon an already vanquished enemy keeps alive, in the manner of a melancholic logic, a threat that works as domination in the form of an absorbing ghostly battle with the past.

So, what if the ghosts we are fighting do not constitute the only, or even the primary, threat? Similarly, Verstraete (2007:58) proposes that the ‘modern

independent-autonomous-sufficient-free subjectivity' of disability research is often considered to be the only alternative to a crushing and oppressive past. Simultaneously, questions regarding whether this view of subjectivity itself may be an expression of power are effectively precluded when walking backwards into the future anxiously watching for the spectres of institutionalisation.

As is argued by Brown (1995:3), critical intentions are often figured within the same paradigms that had previously brought about the powers which they set out to contest. The recurring starting point of designating 'choice', 'autonomy', and 'independence' as the appropriate yardsticks of disability services effectively overlooks how these ideals, taken on their own, compose a mode of putting subjects into being. In this vein, Verstraete (2007:60) argues that an 'accent on autonomy, self-sufficiency and independence (...) tends to confirm who we are at this very moment rather than questioning this kind of subjectivity' (see also Jordan, 2010). Similarly, Clifford Simplican (2015:65) states that disability scholarship which advocates 'emancipation' often hinges its analysis on liberal models of agency and therefore it is often projected that the first step of successful disability activism is to convincingly argue that disabled people are capable of 'independence' and 'self-determination' as understood within this tradition. In other words, my argument here is that the frequent insistence of disability scholarship and advocates to propagate for 'citizenship' and 'independence' does not sufficiently address its own ideological underpinnings (see Brown, 2008:113). Although more or less all disability research is very critical of public powers, in its lyricism of the cold monster, it fails to detect government when it is no longer cold and monstrous, but increasingly dispersed and taking shape as a promise of freedom.

## **Post-structuralism and Intellectual Disability Research**

In light of the above, there is a need to address disability without taking its pre-political existence for granted and without viewing 'citizenship' and 'inclusion' as being equal to 'emancipation'. There have been a number of efforts made by disability theorists which have contributed to such a project. Before presenting the wider theoretical and philosophical discussions that have informed this book, I want to review a number of such approaches. To the extent that I speak to the field of critical disability studies, the literature presented here is where I intend to leave a contribution.

First, knowledge of brains and bodies is intimately linked to the organization of political communities, as Malabou (2008:55) states: ‘any vision of the brain is necessarily political’. This means that the brain is a projection surface for ideas about who is worthy of inclusion, indeed, that the brain is a place where the power intrinsic to separate ‘normal’ from ‘pathological’ is expressed. The relationship among biology, normalcy, and power, has been a main concern of the growing body of literature branded as ‘Crip theory’. By putting queer theorisations of sex and sexuality into dialogue with disability, ‘Crip’ can be seen as an umbrella term for a number of theoretical attempts to understand how disability is socially constituted and responded to. This perspective is most clearly connected to the work of Robert McRuer (2006), who branded the term, but scholars such as Rosemarie Garland Thomson (1997; 2012), Dan Goodley (2014), and Lennard Davis (1995; 2002), among others, share many of its important characteristics. At least two analytical focuses can be discerned within ‘Crip theory’: (1) a focus on interconnections between disability and non-normative sexuality, and (2) the application of theoretical tools of queer theory to understand disability. It is primarily in the second sense that this literature has influenced this book. Often focusing on the construction of the ‘normal’ body, or the ‘normate’ as Garland Thomson (1997) denotes the idea of a human being who functions fully at all times, Crip theory helps us recognise how disability is normatively imbued and always related to an implicit ideal of ‘able’ functioning. In parallel to how Judith Butler (1990, 1993) analysed the construction of sex and sexuality, disability can be seen as ‘performative’, which means that the division between ‘able’ and ‘disabled’ is made real through a ritualised repetition of norms. Viewed this way, thus, there is no disability prior to the yardstick that decides which bodies qualify as ‘able’. We shall return to the more concrete implications of this when summarising the first part of this book at the end of Chapter 3.

These propositions all point towards a radically different understanding of government and power than the one I criticised in my discussion on disability research above. Tremain (2005:9) argues that a ‘juridico-discursive’ conception of power dominates disability studies, where government is understood as centralised and power as possessed by authorities external to the subjects being oppressed. Here, Tremain projects that a Foucauldian understanding of power is better suited to make sense of how people with disability are governed. In addition to Tremain’s own work and the contributions to her edited volume *Foucault and the Government of Disability* (2005), Mark Rapley’s (2004) analysis of the social construction of

intellectual disability is worth mentioning here. Despite only occasionally referring to Foucault, Rapley oftentimes points towards the governmental rationales inherent to classification in a way that is akin to what I will do in Chapter 1. Another example of an analysis of intellectual disability that starts from Foucault is provided by Licia Carlson (2010), who examines how discourses inherent to the philosophy of intellectual disability constitute boundaries for what becomes thinkable about this diagnosis. However, as she mainly draws on early Foucault, her primary focus is the institutional era as a background and foundation for today's philosophising, whilst biopolitics and the linking together of government, citizenship, and bio-pathology remains largely unexplored.

Another disability theorist working with post-structural theory is Dan Goodley (2014). The standout trait of his more recent publications – often co-authored together with Rebecca Lawthom and/or Katherine Runswick-Cole – is the emphasis on understanding 'normal' and 'abnormal' as intrinsically related, captured in the concept 'dis/ability' (see Goodley, 2014; Goodley & Runswick-Cole, 2014; Goodley et al, 2015). As stated already, a related approach will guide my analysis. Similarly, Nirmala Erevelles (2002; 2005) has a special focus on how the ability-disability relationship is embedded in contemporary capitalism, focusing on the intersections between disability and numerous other identity formations. Erevelles (2005), furthermore, provided me with one of my first encounters with how Foucault's terminological apparatus could be brought to bear on disability.

With respect to the work of Goodley and Erevelles, I want to briefly say something about two underdeveloped traits of my own analysis. The first one concerns intersectionality, which both Erevelles (2002) and Goodley (2014) stress as being vital to comprehending disability politics. I believe that an intersectional awareness has guided my work, helping me resist the tendency to see people with intellectual disabilities as one-dimensional subjects only related to one dominating structure of power (the risks of which will be discussed in Chapter 8). However, using intersectionality as an analytical perspective would require a much more thorough analysis of how 'ableism' relates to 'sexism', 'racism' and/or capitalist production, which would be a tough ask considering the scope of the investigation I have set out on. Secondly, again following up on the work of Goodley (2014) and Erevelles (2002), a recent tendency in disability studies has been to understand disability in relation to neoliberal capitalism (see also McRuer, 2003:2-3, 7), exemplified by how Jasbir Puar's work (2007) on the debilitating effects of neoliberalism has influenced some recent work within disability studies (see

Mitchell & Snyder, 2010; Goodley, 2014:94-5). The organization of the economy is obviously implied at many times in my analysis, however, not as an explicit analytical perspective. The reason for this is that I believe that the undertaking required to truly make sense of ‘intellectual disability’ as related to neoliberal capitalism, on the one hand, and the Marxist and post-Marxist traditions of political thinking on the other, is a too much to ask for this book. The way I see it, developing an analysis on intellectual disability which accounts for the play of norm and deviancy in relation to the organization of production involves much more than just adding a bunch of recent criticisms of neoliberalism to a ‘Crip’ analysis of intellectual disability. Rather, I believe that such a project requires a detailed engagement with the placement (and invisibility) of disability in politico-economical thinking in general and the history of Marxism in particular, along with a critical remobilisation of the Marxist origins of the social model of disability. Such a project is much needed, I believe, especially in face of the rise of politics of austerity and how it strikes against people with disabilities (see DPAC, 2014). However, for these reasons, I will save my own engagement for future books.

Lastly, I should say a few things about Stacy Clifford Simpican’s (2015) analysis of how contractual citizenship thinking is premised on a ‘capacity contract’, that is, on implicit exclusions of subjects not conforming to certain ideals of the capacities that citizens possess. Like me, she uses the rift between the constitution of intellectual disability and common notions of citizenship as a springboard to examine how intellectual disability relates to the history of Western philosophy. However, Clifford Simpican’s work is narrower in scope, solely dealing with political theory within the contract tradition, whereas I engage systems of classification, policies, and resistance to offer a broader analysis of intellectual disability as biopolitics. Nevertheless, my own engagement with some of the classics of political theory, presented in Chapter 4, is hugely indebted to her work.

In summary, all of these theorists avoid presuming the natural and pre-political status of disability and the unequivocally liberating force of citizenship. Instead, intellectual disability, power, and subjectivity are understood as tightly nestled together through an array of governmental practices and systems of knowledge. Starting from the work of Foucault and Butler, I will also be analysing ‘intellectual disability’ as inseparable from power and normativity. The theoretical propositions of these two, and a few other, philosophers are what we turn to next.

# Inclusion, Subjectivity, and Government

What will be presented hereunder is an introductory discussion of a set of theoretical concepts and perspectives that I will engage with throughout the analysis. Together, the three themes presented below should be read as a proposal for how intellectual disability politics can be theoretically approached without the problems of disability research which I discussed above. These perspectives are the discursive limits of inclusion/exclusion, queer analysis of subjectivity, and an analysis of government that sets out from Foucault's understandings of power. All of these will prove necessary to understand the contemporary biopolitics of intellectual disability. This very term will be presented under the last heading, reflecting its origins in Foucault's philosophy. I will thereafter conclude the introduction with a section on how the analysis of the rest of the book is carried out.

## **Inclusion/Exclusion**

I have already argued that the politics of post-institutionalisation is structured by the terminology of inside and outside societal belonging, where independence, participation, and integration are expressed as 'inclusion'. The first theoretical theme I want to address concerns how we should understand this way of making sense of politics. Inside/outside as a model for understanding social organization relies on a spatial metaphor, implying a sphere of inclusion and an outside space of exclusion. Daly (2006:3) argues that, in this way, the mental imagery of social injustice has shifted during the last decades, from the perception that inequality is the main problem, hierarchical in nature, to the view of a perceived rift between those who are 'included' and those who are 'excluded', most often in relation to the sphere of 'full citizenship'. Thus, this is not only a way of seeing disability politics, but a more general model of conceiving how societies are structured.

The most prominent feature of 'inclusion' is that it presupposes the existence of a border separating 'included' from 'excluded' without questioning the existence of the border as such. This is a conceptual feature of this lexicon and an ontology underpinning its use. Hence, any call for 'inclusion' in the context of disability politics confirms the divide between included and excluded subjects: where the line is drawn is what is to change. This means that 'inclusion' and 'exclusion' appear as mutually constitutive

opposites (see Daly, 2006:10). However, following Derrida's analysis of language as a system of perpetually deferred differences (see Derrida, 2001), this binary cannot be relied upon as a stable referent of the realities it seeks to name; the division between inside and outside is always threatened with displacement, implosion, or by a dissolving of the border which separates the inside from the outside of societal belonging (see Morton, 2003:26). In other words, the instability of linguistic meaning pinpointed by Derrida threatens our sense of reality, because the concepts we use to name that reality are unstable. We can never be assured that the 'excluded' are securely removed from the 'included' or that our own positioning within this discursive systems is fixed. Attempts to uphold the separation of inside/outside can therefore be analysed as ways of consolidating how we understand social order and the efforts to enclose otherness within the sphere of exclusion as a protection of our sense of community. As I will return to in the analysis, this is why it has been so important to separate intellectual disability and to anchor it in a biology of deviancy; it is a way of safeguarding a notion of subjectivity founded on ideals of reason and rationality that must be removed from the 'normalcy' of the fully included citizen.

Most often, the inside of inclusion is figured as made up of the full members of a political community and such membership can, according to our inherited ways of conceptualising the relationship among individual, community, and state, be understood in terms of 'citizenship' (Yuval-Davis, 2007). As has been posited already, the general problem this book addresses concerns the politics of inclusion and 'citizenship' is tightly linked to contemporary articulations of such politics. However, although 'inclusion' is most often viewed as 'citizenship', it is not citizenship *per se* which 'inclusion' refers to, but the movement from an outside to an inside, into community belonging. In this way, 'inclusion' denotes a particular kind of movement and citizenship has become a standard term for how this movement is substantiated. It follows that the ultimate goal of 'citizenship inclusion' cannot be a world without borders to separate insiders from outsiders (see Thomassen, 2005); it can merely be a world in which inclusion and exclusion, by means of citizenship, are allocated differently.

This suggests that there is a latent danger that demands for inclusion reinscribe what is seen as its content and prerequisites. In a sense, this was my criticism of much social scientific intellectual disability research above: by parsing political demands in the terminology of 'citizenship inclusion', the subjectivity presumed as necessary for being included is being reprised. The

same problem is highlighted in Homi Bhabha's (2004: xiii) discussion on the logic of post-colonial integration, which he describes as:

normalizing discourses of progress and civility [...] that only "tolerate" differences they are able to culturally assimilate into their own *singular* terms, or appropriate within their own *untranslated* traditions. [italics in original quote]

Bhabha continues by stating that his example of a racial optic can serve as a stand-in for any form of social difference or discrimination. For him, the limits of inclusion follows the ability of 'others' to meet citizenship requirements of civility and lawful participation. In plain speak, this means that 'inclusion' is premised on subjects worthy of inclusion. Thus, not only is there the power to exclude, but also the power to put the goals into place that the excluded strive for, and the ideals they must meet in order to be perceived as citizens. Discourses of 'citizenship' and 'inclusion' often direct our focus towards questions of *entry* and *exit* at the expense of how the normativity of citizenship operates *within* spheres of inclusion (see Daly, 2006:4). But, as Isin (2009:372) notes, citizenship always means more than being an insider; it also requires upholding and mastering conduct which is understood as appropriate for citizens.

As was stated above, if the relationship between inclusion and exclusion is mutually constitutive, the sphere of inclusion must be founded upon the existence of a constitutive outside which is separated and distanced from the normativity of inclusion (Butler, 1993: xiii). However, as Butler notes, any such separation will mean that the normativity of inclusion includes the outside as its condition of possibility. Butler (1993:26-7), clearly influenced by Derrida, describes this as a latent presence of what is excluded in the form of a threat of a terrifying return. Constitutive outsides are composed of exclusions that are internal to the system as its own 'non-thematizable necessity', emerging as incoherence, disruptions, and threats to social order (Butler, 1993:13). This, again, points to the failure of divisions – between inside and outside, normal and deviant, and so on – to consolidate and reach closure. Whatever norm of appropriate and normal functioning underpins social organization is perpetually haunted by what it has excluded in order to appear to be a reasonable characterisation of humanity.

## Subjectivity

From what has been said so far, it follows that the division between ‘included’ and ‘excluded’ operates by structuring how we perceive our world and therefore also how our identities are shaped. It is a binary that is tied to several other divisions that will reappear throughout this book, as for example between ‘normal’ and ‘abnormal’, ‘healthy’ and ‘pathological’, ‘reason’ and ‘lack of reason’, and ‘independence’ and ‘dependence’. The formation of subjects takes place in such discursive systems of signifiers organized together. I will here try to introduce how I see this.

When framing the problem of this book, I have referred to an ideal ‘citizen-subject’ at some occasions, defined by reason, rationality, and independence. Much feminist and post-colonial theory has analysed the racialized and gendered nature of this ideal and, at times, Crip theorisations of citizenship have similarly analysed how ‘the citizen’ is tied to the ideal of an ‘able’ body (see Davis, 2002; Jordan, 2010). Bridget Anderson (2013) argues in a slightly different terminology that there is a ‘liberal individual’ at the heart of ‘liberal citizenship’, formed around the idea of self-ownership of their body, their labour, and their mind. Hence, inherent to modern political thinking is a story of an ‘I’ that is exercising self-mastery through reason – an idea that can be traced back to the moral philosophy and epistemology of Kant and the individualism of Descartes (Lenz Taguchi, 2006:27-8), and which designates autonomy, competence, and reason as necessary preconditions of citizenship (see Shildrick, 2000 in Clifford Simplican, 2015:99; Erevelles, 2002:6). It is important to point out that this ideal links political and societal belonging to the inner life of the individual, precisely since we enter relations with the political community as ‘citizens’ by merit of our capacity to meet this model of subjectivity. I will refer to this ideal construction as ‘the humanist subject’, where ‘humanism’, based on Foucault’s ideas, is understood as a set of propositions that tie us to a specific notion of personhood. For Foucault, ‘humanism’ is a model of thinking that seeks to define human beings by our ‘natural’ characteristics (see Pickett, 1996:542). In my analysis the ‘humanist subject’ is a bit narrower, specifically understanding ‘humanism’ as the idea that human beings are defined by reason, deliberative capacity, and rationality.

Now, the humanist subject is central to divisions between inclusion and exclusion and therefore also to how subjectivities are shaped in relation to this division. As Morton (2003:37) notes, throughout Western history, certain people, concepts, and ideas have been defined as ‘other’ in relation to

‘civilized’ society and it is by the relegation of otherness to the exterior of normalcy that the sovereignty of the humanist subject is guaranteed: ‘normal’ people appear as subjects of reason because some people are excluded. This has some important implications for how we understand people as belonging to certain identity categories. According to Butler (2005), the process of coming into being as a subject will always be framed by discourses which are prior to us but nevertheless constitute the conditions of possibility of our emergence. This means that categories such as ‘abnormal’ and ‘normal’, for example, are always already there when we appear to inhabit them. We cannot choose exactly who we want to be, as a crude reading of the humanist subject would suggest, but come into being provided a set of already established categories. In turn, inhabiting the position of the ‘citizen’ – as understood within the humanist tradition – means coming into being in relation to a prior normativity which designates the capacities that ‘citizenship’ requires.

In this context, Butler’s (1990; 1993) notion of ‘performativity’ provides a theoretical vocabulary to understand the way subjectivity is formed in relation to the social categories that define the kinds of people we are. She begins by saying that subject positions are premised on pre-existing discourses and exclusions. It is important to note that Butler does not suggest that identity itself is performed, as in ‘acted’, but that performativity as a societal and ritualised repetition of norms is the condition which makes it possible for subjects to emerge. At this point, Butler’s indebtedness to Lacan is obvious, as her central point is that subjectivity is linguistically structured (see Žižek, 2006:3). Thus, when Butler speaks of language, she speaks of the foundations of subjectivity, and when she speaks of the performativity of language, she refers to how our actions will always be discursively situated. There is a grammar to how we come into being, which is prior to us and therefore gives rise to the defining lack that was central to how Lacan imagined the psyche. In Butler’s (1993: xxi-xxiv) analysis, discursively constructed categorisations function by being unattainable: we can never be reassured of belonging once and for all, in her analysis to the ideals of ‘masculinity’ and ‘femininity’. But since such categories still precondition our recognition as subjects, they are necessary to our sense of identity, which means that our behaviours will iterate prior ideals of ‘maleness’ or ‘femaleness’ in order to secure our belonging. The performativity of subjects is how our behavior unconsciously mimic the unattainable ideals of subject-positions to produce our identity. Hence, these categories and ideals are constantly reproduced, by individuals and throughout society. In the

concluding pages of the first part of the book, I will discuss how the ritualised repetition of norms also can be analysed with respect to intellectual disability.

Another theme that will reappear throughout the first three chapters concerns the designation of biological differences as prior to politics and as defining characteristics of subjects. Again, Butler's analysis of the biology of 'sex' is an apt illustration: by referring to biological differences between the sexes, this division is made to appear as prior to politics and hence as beyond the reach of politics and criticism (see Butler, 1993:4-7). Parallel to this, Urla and Terry (1995) argue that a common way of securing the 'humanist subject' has been to locate the foundations of its otherness in the materiality of deviant bodies. Biological differences are thereby put to work as a way of naturalising omissions of certain phenomena from what is considered 'normal', thereby giving them a biophysical foundation (see Siebers, 2008:6). This process is what Butler (1993: xix-xx) discusses as 'materialisation', in which certain bodily differences are singled out and seen as proof of the natural existence of certain socially constituted categorisations.

Some critics within disability studies have proposed that Butler's theorisation of subjectivity and the body risks leading to a neglect of the material realities of disability and have warned against a facile translation of 'sex' into 'disability' (Samuels, 2002; Siebers, 2008: 6-7). In order to forestall a few possible misunderstandings, I shall briefly respond to these cautions. First, the way I read Butler is not as saying that embodied experiences or material bodies are not 'real', for example indicating that various hardships associated with atypical cognitive functioning can be comprehended as 'mere' social constructions. Indeed, this accusation is premised on a division between 'reality' and 'construction' that Butler posits as one of her main targets. Rather, her point is precisely the inseparability of body and society (see Siebers, 2008:56), arguing that what can be understood about the subject and their body is 'set out within the cultural frames of intelligibility' (Taylor, 2013). Secondly, humanity is composed of an incalculable array of differences – but not all differences matter. Only some differences are interpreted as constitutive, fundamental to what we are, and hence incite medical and psychological scrutiny to map behavioural characteristics and biophysical correlates. The process of choosing exactly which bodies matter in what ways is always culturally embedded and socially invested (Butler, 1993). Hence, I will not argue that people with intellectual disabilities do not differ, but I will contend that the social process of deciding which differences matter is what makes 'intellectual disability' intelligible to

us. Furthermore, in conjunction with the above discussion about how inclusion forms a necessary and constitutive relationship to a sphere of exclusion, Butler's (1990; 1993) overarching argument can be read as proposing that the normativity inherent to the humanist (or any other) conception of the subject is also what creates people that are defined by failing to meet the standard it establishes. Disability hinges on such prior normativity. This does not imply that biological or behavioural differences do not exist, but that they must be *put into existence* to become part of how we perceive the world.

At this stage, I have introduced a number of theoretical vocabularies that are related to one another, overlap, and which are quite possibly difficult to differentiate. I will try to clarify things a bit here. First, the dichotomy of inclusion/exclusion is a political creation and way of understanding intellectual disability politics. As such, it is underpinned by the spatiality of inside/outside. Subjects come into being in relation to this discursive construction, as 'included' or 'excluded', which in turn relates to divisions between 'normal' and 'pathological', 'reason' and 'lack of reason', and so on. The removal of some ways of being from the ideals of how humanity is defined and the insertion of them into a dichotomous relationship with these ideals constitutes 'otherness'. However, 'exclusion' and 'otherness' should not be confused with 'constitutive outside' in the sense it is used by Butler. The 'constitutive outside' is that which must be removed for an ideal or a norm to exist and to be comprehensible, but that does not require the construction of otherness. Thus, the exterior of the norm of human reason is a constitutive outside, prior to its rendition as the binary opposite of the humanist subject. Indeed, since the constitutive outside threatens the norm that it is differentiated from, it must be contained, named, and inserted into discourse. Through this process, it becomes an excluded otherness that can be targeted by politics. In this way, the threat of the constitutive outside, here made up of the particular segment of the population which we call 'intellectually disabled', is handled by inserting it into a dichotomous relationship with the humanist subject as its 'other'.

By recognising these things, we are able to put forth a number of crucial questions regarding intellectual disability: why are these people understood as belonging to the same category? What do they have in common? What forces are deciding on the line of demarcation which allows for their existence? How are they constituted as citizen-subjects and what happens if they fail to meet the implicit norms that characterise members of the

citizenry? In response to such questions, we shall now turn to what I mean by ‘government’ and ‘biopolitics’.

## Government

The overarching analytical term of my examination is ‘biopolitics’, in a sense functioning as an umbrella under which the above discussions on inclusion/exclusion and subjectivity are incorporated in the context of this book. However, there are also some specifics in Foucault’s analysis of government that need to be presented.

For Foucault, biopolitics is a form of government that takes the individuals and the totality of the population as its target, emerging during the 18th century when the importance of sovereign control over territory decreased. He describes the advent of this form of rule as the orchestration of:

the set of mechanisms through which the basic biological features of the human species became the object of a political strategy, of a general strategy of power, in other words, how, starting from the eighteenth century, modern western societies took on board the fundamental biological fact that human beings are a species. (2007:1)

The concept of ‘population’ is here understood as stretching from the biological rootedness of human beings to the social practices that help us navigate society, constituting a field of realities that compose the pertinent elements for mechanisms of power to act on (Foucault, 2007:75). Hence, the way we conduct ourselves, understand ourselves, and regulate our behaviour, are all targets of government, as well as our material composition, and the way it mixes with others’ to form a populace. Foucault (2007:70) here describes that ‘the population’ is conceived of as a set of processes to be managed. The range of this field of management is reflected in the terminology of use: *biopolitics* (or ‘biopower’) *is the power of life itself*. Seeing ‘intellectual disability as biopolitics’, as I state in the title, is to understand this condition as the outcome of, and embedded in, the government of human life.

Under the previous heading, I discussed how subjects – by ‘performativity’ – are shaped in processes of internalising social norms and categorisations. A central aspect of that regards how subject-formation relates to socially mediated conceptions, ideas, and presumed assumptions

concerning what it means to be human and precisely what kind of human one is. In a considerably broader sense than dictated by its everyday use, Foucault sees such ideas – produced and upheld through science, culture, media, folklore, and so on – as examples of ‘knowledge’. In Foucault’s analysis of government, power and knowledge are always intertwined, where knowledge is attributed with the power to produce subjects and where power works by deciding what qualifies as knowledge. Of special importance here, as Urla and Terry (1995) among others have argued, is the production of scientific knowledge functioning as an instrument for making the population governable; by segmenting it, ascribing to it specific characteristics, and by mapping its behaviour at an increasing level of detail (see Foucault, 2007:77-9; Rose, 2007). In the words of Hacking (1986), subcategorising the population by ‘making up people’ creates division that governmental interventions can target. Concurrently, biopolitics also implies management on the micro-level, targeting the individual and their behaviour, where each individual represents an unfulfilled promise of improvement. Foucault (see 1990:139-42) continuously engages this dual nature of government, exercised on the individual body and mind and on the population as a whole. These two poles – of governing individuals and regulating the population – create technologies of power present at every level of society and utilised by a diverse set of institutions (Foucault, 1990:141).

To understand the implications of Foucault’s analysis, it is necessary to say a few things about its underlying ontology of power and subjectivity. First, as I just explained, there is an intrinsic relationship between power and knowledge. By taking subjectivity as its target, technologies of power act on depictions of the biophysical constitution of people, about their lives, and about how these can be organized. In the spirit of Nietzsche, this means that questions of knowledge do not pertain to the distinction between ‘false’ and ‘true’, but are questions of truth themselves – of how ‘truths’ are *made* and internalised into our worldviews (see Simons, 1995:19). Secondly, Foucault (1982; 2003:27-8) argues that the study of politics needs to abandon the idea that power is located at a certain centre from which it reigns over and down on people. Rather, the ways that different technologies of power intervene in the lives of individuals at different places and through different means is what is important. This view can be juxtaposed with the idea of power as repressive and exercised *over* individuals which I discussed above as a shortcoming of some social scientific disability research. Here, power is seen as productive rather than repressive, as something that shapes subjectivity and social relations. It follows that the government of the population does not

always require force and coercion, but may just as well function through self-regulation and internalisation of certain norms, that is, by moulding the capacity of individuals to govern themselves (see Cruikshank, 1999; Rose, 1999). Rather than an inherently bad thing that should be discarded, power should instead be seen as a necessity of social organization. It is important to point out that, although power emerges from everywhere, power can also consolidate to favour certain groups. This means that the general analysis of power sketched out above can be seen as an ontological argument, but that Foucault's various engagements with actual government – in prisons, clinics, ancient Rome, and so on – rather describes specific empirical instances of how power has been consolidated and put to use to produce subjects by various methods. As we shall see in the last part of the book, Foucault came to rearticulate the nature of 'subjectivation' during the last years of his life – from seeing subjects as effects of power to seeing power as a precondition for the emergence and becoming of subjects – with notable consequences for how he came to understand critique and self-reflexivity as instances of resistance. I will present this aspect of Foucault's thinking in the opening pages of the third part of this book.

All of this is to say that power shapes subjectivity. The link between subjectivity and government highlights a specific role of normativity in Foucault's analysis of government. The emergence of biopolitics meant a growing importance of the norm since a power whose objective is life itself needs continuous regulatory and corrective mechanisms. Such a power cannot display itself in its 'murderous splendour', as he dramatically formulates it (Foucault, 1990:144), it rather works by distributions around the norm in processes that are largely driven by self-regulating individuals. In order to be a full member of society, one has to achieve 'normality' through working on oneself (see Davis, 2002:106) and, in this way, the practice of self-government underpins biopolitics. I will discuss the regulating and evaluative effects of norms as 'normativity' and the idea that there is a normal span of capacities as an ideology of 'normalcy'.

Now, an important implication of this understanding of power is that we have to abandon the view that there is a dichotomous relationship between subjects acting freely and the government intervening in such processes of self-creation. Government does not have to rely on repressing and constraining freedom, but can also work by putting in place a specific configuration of freedom and shaping the fields of action where it is exercised, meaning that it is, *acting on*, rather than *supressing*, individual agency. This means that government is 'the conduct of conduct' (Foucault,

2000:341; see also 1982:789 for an alternative translation). For example, in Chapter 6 I will elaborate on how group homes for people with intellectual disabilities are not only places where freedom is restricted, but also where individuals are shaped to understand themselves as ‘free’ in a certain sense and are impelled to exercise this freedom in specific ways. The government of the support workers consists in acting on the conduct of the people with intellectual disabilities that they work with, to make them conduce a certain way. Hence, ‘free citizens’ are created rather than born and this process is one aspect of what the government of intellectual disability has turned into.

## **Examining the Politics of Post-institutionalisation**

Studying the politics of inclusion with respect to the theoretical themes presented above obviously gives rise to a number of questions regarding how I will go about this study. I will try to answer the most important ones here, while postponing more detailed issues about methods and selection of material to the individual chapters.

First, in my investigation I draw on Butler’s specification of what she calls a ‘genealogical critique’, in her case on the categories of gender. At the opening of *Gender Trouble* (1990: xxxi) she explains that:

a genealogical critique refuses to search for the origins of gender, the inner truth of female desire, a genuine or authentic sexual identity that repression has kept from view; rather genealogy investigates the political stakes in designating as an *origin* or *cause* those identity categories that are the *effects* of institutions, practices, discourses with multiple and diffuse points of origin.

Similarly, the focus of my analysis will be on how intellectual disability is constituted, that is, how it is *done*. This is what compels me to view the production of intellectual disability from the perspective of biopolitics. However, this does not imply that I will seek to do away with ‘intellectual disability’ as such or that the differences that mark this group are, in fact, irrelevant. Rather, the project is to examine *how* ‘intellectual disability’ comes to matter by focusing on how the category functions and is targeted by politics of inclusion. In a terminology of deconstruction I will thus attempt to *cross-over* rather than discard ideas of ‘intellectual disability’ and its biology; displacing its meaning, enhancing perspectival shifts, and thus hopefully allowing for the chance to see the politics of the condition in new ways (see Butler, 1993:5-6).

Since structures of language, knowledge, and politics all constitute a field of power, there is no position outside this field from which I can claim to access an alternative truth of this condition or its politics (see Butler, 1990:7). This suggests an analytical strategy of tracing how contemporary understandings of intellectual disability are supported, in the language of classification, clinical records, and policy. The purpose is not to reveal the inner 'truth of power', but simply to study how it operates. As is implied by the theoretical propositions elaborated upon above, 'discourse' is seen as vital in this respect, setting the limits for how interpret and experience social reality. It is also assumed that discourse does not neutrally reflect this social reality, but that speaking and writing are social and normative practices. The instability of discourse suggests that attempts to determine sites of meaning, in this case of 'intellectual disability' and 'inclusion', tend to produce rifts and displacements which challenge discursive intelligibility (Butler, 1993: xxiv). This, I take as an impetus to pay special attention to the places where the discursive formation of 'intellectual disability' contradicts and cracks. These propositions, however, do not mean that I will provide a 'discourse analysis', as in the specific method of text analysis. 'Discourse' here is a theoretical concept concerning how use of language shapes what is possible to know; it is a name for the interconnectedness of power and knowledge in language (Foucault, 1990:100).

It follows that the general method of this book will be to discuss a set of concepts and ideas, such as 'inclusion', 'normality', 'intellectual disability', and 'citizenship', by theoretical analysis of a variety of empirical sources. For better or worse, this genre of political theory rarely commits to detailed methodological recommendations or schemes (see Cruikshank, 1999; Rose, 1999), although the more specific ones that I have followed, concerning treatment and analysis of particular materials, will be presented along the way. The empirical matters analysed in the respective chapters have been vital to develop my arguments, but they do not aspire to produce generalizable truths or anything of the sort. The material will consist of historical and contemporary policy texts, scientific works, and philosophical arguments, but also of, all in all, 40 interviews with support workers, bureaucrats, and disability activists and advocates, both with and without intellectual disability. The interviews have been conducted over a timespan of six years and will be presented further as they appear throughout the book.

Lastly, I want to say a few things about the diversity of topics in this book. As is clear, answering the question of how we should understand intellectual disability politics requires that I engage with a wide range of

sources and examples. Rather than a systematised selection of well-defined materials or anything of the sort, the theoretical arguments will be the glue that holds this book together. I do believe that the diversity and range of issues serves a purpose, not of covering everything, but of setting free the potential for theory to surprise us when confronted with concrete instances of how particular groups are understood and managed. This means that the value of the study is bound up with the interpretations I will offer, their novelty and their capacity to spark new and fruitful ways of comprehending intellectual disability politics. It goes without saying that other theoretical perspectives would have enabled different interpretations which may have been just as useful.

### *On research ethics*

Finally, I want to offer up a few notes concerning the ethical considerations that have guided this work. First, it should be noted that this book stems from my background working within disability services, as a street-level support worker, then for a brief period as a bureaucrat and evaluator. Along the way, I have come to know many people labelled 'intellectually disabled'. My experiences have caused a great sense of personal distress revolving around the (discursive) border which separated me from the people with intellectual disabilities that I met. What does it mean to provide support for these people? What makes my outlook on things appear to be more valuable than theirs in most contexts? How are we controlling members of this group and how am I complicit? In a sense, this book is an attempt to find a language to make sense of these experiences. Hence, my personal biography is ingrained in this book in the sense that I need to be able to articulate what contemporary disability services are about. In the search for such a vocabulary, I have followed and supported the self-advocacy movement, even before embarking on this project. Although I have not always agreed on everything with the activists I have met, I share their urge for finding a way of organizing society where divisions between 'able' and 'disabled' function differently (or are dismantled).

Secondly, in defining the problem this book sets out to tackle, a central ethical stance is conspicuous: my primary interest is not how people with intellectual disabilities view the world, what is in their best interest, or how they function, but how the condition is constructed and governed. Again, I do not wish to consolidate the appearance of the natural existence of this group, but to enable our critical capacities by denaturalising it. Indeed, it appears to me that projects that seek to represent intellectual disability or the interests of

individuals labelled as such not only have a tendency to slate over considerable differences within the group, but also assign themselves the role of speaking *for* people with this condition in a way that rests on an implicit and deeply problematic hierarchy. In light of the historical treatment of people with intellectual disabilities, I believe that it is imperative that disability research does not make itself complicit in that. Similar to Carey's (2009) approach, the point here is to create a space for politicisation, a space from which people with intellectual disabilities can speak, and to do this (and here ends the similarities with Carey) by uprooting presumed assumptions about the inherent deficiencies of the group's members. In Chapter 8, issues concerning representation, privilege, and speaking on behalf of people with intellectual disabilities will be thoroughly handled as they relate to strategies of resistance.

To turn to the less abstract dimension of research ethics, it goes without saying that some material gathered is sensitive and may present risks for people interviewed or referred to in interviews. This can be so for support workers, but even more for people with intellectual disabilities. Hence, all support workers quoted or referred to are made anonymous so that they cannot be identified, even by persons with considerable insight into the specific services examined. For the interviews with political activists with intellectual disability, I have been granted ethical approval by the Swedish Board of Research Ethics, which, in turn, requires that I refrain from using their real names. The persons active in Swedish disability organizations who have been interviewed in the last chapter of the book, however, appear with their real names as they are (or have been) official spokespersons for their respective organizations.

Throughout the book, I have tried to use the language prescribed by organizations of disabled people. However, it goes without saying that different organizations and activists prefer different ways of denoting 'intellectual disability' and 'intellectually disabled people'/'people with intellectual disabilities', which perhaps should make us suspicious towards the idea that there is a 'correct' way of speaking about this diagnosis or that people with this condition can provide the answers to such questions. Historical references to intellectual disability which, today, appear to be derogatory will be analysed against the background of their emergence, marked by quotation marks to indicate that they are not a part of my preferred vocabulary. Still, I have probably expressed myself in ways that, not least with the benefit of hindsight, will appear as offensive and ill-advised. For that

I can only apologise in advance. After all, as all writing, mine is a product of its historical and social settings.



# *Part I: Pathology*

‘But I don’t want to go around mad people,’ Alice remarked.

‘Oh, you can’t help that,’ said the Cat: ‘we’re all mad here. I’m mad. You’re mad.’

‘How do you know I’m mad?’ Said Alice.

‘You must be,’ said the Cat, ‘or you wouldn’t have come here.’

Alice didn’t think that proved it at all; however, she went on. ‘And how do you know that you’re mad?’

‘To begin with,’ said the Cat, ‘a dog’s not mad. You grant that?’

‘I suppose so,’ said Alice.

‘Well, then,’ the Cat went on, ‘you see a dog growls when it’s angry, and wags its tail when it’s pleased. Now *I* growl when I’m pleased, and wag my tail when I’m angry. Therefore I’m mad.’

LEWIS CARROLL

*Alice’s Adventures in Wonderland*

The judges of normality are present everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the ‘social-worker’ judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behaviors, his attitudes, his achievements.

MICHEL FOUCAULT

*Discipline and Punish: The Birth of the Prison*

# 1. Classification

This and the coming two chapters focus on how ‘intellectual disability’ is constituted as an object of knowledge for government purposes, that is, how questions concerning what this condition is are answered by medical and psychological science and how the answers provided are integral to the government of the group. Classification offers the most obvious answer to the question of what intellectual disability is. The diagnosis is constructed by criteria of intellectual functioning and behaviour, originally emerging together with the invention of psychometric measurement instruments early in the 20<sup>th</sup> century, and since then, evolving to produce the definition of intellectual disability that we have today. Throughout its history, classification has been of vast importance by demarcating who needs to be targeted by public policy. Thereby, classification systems are integrated into the organization of disability politics and are necessary to understand in order to make sense of post-institutionalisation.

This is far from the first account seeking to lay bare the social and political dimensions of intellectual disability by analysing the history of measurement technologies and definitions (see Rapley, 2004; McClimens, 2007; Carlson, 2010; Sleeter, 2010; Goodey, 2011; Simpson, 2012). Those histories may focus on schooling (Axelsson, 2007; Sleeter, 2010), the emergence and development of psychology as an academic discipline (Rose, 1985; Rapley, 2004), eugenic concerns about population degeneration (Sleeter, 2010), or on the philosophical and theological background of early classification (Goodey, 2011). I have, myself, published work on the underlying logics of present classificatory practices (Altermark, 2015). This chapter reads as an addition to this literature, where I analyse how historical continuities and discontinuities in definitions impose limits concerning what becomes possible to think and know about the group (see Carlson, 2010:17). The account of classification that I offer differs from the above examinations in that it uses Foucault’s biopolitics as the starting point to discuss the relationship between knowledge and government.

In addition to secondary literature on the history of classification, the analysis draws on three principle sources of material. The first consists of the dominating classification systems. The second is composed of historical accounts of what we today call intellectual disability. I specifically focus on the period from 1850 and roughly three quarters of a century onwards as this covers when the condition came into being. Lastly, in this and the next chapter, I will continuously refer to what I call the ‘clinical literature’ on intellectual disability. This denotes psychiatric, psychological and medical depictions of the condition, written for professionals and students, and primarily published in or as textbooks and reference books. This material provides a general depiction of the agreed upon state of knowledge concerning what intellectual disability is. The books most thoroughly engaged with are Emerson et al’s (eds.) (2004) *Applied Research in Intellectual Disabilities*, Bennett’s (2006) *Abnormal and Clinical Psychology: An Introductory Textbook*, Harris’s widely cited (2006) *Intellectual Disability: Understanding its Development, Causes, Classification, Evaluation and Treatment*, Carr et al’s (eds.) (2007) edited collection *The Handbook of Intellectual Disability and Clinical Psychology Practice*, Jacobson et al’s (eds.) (2007) *Handbook of Intellectual and Developmental Disabilities*, Kring et al’s (eds.) (2007) textbook *Abnormal Psychology*, and Odom et al’s (eds.) (2007) *Handbook of Developmental Disabilities*. Note that Odom et al, Emerson et al, and Carr et al, all combine social scientific and clinical contributions, where I have only focused on the latter. Bennett as well as Kring et al, on the other hand, are preoccupied with ‘abnormal’ psychology, in general, and in these two cases I have solely focused on the sections related to intellectual disability.

## **Intellectual Disability and Classification**

Intellectual disability is popularly understood as a condition of deficient cognitive functioning, which, in turn, has extensive effects on the living conditions of the individuals labelled so (Bennett, 2006:341-345; Harris, 2006:3-5; Carr & O’Reilly, 2007a:17-27). By this view, the objective of disability politics will be related to the social arrangements affecting the lives of those diagnosed, as through, for example, care organizations, group home living, and sheltered employment, whilst the condition as such is rendered outside the scope of politics. This means that intellectual disability is conceptualised as prior to social organization. As I will elaborate upon in the

following, this way of making sense of the relationship between diagnosis and politics neglects how governmental concerns, from the outset, have been integrated into classificatory practices. Rather than a biological condition that politics answer to, I will argue that intellectual disability is a political construction that classification seeks to dress up as a neutral and natural fact about certain people.

I want to start here by some general propositions regarding the past and present definitions of intellectual disability. Historically, the classification of this condition has gone through a series of revisions, as concerns their terminology and as concerns their criteria (see Harris, 2006:3; AAIDD, 2010:8-9). Presently, all globally used classification systems define intellectual disability as the concurrent featuring of intellectual and adaptive behaviour deficits that can be scientifically measured and which appear during the developmental period of life. Although classificatory systems have undergone repeated revisions, the coupling of psychometrically deficient intelligence and behavioural problems has been a prevailing foundation of how intellectual disability is understood. Currently, three classificatory definitions are globally used: the ICD-10 and ICF of WHO, the DSM-V of the American Psychology Association (APA) and the classification of the American Association of Intellectual and Developmental Disabilities (hereafter: the AAIDD-system) (Harris, 2006:46). Although, these systems vary in focus (ICD-10 classifies diseases, DSM-V psychiatric conditions, and the AAIDD intellectual disabilities, specifically) they all overlap in how they answer the basic questions regarding what intellectual disability is (Carr & O'Reilly, 2007:9)<sup>1</sup>.

To exemplify what a definition can look like, consider the current ICD definition of 'mental retardation' (which is understood as synonymous with 'intellectual disability'):

Mental retardation [intellectual disability] is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, contributing to the overall level of intelligence, i.e., cognitive, motor, and social abilities. (ICD-10, 1996:1)

In turn, this definition is expressed by the bellow diagnostic criteria:

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<sup>1</sup> Many clinical accounts favour multi-axial classification that allows for taking social services, family setting, health conditions, and so on, into account. All of the systems here analysed offers such possibilities. I will discuss the implications of the incorporation of social factors into classification in Chapter 3.

For a definite diagnosis of mental retardation [intellectual disability] there should be a (A) reduced level of intellectual functioning in (B) diminished ability to adapt to the daily demands of the normal social environment. The assessment of intellectual level should be based on clinical observation, standardized ratings of adaptive behaviour and psychometric test performance. (Carr & O'Reilly, 2007a:7)

The newly released DSM-V (2013) downplays intelligence on behalf of adaptive behaviour and has discarded IQ as an explicit criterion, however, IQ-testing remains integral to the suggested classificatory toolbox in the new diagnostic manual also in this classification system (APA, 2013). Hence, the criteria for intellectual disability are today universally operationalised as an IQ-score below 70 (often accounting for standard margins of error), significant limitations in adaptive behaviour estimated by clinical professionals, and manifestations of these symptoms before adulthood or 18 years of age. Also the classificatory recommendations of AAIDD (2010:28) relies on these criteria, although this system includes a slightly different conception of 'adaptive behaviour' (AAIDD, 2010:79)<sup>2</sup>.

This understanding of intellectual disability implies that there is no single cause or prognosis covering all diagnosed individuals. Thus, 'intellectual disability' covers inherited syndromes, traumatic injuries, and more than 1 000 genetic conditions that have been associated with the condition (Tartaglia, et al, 2007:98). Still, in a majority of people diagnosed, no known biological explanations exist (Bennett, 2007:343; McDermott et al, 2007:9)<sup>3</sup>. Moreover, it is maintained that genetic, medical, psychological, and environmental factors all contribute to determine the level of cognitive impairment (Bennett, 2006:343), that many malfunctions can conjoin in one individual, and, furthermore, that cognitive limitations are often added to by perceptual and motor impairments (Harris, 2006:12; McDermott et al, 2007:3). Despite the heterogeneity of sub-diagnoses and differences as concerns functioning and service needs contained within the category of 'intellectual disability', it is important to note that the condition is still seen

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<sup>2</sup> In the 1992 edition of the AAIDD-system (then called AAMR), focus was shifted towards 'levels of support' as the central classificatory feature. This, however, did not change classificatory criteria (see Borkowski et al, 2007:261).

<sup>3</sup> Here, there is a range of numbers in the literature, spanning between one fourth and one half of those with intellectual disabilities. This depends on when the account was published (as an increasing number of biological correlates are described in the literature) and as concerns whether the statement is made of intellectual disability/mental retardation' or 'learning disabilities'.

as a specific way to be in the world, entitling to specific services and associated with certain problems. Understanding intellectual disability as biopolitics means understanding how intellectual disability was consolidated as a singular class of human being and what governmental purposes this serves.

## **Psychometrics**

Throughout the 20<sup>th</sup> century, the classification of intellectual disability has followed two conjoined trajectories: the quantitative measurement of intelligence by psychometric testing and qualitative judgements of behaviour (see Simpson, 2012). In conjunction, these have come to constitute intellectual disability as an object of knowledge, which is to say, as a group that can be separated from the rest of the population, which is defined by certain characteristics, and which can be targeted by certain technologies of government. We shall start by examining the quantitative path of this history, beginning with clarifying a few things about how intelligence is understood.

### *The ontology of intelligence*

The introduction of intelligence testing during the early 20<sup>th</sup> century considerably changed understandings of mental deficits (Goodey, 2011:1). First, these changes involved making possible a clear-cut distinction between physical and mental impairments which had previously been blurred, and second by differentiating mental deficits from mental illnesses (Goodey & Stainton, 2001:225; Carlson, 2010:24). Furthermore, psychometrics introduced scientific rigour as an overriding ideal. As is suggested by Jenkins (1999:17 in Rapley, 2004:32), throughout the 20<sup>th</sup> century the statistical plotting of normal curve distributed intelligence has been a primary tool of defining intellectual deficiency. An important reason for its success was the appearance that IQ presented accurate and objective representations of naturally existing phenomena. Hence, the dawn of IQ-testing exemplifies what Canguilhem (1991:47-8) analyses as a shift from a qualitative to a quantitative conception of sickness and abnormality, where pathological phenomena went from being seen as differences of sorts to measureable

variations which could be plotted around a statistical norm (see Vailly, 2008:2532)<sup>4</sup>.

The dominating conception of 'intelligence' of today can be exemplified by Harris' (2006:99) statement that 'intellect' refers to 'the power of thought', distinguishable from perceptions and emotions. This is congruent with Jensen's (1998:336 in Rapley, 2004:36) description of intellectual disability as a 'thinking disability'. In this way, intelligence is understood as the capability of understanding and solving problems (Harris, 2006:99) or, as stated by the AAIDD (2010:15) clinical guidebook:

*Intelligence* is a general mental ability. It includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience [...]. As reflected in this definition, intelligence is not merely book learning, a narrow academic skill, or test-taking smarts. Rather, it reflects a broader and deeper capacity for comprehending our surroundings – catching on, making sense of things, or figuring out what to do.

By psychometrics, intelligence is measured by the administration of IQ-tests and statistical analysis, deducing from test answers a theoretical model of the capabilities used when solving mental tasks (O'Reilly & Carr, 2007:97). Charles Spearman is strongly associated with this conception of intelligence (O'Reilly & Carr, 2007:97-8), advocating the idea that there is an underlying factor explaining correlations between performances in all sorts of cognitive tasks. He has termed this element of our minds the 'g-factor' ('g' for 'general'). The g-factor explains why individuals tend to perform on the same level within different types of mental undertakings. It is seen as psychologically rooted, and hence differing between individuals. Notably, this means that intelligence is conceptualised as having an independent ontological existence, irrespectively of how it is measured. Although the conception of 'g' has been much debated within psychology (see O'Reilly & Carr, 2007:102-13), testing for intellectual disability is still underpinned by the idea that 'intelligence' is a single and more or less static characteristic residing in an individual's mind (see Borowski et al, 2007:267, 273).

There are a number of more or less acknowledged problems concerning the reliance on intelligence testing in definitions and classificatory practice of intellectual disability. First, psychometric tests differ in how they measure

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<sup>4</sup> As we shall see in the next chapter, this shift from qualitative to quantitative was never completed when it comes to intellectual disability, where the condition is still perceived both as a difference of sorts and as quantitative in nature.

and conceptualise intelligence and this can explain why it has been shown that IQ-test results vary depending on the IQ-test taken (see AAIDD, 2010:40). Similarly, it has been noted that in certain tests, ‘nonstable’ discrepancies occur between ‘potential’ and actual achievement (Borowski et al, 2007:266). Another cause for concern for proponents of the accuracy and real-world existence of IQ is the so-called ‘Flynn-effect’, denoting that average IQ-scores within any population increase over time. In effect, this means that the number of individuals meeting the ‘below IQ 70’-criteria for being intellectually disabled gradually decreases until tests are re-normed (see O’Reilly & Carr, 2007:126-127). This means that the timing of testing has an effect on how large a share of the population will meet the criteria for intellectual disability<sup>5</sup>. Consequently, both the choice of test and the timing might influence whether one becomes classified as ‘intellectually disabled’ or not.<sup>6</sup>

This may seem to raise serious questions concerning the persistence of the use of IQ-tests. However, as I will argue, the motivation behind psychometric testing and the role it plays in definitions of intellectual disability has less to do with its real world significance or the accuracy of measurements, than with its actual usefulness for politics. We do not label individuals with their IQ-scores because we think it is a valid and appropriate way of describing individual functioning, but because it is an efficient way of specifying a section of the population that is perceived as requiring governmental responses. To better understand this, we need to understand how psychometrics first emerged as a way of demarcating elements of the population that were thought of as disturbing social order and threatening the quality of the citizenry.

#### *Psychometric histories of government*

As Goodey (2011:1) notes, the idea that ‘intelligence’ is a defining characteristic of humanity is distinctively modern, combining a strong belief in the capacity of science to make the world measureable with the hallmarks of modern philosophical conceptions of humans as mastering the world by

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<sup>5</sup> On this issue, the clinical literature, with a few exceptions (see O’Reilly & Carr, 2007:120-8), testifies to a peculiar kind of well-informed ignorance: although the Flynn-effect is well known, and mentioned in a majority of the books analysed, its implications for intellectual disability is only rarely spelled out.

<sup>6</sup> To say something of the stakes involved: it is worth noting that in some American states, this has implications for whether an individual may face the death penalty or not.

reason. From our current historical location, we can easily recognise the normative investments made in historical ways of naming and speaking of intellectual disability, but we are less inclined to see the path-dependency of the condition and the continuities of how it is specified. In order to understand the linking together of measurements of deviancy, humanist ideals of reason, and social anxieties concerning people seen as intellectually deficient, it is necessary to return to when diagnoses of intellectual deficiencies first appeared.

During the first decades of the 20<sup>th</sup> century, a distinctively new understanding of deficient intelligence began to seduce social policy makers and scientists studying the human mind. From the 1820s onwards, western states had begun to amass statistics on various forms of human deviancy (Hacking, 1986:161). Over the course of the second half of the 19<sup>th</sup> century, there was an explosion of interest on deviancies of the intellect. Since any notion of intellectual deficiency presupposes a conception of what intelligence is – a norm and standard that people are deficient in relation to – the constitution of ‘mental deficiency’ must be understood against the background of the then prevailing conceptions of ‘intelligence’. During the second half of the 19<sup>th</sup> century, intellect was widely referred to as the capacity to ‘adjust’ to different situations and to do so by means of ‘reason’ (see Axelsson, 2007:223), an idea which still remains integral to our present-day conceptions. The idea has a clear origin in Enlightenment conceptions of humans as defined by reason, which, for example, can be seen in how Paton (1905:29)<sup>7</sup> argued that the adult human mind is characterised by the ability to rise above sensations and emotions to produce detached thinking governed by rationality. Here, Paton echoes Kant’s self-governing subject, capable of taming their emotions by laws of reason, which influenced a number of early thinkers on ‘normal’ and ‘deficient’ intelligence (see Goodey, 2011:210). Another prominent figure of Enlightenment thinking who influenced early conceptions of intelligence was John Locke, whose notion of a strictly intellectual disability, differentiated from insanity and lunacy, recurs in the literature at the time (see Brady, 1865:6; Harris, 2006:140; Goodey, 2011:12, 246). Consequently, the growing concerns of ‘mental deficiency’ came to echo Locke’s philosophical efforts to differentiate ‘normal’ humans, characterised by faculties of reason, and groups (such as ‘changelings’ and

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<sup>7</sup> A majority of the books from 1800-1930 are accessed through the digitalised collections of the Wellcome Library ([wellcomelibrary.org](http://wellcomelibrary.org)).

‘idiots’) that lacked this characteristic (Locke’s arguments will be thoroughly dealt with in Chapter 4) (see Goodey, 2011:313-5; Clifford Simpican, 2015:22). Goodey’s thorough account of early classification argues that Locke’s conception of human beings as defined by reason was absolutely central to how ‘deficient intelligence’ emerged as a scientific object of inquiry. Hence, prior to the breakthrough of psychometrics and its figuration of intelligence as a measureable quantity, was a general idea of the ‘normal’ rational human mind that was capable of conforming itself to various social situations, that was capable of abstract reasoning, and that governed action by rationality; it was a notion of intelligence moulded after the ideals of Enlightenment humanism. Provided the stronghold of this conception, any deficiencies became noticeable and perceived as troublesome, which is aptly captured by Clouston (1883:2):

The whole conduct of things in the world is necessarily so based on the assumption that every man is a responsible being with a sound mind, that any exception to this, when it occurs, has a very startling effect.

This notion of what defines humans, was, of course, pivotal to perceptions of the relationship between the individual and the state, that is, to the idea of ‘the citizen’. The well-ordered society needed a citizenry composed of self-restrained and autonomous individuals guided by reason, as Herbert Spencer (1890 in Axelsson, 2007:48) – one of the originators of psychometrics – argued. As a result, an important aspect of the citizenship making of Western states became the targeting of individuals seen as unable to meet the overarching objective of a self-ruling citizenry (see Axelsson, 2007). Howe’s (1858:vi) statement that such people lack ‘the light of human reason’ would become repeated throughout the coming decades in efforts to separate people who failed to meet the Lockean and Kantian ideas of what characterises a human being.

For people perceived as lacking proper faculties of reason, the ideology of intelligence resulted in judgements concerning their ability to fulfil civic responsibilities, seen in how Tredgold (1908:2 in Rapley, 2004:60) defined ‘mental deficiency’ as a state of ‘incomplete cerebral development’ with the result that ‘the person affected is unable to perform his duties as a member of society in the position of life to which he is born’. ‘Intelligence’ thus functioned as something more than a description of an individual characteristic; it was also a normative yardstick linked to ideals of citizenship and the defining characteristics of humanity. In this way, the linkages between a philosophical ideal-subject, citizenship, and scientific conceptions of intelligence, were of

the utmost importance, as they envisioned the ‘mentally deficient’ person as an alien and abject outsider. During the first decades of the 20<sup>th</sup> century, numerous societal problems and threats were linked to people of deficient intelligence. In their preface to the popular summary of the Royal Commission of the Care and Control of the Feeble-minded (preceding the UK Mental Deficiency Act of 1913), Darwin et al (1909) stated that people of deficient mental powers were ‘unhappy in themselves, a sorrow and burden to their families, and a growing source of expense and danger to the community’. In a similar way, Henderson (1901:180-1) proposed that ‘the evils of feeble-mindedness’ constituted a ‘perpetual source of danger and injury’. In this way, poverty, criminality, and social unrest could all be understood in light of mental degradation and deficient intelligence (see Henderson, 1901; Webb & Webb, 1912; the Mental Deficiency Act, 1913; Kelyack, 1915). By that, managing the ‘mentally deficient’ became a question of ensuring the social order (see Binet & Simon, 1914:10). In this respect, a special problem concerned people of ‘deficient intelligence’ who could easily pass as ‘normal’, not bearing any visible or physical characteristics, which meant that they risked going undetected (Binet & Simon, 1914: vi; Galton, 1914 in Penrose, 1954:11). Henderson (1901) argued that such individuals of a ‘feeble and distorted nature’ were bent towards anti-social conduct (252), that they were particularly pliable to temptation and distress (252), and that when persons of this group were surrounded by a vicious environment, they were apt to develop a craving for stimulants arousing ‘the beast within’ (253).

In this way, ‘intelligence’ facilitated a linking together of certain social anxieties with a specific class of individuals seen as lacking human reason (see Walmsley, 2005:51). At the same time, ideas concerning the hereditary nature of mental deficits and the increasing biologisation of how the mind was interpreted put the quality of the population at stake, leading Darwin et al (1909) to declare that the procreation of such people ‘threatens the race with progressive deterioration’. For Henderson (1901:22), this created a need to find ‘methods by which the suffered [of dependency] may be mercifully cared for without being permitted to injure the quality of the race hereafter’ (22). Eugenics would emerge as the most obvious expression of how concerns of the quality of the citizenry and the hereditary nature of deficient intelligence were linked together, as is expressed by Kelyack (1915:vi-vii):

The nation is awake to the urgent necessity for securing the conservation of its children. Every form of defectiveness must be reduced to its minimum, and all varieties of preventible disorder must be dealt with by effective agencies, if we are to provide healthy citizens for coming days.

Note how the quote alludes to a sense of urgency seen as concerning all members of the community. Provided these sentiments, and at roughly the same time, the countries in Northern Europe and America created laws and policies aiming to separate, educate, and prevent from mating, the mentally deficient (see Stiker, 1999:127-30, 155-6; Walmsley, 2005:52; Grunewald, 2008:68-73, 107-9). These laws were closely connected to psychiatric and psychological accounts of the time, wherein the scientific description of deficiency and the urgency of intervention appeared to be intertwined (see Henderson, 1901). Davey's introduction and commentary to the UK Mental Deficiency Act is illuminating in this respect:

Of the Gravity of the present state of things, there is no doubt. The mass of facts that we have collected, the statements of our witnesses, and our own personal visits and investigations compel the conclusion that there are numbers of mentally defective persons whose training is neglected, over whom no sufficient control is exercised, and whose wayward and irresponsible lives are productive of crime and misery, of much injury and mischief to themselves and others, and of much continuous expenditure wasteful to the community and to individual families. (Davey, 1914:2)

This obviously called for action, as Davey comments:

[there is a need to] create a system by which these mentally defective persons could, at an early age, be brought into touch with some friendly authority, trained and, as far as need be, supervised during their lives (Davey, 1914:3).

This, however, raised new problems regarding how government could efficiently pinpoint these individuals to direct necessary interventions. The necessity of knowledge of the group in order to govern them is clearly expressed in a grounding principle of the 1913 UK Mental Deficiency Act itself:

Our third principle is that if the mentally defective are to be properly considered and protected as such, it is necessary to ascertain who they are and where they are, and to bring them into relation with the local authority. This should, we think, be done chiefly through the agency of the education authority and other public or *quasi*-public authorities without any undue invasion of the privacy of the family (in Davey, 1914:6, italics in original)

As such, this aptly captures Foucault's proposition of biopolitics: in order to govern the population, the population needs to be known. And it was provided this background that IQ-testing and psychometrics rose to

prominence (see Axelsson, 2007:58; Hansson, 2007:63; Carlson, 2010:47). The French psychologist Alfred Binet invented the first IQ-test to help the Parisian school board decide which children needed special schooling (Borkowski et al, 2007:262; Kring et al, 2007:84). The method quickly spread throughout Europe and over the Atlantic. Previously, estimating cognitive capabilities had been a difficult and time-consuming process, complicated by the fact that some people were considered 'mentally deficient' without any visible or physical characteristics. Psychometrics provided a fitting response to these problems, conceptualising intelligence as an invisible characteristic, residing *within* rather than on the surface of the individual; a feature of the interior landscape that became possible to detect with mass-administered tests designed to capture the mystical entity known as 'intelligence'. IQ-testing also arrived with the promise of solving the problem of the group falling precisely below the 'normal range' whose appearance did not reveal obvious signs of malfunction. Terman (1916), who would translate and adopt the Binet-Simon test for American conditions (still known as the Stanford-Binet test) described the potential benefits:

It is safe to presume that within the reasonably near future intelligence tests will bring tens of thousands of these high grade cases under surveillance and protection of society. This will ultimately result in curtailing the reproduction of feeble-mindedness and in the elimination of a vast amount of crime, pauperism and industrial inefficiency.

In this way, the early proponents of intelligence testing described it as a tool to discern mental deficiencies, imitating in their measurement of minds the mathematical precision of how engineers measured the physical world (Danforth, 2002:53 in Rapley, 2004:16). In the US as well as in Europe, the task of identifying and separating affected children from the rest of the population often fell upon the emergent mandatory school systems (Axelsson, 2007:50). After sorting out the individuals belonging to this group, the separation and training of its members became the responsibility of a growing number of special institutions. In the emerging knowledge regime of 'mental deficiency' that arose during the first half of the 20<sup>th</sup> century, the scientific discipline of psychology would come to play an important role, as Rose (1999 in Rapley, 2004:12-3) argues, bound up with the promise of solving 'social problems'. As such, the interconnectedness of societal normativity, state institutions, governmental concerns, and scientific knowledge, came to constitute a central instance of biopolitics.

Before turning to present conceptions of intellectual disability, I want to make a last theoretical point as regards the relationship between ‘norm’ and ‘deviancy’ at the time intellectual disability came into being. As is explicitly indicated by several of the early thinkers of cognitive impairment who have been quoted here, conceptions of normalcy and cognitive deviancy are interlinked (see also Henderson, 1901; Mercier, 1905):

The preceding description of mind will apply to Minds of all kinds. It is therefore necessary to investigate the characteristics special to the feeble mind and this can only be done by erecting a standard of the normal mind for purposes of comparison. (Sherlock, 1911:70)

Since every community consists of individuals varying very greatly in the extent of their mental development, it is necessary to explain what is meant by “normal,” and to state what is the criterion adopted to differentiate the normal from the mentally defective. (Tredgold et al, 1912:66)

Hence, the construction of the ‘normal’ mind is imperative for the differentiation of the ‘feeble’ mind and the separation of ‘mental deficiency’ is necessary to uphold the norm of human reason. This is the relationship between inside and outside, between norm and deviancy, mutually constitutive and hence only meaningful in relation to each other. Psychometrics was bound up with the promise of doing the sorting, or reducing uncertainty as concerns which category people belonged to. In this way, psychometrics exemplifies a way of *constituting* what it presents itself as, *describing* by reference to a prior norm of how human beings *should* function. To speak with Butler (1993:xiii), this is an example of the constitutive force of normativity, where an ideal of human reason simultaneously institutes an outside threat which must be known, controlled, and handled.

In summary, the importance of psychometrics during the first decades of the 20<sup>th</sup> century can be explained by its capacity to pinpoint individuals already seen as problematic and as requiring governmental management; it was a tool of rule as much as a tool of science. By psychometric knowledge, IQ was linked to how citizens understood their rights and duties and thereby became instrumental to a functioning public (Zenderland, 2001 in Axelsson, 2007:60), at the same time both an expression and a reinforcement of societal norms concerning which capacities characterise humanity. As Clifford Simplican (2015:22, 50) notes, the philosophical construction of a subject of deliberation and self-management was incorporated by early psychology and psychiatry in order to lend credence to their scientific mapping of deviancy,

which, on the other hand, provided tools that could be used to govern. And in this way, I argue that classification came to embody the normativity of the humanist subject.

### *The IQ-criterion*

Of course, the above is not mere history, but historicity as a method of denaturalising present knowledge. As Hacking (2007:299) notes, when we ascertain that a certain kind of person exists across time and space, it seems to lend credibility to the seriousness and reality of the category in question. On the other hand, when we recognise that the invention of ‘mental deficiency’ was moulded after a specific configuration of the subject, arguably pervasive to Enlightenment and modernity, that it was linked to a specific set of governmental concerns, and that it arose with the invention of specific measurement technologies at a particular point in history, we are provided with the tools to acknowledge the contingencies of the category. Furthermore, the history of intelligence testing is inscribed into contemporary understandings of intellectual disability, as regards the continuity of what kinds of instruments are used to detect the condition and concerning their underlying normativity. Through the shifts in classificatory criteria, lay-conceptions, and psychological theorisations, what has remained constant to the notion of ‘intelligence’ is the fact that it has been the outcome of a historically contingent social consensus concerning what is ‘normal’ and what is ‘abnormal’, as Goodey (2011:1) expresses it. To better understand this, we shall now turn to a more detailed engagement with the two classificatory criteria of intellectual disability, starting with IQ.

The mutually constitutive relationship between ‘norm’ and ‘deviancy’ is a discursive feature which also permeates present conceptions of intellectual disability: just like before, today’s clinical depictions often define intellectual disability by comparing it to the development of ‘normal’ individuals (Carr & O’Reilly, 2007b:71). This normalcy, furthermore, seems to be moulded after very similar ideas of adaptability and self-regulation which were integral to the first modern conceptions of intelligence. Note, for example, how Borowski et al (2007:271-3) proposes that the defining characteristic of people in this group is their lack of ‘self-regulation’, denoting processes of monitoring one’s own learning and development, and being able to consciously oversee and control one’s behaviour. In a similar way, Carr & O’Reilly (2007b:74) refer to an intellectually disabled ‘personality profile’ which is characterised by a lack of motivation to learn new skills due to a lack of self-control. As it appears, there is an important linkage here to the

idea of ‘adaptability’ as conceived of in 19<sup>th</sup> century conceptions of ‘intelligence’ and further back to the philosophical notions of a subject of reason. However, it is not only the underlying conception of intelligence which has persisted to the present: granted that two of the three major classification systems still use IQ in their classificatory recommendations, and provided that IQ has been foundational to the diagnosis since its emergence, a more detailed examination of contemporary psychometric testing is here called for.

First, IQ is not and has never been a straightforward measurement of intelligence, but of each individual’s intelligence *compared to the rest of the population*. IQ-scales are normed and tests constructed so that the average member of the population (that the specific test is constructed for) has an IQ of 100 (Hacking, 2007:316). This follows the outline of Galton’s groundbreaking application of normal distribution to individual psychological features, with the consequence that IQ-tests do not measure intelligence in absolute terms, but in relation to a statistical norm. Following Jenkins (1999:17 in Rapley, 2004:32), this suggests that the present understanding of ‘intellectual disability’ cannot exist before the invention of normal distribution. What is also reflected here, by the relative nature of IQ, is that the notion of ‘ability’ can only be known in relation to certain others (Goodley, 2014: xii); first in the sense that it needs external points of reference to be graded, and second in the sense that it requires an external viewpoint from which it can be measured.

Now, placing the cut-off point at an IQ of 70 designates two standard deviations below average, which means that 2.27 % of any population assumed falls under the bar if the test is correctly constructed and intelligence is normally distributed. Following these assumptions, the 2.27 % of any population performing worst on tests will meet the IQ-criterion for intellectual disability. Consequently, this placement of the cut-off precludes the possibility that more than about 1-3 % of the population is intellectually disabled (see Carr & O’Reilly, 2007a:29). This means that there are no necessary linkages between IQ-testing and the biology of cognitive functioning, precisely because IQ is a statistical measurement that only makes sense relative to the population that the test is constructed for. The inventors of the first IQ-test, Binet and Simon (in Carlson, 2010:49), noted this:

Our purpose it to be able to measure the intellectual capacity of a child who is brought to us in order to know whether he is normal or retarded. We should therefore, study his condition at the time and that only. We have nothing to do either with his past history or with his future; consequently we shall neglect his etiology.

Of course, as we will get back to, this seemingly contradicts the view that intellectual disability can be localised in the biophysical properties of the brain. However, IQ-testing soon became inextricably bound to hereditary explanations of 'feeble-mindedness', despite the intentions of Binet and Simon (Carlson, 2010:49). In some present psychiatric and psychological works, it is maintained that IQ is not normally distributed since there is a 'genetic hump' at the lower end of the bell-shaped curve caused by biological pathogens such as genetic disorders and prenatal damage (Bennett, 2006:343; Harris, 2006:80; McDermott et al, 2007:6). This means that among those with an IQ under 70 there are individuals with IQ scores that can be attributed to the 'genetic bump' and individuals whose IQ scores can be attributed to normal distribution. However, a known condition associated with intellectual disability does not always guarantee a specific IQ-range: you can, for example, have Down's syndrome but an IQ higher than 70 and you can have an IQ below 70 without an associated syndrome (see McDermott et al, 2007:9).

The lack of pathogens appearing precisely at an IQ of 70 begs the question why the cut-off point should be placed at this particular point. In retrospect, this placement has been interpreted as stemming from a general impression that 2-3 % of the population are intellectually disabled judging from their 'real world behaviour' (O'Reilly & Carr, 2007:126), which is to say that it is based on a judgement of what kind of behaviour passes as acceptable. Interestingly, the originator of the IQ 70 cut-off point, the psychologist David Wechsler, provided no references or guidance to any clinical studies justifying why he chose the IQ 70 yardstick when it first emerged in a 1944 article (quoted in Flynn & Widaman, 2008). In his treatment on the nature of intellectual disability, he oscillates between regarding mental deficits as quantitative and qualitative in nature. Like 'genius', he states, cognitive deficiencies are a question of difference in degree (Wechsler, 1952:133). However, as mental capacity falls below certain thresholds, it will result in behaviours that appear to be qualitatively different. The below quote follows this template:

they actually “look” and “act” differently’. And these differences in “looks” and “behaviour” can be explained by assuming that human intelligence when passing certain points takes on new configurations which for phenomenological reasons we find it convenient to recognize as different totalities. (Wechsler, 133-4)

Thus, the qualitative difference between intellectual disability and normalcy, and the underlying rationale for the placement of the IQ cut-off point, appears to be ‘convenience’ and the ‘appearance’ of a difference of sorts. To support this – which, from a scientific viewpoint seems a rather suspect – argument, Wechsler states that one only needs to ask people who work with members of the group to get his view confirmed (133). On the one hand, he argues that IQ and mental age tests are as real as physical measurements, and that they detect quantitative differences of ‘mental energies’ (133). On the other hand, he states that the lack of such energies means that the individual acquires new qualitative traits that constitute differences of sorts, but that the thresholds in question cannot be compared to physical cut-offs such as the boiling point of water. His argument for the existence of such ‘critical points of achievement’ (134), assumed to exist in all human capacities, consists of vague references to how we perceive these differences as qualitative. As it stands, it appears that the justification for the placement of the cut-off consists of little more than the gut feeling of its originator and the subsequent consensus formed in the scientific community. As Carlson (2010:28-33) argues, the blurred boundaries between quantitative and qualitative differences that we can witness here have characterised intellectual disability from the outset, for example, seen in how we measure intelligence quantitatively today, but maintain that people with this condition can be qualitatively distinguished on merits of biological causes. We shall return to this in the next chapter.

Justifications of the placement of the cut-off point are notably scarce in the contemporary clinical literature, as well (see Bennett, 2006:343; Harris, 2006; O’Reilly & Carr, 2007). However, before the designation of the cut-off point, and given the lack of identifiable pathogens appearing precisely here, a prior recognition concerning who needs to be targeted must be made; we must recognise that some people behave in ways that constitute ‘pathology’ and that psychometric tests are capable of doing the sorting of them. The placement of the IQ cut-off point and the lack of justifications for it are significant with respect to the general perspective of clinical books on intellectual disability, maintaining that intellectual disability constitutes pathology and is anchored in the biology of the individuals labelled so. What this placement really exposes, however, is how judgement of behaviour is at

the core of scientifically dressed-up justifications. IQ tests did not provide new knowledge of a group already in existence; they invented a group which conformed to specific understandings of the relationship between intelligence, behaviour, and social problems.

I shall briefly mention that the clinical literature sometimes demonstrates an alliance to an understanding of intellectual disability as a socially constructed 'administrative category' (see Parmeter, 2004:13-4; Borowski et al, 2007:273; Stoneman, 2007:37), in order to, for example, allow communication about the group, to direct research, and to decide eligibility for services and benefits. Still, these authors are not disposed to acknowledge any critical questions of power and government which follow from this view. What these admissions actually expose, however, are the governmental rationalities that are ingrained in understandings of intellectual disability. Consider Harris's (2006:46) statement:

Diagnosis and classification serve many purposes. For example, the diagnosis is used for medical care, to determine eligibility for services, to designate educational programs, for research, and for legal purposes. Likewise, there are different purposes for classification, such as to organize information, to evaluate an individual, to plan research, to plan intervention, and for determination of eligibility for services.

Similarly, the AAIDD (2010:29) clinical guidebook argues:

If the diagnostic criteria are met, the diagnosis may be applied to achieve several focused purposes, including, but not limited to, establishing the presence of the disability in an individual and confirming an individual's eligibility for services, benefits, and legal protections.

Now, my argument is that the responses to disability described in this second quote, described as emerging *after* diagnosis, actually explain why intellectual disability came to exist. If we assume that intellectual disability is a natural thing which exists irrespective of its measurement, the IQ-criterion appears to be peculiar, verging on nonsensical. As soon as we approach IQ as a tool of biopolitics, however, these peculiarities disappear. From such a perspective, the perception that approximately 2-3% of the population behave in ways that call for socio-political measures is a perfectly logical starting point for psychometric measurement technologies. This may not reflect whatever intentions the inventors of intelligence testing had, or the stated objectives of those upholding the practice today, but it surely reflects the inner logic of psychometrics and why certain institutions preoccupied with

dividing up the population are lured in by the technology. The relevant question for these is not whether IQ corresponds to an external reality, but the extent to which it can help detect individuals who need to be managed.

### *Adaptive Behaviour*

Along with psychometric testing, a diagnosis of ‘intellectual disability’ also requires the presence of behavioural problems. The adaptive behaviour criterion was first included in classification in 1959 by the AAMR (today AAIDD) (Parmeter, 2004:10, 14) and became a feature of all classification systems during the latter half of the 20<sup>th</sup> century (McDermott, 2007:5). In the mid-20<sup>th</sup> century, there were concerns that the sole reliance on IQ-testing produced a too narrow measurement of deficient intelligence. The introduction of adaptive behaviour tests was an answer to this, founded on the rationale that the day-to-day functioning of the individual needed to be integrated into classificatory practices. In order to measure daily living, adaptive behaviour usually relies on information provided by parents or service providers concerning the functioning of individuals. Perhaps not surprisingly, considering the entanglement of knowledge production and government, the first adaptive behaviour tests were developed to pinpoint individual characteristics of people who were already known to be intellectually disabled; the conception of adaptive behaviour was thus moulded from the group that it subsequently has been used to detect (Borthwick-Duffy, 2007:287).

Importantly, invoked into conceptions of ‘adaptive behaviour’ is the specification that it should be measured with reference to expectations on one’s age and cultural group (ICD-10; DSM-IV; AAIDD, 2010:16). This relative component is a basic building block of how the term is made sense of, psychologically and in classification (Schalock, 2004:369, 379; Borthwick-Duffy, 2007:284). Consequently, the criterion resorts to a notion of what is considered deviant; the comparison with one’s peers, from which one could expect similar adaptive skills, essentially means that it amounts to ‘not as good at coping with situations of everyday life, when compared with others’. In much the same way as with IQ tests, the mechanism at play is relative and designed to separate those who are deemed to be worse off than others.

Although the clinical literature tends to treat ‘adaptive behaviour’ as separate from intelligence and analytically distant from the IQ-criteria, these two components used for classifying intellectual disability have a shared history. The introduction of adaptive behaviour into classificatory schemes

formalised concerns about social adjustment and appropriate behaviour which were already being heavily emphasised when mental deficiency emerged as a classificatory category (see Borthwick-Duffy, 2007:279; AAIDD, 2010:15-6). Consider, for example, Mercier's (1905:99) ideas on 'insanity' (in this context understood as encompassing intellectual deficit) as an incapability to manage oneself and one's affairs or Sattler's (1992 in Rapley, 2004:36) statement that 'Adaptive behavior refers to the effectiveness with which individuals meet the standards of personal independence and social responsibility'. In a similar way, Tredgold et al (1912:66) declared:

the standard of normality is that of capacity for independent adaptation to ordinary social requirements, and that mental defect is a state in which the individual is without this capacity save under some degree of care, supervision, and control.

Furthermore, the relative component was essential from the outset. For example, Henderson (1901:14-5) urged the analyst to account for appropriate race standards when estimating intellectual defects, suggesting that certain traits associated with the 'Negro' would be monstrous in an 'Aryan' (see Carlson, 2010:32). In parallel to how present criteria requires invoking people of similar backgrounds, Henderson leaned on a preconceived notion of 'race', illustrating that some standard must be present which takes into account the normalcy of other people, who essentially become the yardstick of measurement. We also see how the ideals of an 'independent' and 'responsible' human being provide the substance of the criterion, along the lines of ideals of humanist subjectivity. What happens with the addition of 'adaptive behaviour' to formal classificatory criteria is that, once again, this trope is made visible in the formal structure of diagnosis.

Today, and despite being a judgement on qualitative differences concerning individual behaviours, adaptive behaviour is largely measured quantitatively. Carr and O'Reilly (2007a:20-1) state that factor analysis shows adaptive behaviour falls into three categories: *conceptual skills*, which include language, literacy, numeracy skills, money skills and self-direction; *social skills* such as the capacity to make and uphold relationships, accept responsibilities appropriate one's age and ability level, the capacity to maintain an adequate level of self-esteem, the ability to recognise and follow informal rules for social interactions, and the ability to interpret social situations accurately; and lastly, *practical skills* which include activities necessary for daily living such as eating, toileting, washing, dressing, meal preparation, housekeeping, mobility, and managing the occupational

demands of work situations. Rather than undeniable signs of pathology, this reads as little more than a shortlist of things required to get by in contemporary Western societies. Nevertheless, it is presumed that adaptive behaviour exists independently of its measurement, that certain models of adaptive behaviour can be 'validated', thus indicating their real world existence, and that the disputes concerning their measurement may be resolved by improved statistical methods (Schalock, 2004:371, 376). In addition, since the actual measurement of adaptive behaviour relies on information gathered through third party respondents, the core of diagnosis is qualitative judgements in which psychologists are supposed to decide whether the answers of interviewed relatives and service providers compose deficits that constitute more than two standard deviations below average (Borthwick-Duffy, 2007:286). Interpreting the result of any such judgement as indicative of an objectively existing pathology stretches the imagination, to say the least. Thus, when Borthwick-Duffy (2007:283) calls for 'precise and objective measures of adaptive behavior', she misses the point: the very formation of this concept is premised on a prior normativity concerning which behaviours are appropriate and necessary for getting by in society.

Hence, like IQ, adaptive behaviour appears as inapt with regards to the epistemological aspirations of the clinical literature, but can be utilised as a handy instrument of biopolitics. As a complement of intelligence tests, it facilitates the creation of an overall estimation of 'personal competency' (see Schalock, 2004; Borthwick-Duffy, 2007:280), sometimes referred to as 'the essence of mental retardation [intellectual disability]' (Borthwick-Duffy, 2007:280). When considered as biopolitics, it is precisely those individuals who fail to provide for themselves, to manage their own lives, and to maintain adequacy of conduct, that a system targeting deviancy would want to identify and focus suitable interventions on. As is noted by Schalock (2004:380-1) and others, adaptive behaviour can, of course, be important for educational and other interventions, helping the individual to acquire competences to get by in present societies. Still, this does not do away with the fact that the criteria is a normatively imbued measurement of those that fail to manage life as well as their peers. I believe that my analysis shows that what is most often understood as a 'natural' condition is an offshoot from a distinctively modern obsession with mental abilities measured by IQ and a list of behavioural requisites which appear to be distinctly tied to the ideal of the modern, self-sufficient and independent, subject. In turn, the knowledge systems surrounding intellectual disability constitute a paradigm that is ultimately self-serving, upheld by professionals whose status is tied to the

content of it, and whose profession and expertise is a specialisation in intelligence and adaptive behaviour evaluations (see Hacking, 2007:297).

## **Classification and Government**

The two criteria constituting ‘intellectual disability’ are formulated so as to designate those in the general population who are worst off, as concerns performances on intelligence-tests and estimations of adaptive behaviour. However, nothing in these criteria indicates that ‘intellectual disability’ holds an ontological existence independently of how it is measured; it is there because the tests show that it is there and the tests are motivated by the prior recognition that it is there. The symptoms of intellectual disability are not indicative of anything else but themselves, which means that they effectively become the condition as such. This suggests that intellectual disability is a ‘hypothetical construct’ disguised as a ‘diagnosis of disorder’, as Rapley (2004:44) aptly formulates it.

As a result, the symptoms of intellectual disability are equated to the label itself (see Rapley, 2004:40-3.). Intellectual disability is sub-average intelligence and deficits in adaptive functioning as expressed by sub-average intelligence and adaptive functioning. This effectively turns into a loop of circularity as soon one tries to render the definition of the group explanatory. Running parallel to Rapley’s (2004:40-5) argument: how do we know that someone is intellectually disabled? We know this because they have sub-average intelligence according to IQ-tests and because they are unable to care for themselves according to behavioural measurement assessments. Then, why do they have low IQ and why are they unable to care for themselves? It is because they are intellectually disabled, which means that they have sub-average IQ and adaptive behaviour problems. And so on. In this way the label of intellectual disability explains nothing more than the criteria constituting it. Indeed, the vocabulary of ‘diagnosis’, ‘condition’ and ‘pathology’, imported into psychology from medicine, appear as little more than an exercise in dressing up judgements on socially troublesome individuals in scientific and medical language. However, what follows once the condition is formed is the creation of a body of knowledge on the condition, its characteristics, and its common traits, which direct evermore elaborate knowledge systems and governmental programs.

Hence, rather than as a pre-political pathology, it seems reasonable to approach intellectual disability as a historically contingent way of making

sense of some individuals recognised as needing intervention and management (see Rapley, 2004:42); the figuring of certain social problems and the idea that government need to respond to certain deviances explain the construction of the diagnosis. This suggests that the technologies which are allegedly used to *describe* an independently existing 'disordered cognition' in fact function to *manufacture* this 'disordered cognition'. When intellectual disability first appeared, one important reason for separating this group was to be able to direct interventions so that members of the group did not procreate or created societal unrest. Today, the need to diagnose intellectual disability stems from a perception that a long-term government commitment is needed, although no longer through blatant forms of eugenics and permanent institutionalisation. Thereby, the common logic of classification is reversed: we are not dealing with a group which exists out there, detected by measurement instruments, and towards whom government is directed. Rather, we are dealing with governmental concerns, underpinning measurement instruments that are put to work to constitute subjects as 'intellectually disabled'. In the introduction, I argued that people who are considered to be 'intellectually disabled' today are being included by the same normativity that produced their exclusion in the first place. The history of the emergence of psychometrics as a method of identifying 'mental deficiency' helps us see why: the specification of this group was founded on their failures to meet norms of reason, foundational for conceptions of intelligence and linked to ideas of citizenship. The politics of inclusion that evolved nearly a century later meant that precisely these ideals of citizenship were to embrace the group.

For the sake of clarity, the arguments proposed in this chapter do not contest the existence of intellectual disability, but are meant to engage in a discussion concerning what we take 'existence' to mean when talking about this group. Some may counter that it would be foolish to state that there are no differences between members of this group and other people, but I have merely proposed that considerations regarding *which* differences matter, of *how* and *why* they matter, and *when* they need to be acted on, are all best made sense of as governmental concerns, that this has been the case throughout history and is the case today. Neither have I argued that classification is of no use: on the contrary, this diagnosis has proved highly useful in the management of the population, the problem is that this role as a tool of government is often unacknowledged and very rarely politicised. This also means that the arguments proposed are not meant to suggest the abandonment of services and support systems that are underpinned by

classification in deciding eligibility. Rather, what I have added to the generic understanding of the social and administrative nature of intellectual disability is an analysis of the governmental rationales underpinning the practice. However, the use of quantitative measurement instruments to categorise differences of sorts, to designate an otherness of human reason, will inevitably produce liminal zones of ambiguity, where a firm demarcation between 'other' and 'us' is hard to maintain. The response to this problem is what we turn to next.

## 2. Biology

Present only by merit of their absence in the classification of intellectual disability, biological causes appear as the displaced centre of efforts to define and categorise this condition. The classificatory criteria are meant to capture pathology, but their segmenting function is relative to statistical or behavioural norms and originates in ideas of deviancies that are judged to be troublesome. In this chapter, I will examine how the intellectual deficiencies detected by classification are projected onto the biology of the individual, that is, how judgements on disorder are returned to the body through psychiatric and medical knowledge. I will argue that the main ideological function of research on the medicine and biology of intellectual disability thereby is to naturalise the condition to make it appear as a neutral fact rather than an outcome of government.

Throughout history, people defined by lack of reason and deviant behaviour have represented a fundamental otherness, outside the realm of 'normalcy' and opposite to the idea of the 'good citizen'. However, the separation between this group and 'normal' human beings is far more tenacious than it appears at first glance. Ideas concerning which behaviour constitutes aberrations demanding government responses are historically situated and, as such, fluid and in processes of constant renegotiation. In addition, as was discussed in the previous chapter, every quantitative measurement which operates by separating groups will create liminal zones of ambiguity where the boundary between 'normal' and 'abnormal' cannot be clear-cut; the placing of the cut-off point for intellectual disability will inevitably be deemed arbitrary by some, implying that the separation of people with this condition is, in fact, neither 'natural' nor evident. Thus, although people labelled 'intellectual disabled' represent the outside of reason, the line which demarcates this outside is fragile and unclear. Efforts to naturalise intellectual disability by making it a biological fact can be seen as a constant process of answering to this by re-inscribing and protecting the boundary towards 'lack of reason'. As Butler (1990:10; 1993:4-7) and Urla and Terry (1995), among others, have argued: mapping the biology and the

bodily characteristics of excluded groups has historically served as a method of making judgements of ‘otherness’ appear as natural and beyond critique. By rooting deviancy in the body, by linking it to neuronal organization or number of chromosomes, we can maintain the idea that this difference is something more firm than normative judgements about appropriate and inappropriate behavior. We can ascertain that we are dealing with a ‘natural kind’, as Hacking calls it, whose existence is an objective and measureable fact of the world. In this way, the differences in degree and behavioural judgements of classification can be transformed into solid differences of sorts detected in the biology of the individual.

I will go on to show that biological knowledge, here, plays two related ideological roles. First, it constructs intellectual disability as firmly removed from ‘normalcy’ in a way that classification cannot and, by the same manoeuvre, biological knowledge comes to mask the political and normative constitution of intellectual disability. The second purpose regards making attainable certain governmental tools for preventing and curing the condition, where a pervasive discourse of ‘risk’, ‘disorder’, and ‘pathology’ are consistently leaned on to construct the condition as something that should be avoided.

## **In the Body**

### *Histories of biological deviancy*

Again, a retrospective view is needed. Over the course of the second half of the 19<sup>th</sup> century, a significant shift occurred regarding the way that ‘mental deficiency’ was comprehended. Previously, ‘idiocy’, ‘imbecility’, and ‘feeble-mindedness’, had been regarded as unfortunate results of metaphysical forces – of the rage of God or the incidence of nature figured as abstraction. Thought was mostly comprehended as metaphysical in nature, sometimes linked to the divine (see Dendy, 1853:3-4 for an example). In the literature at the time, linkages between the biology of the individual and the deficient mind were rare. Concurrently, the educational efforts of Seguin and other philanthropists pictured the ‘mentally deficient’ as worthy targets of benevolence and there was a widespread optimism concerning the possibilities of ameliorating the lacking intellect of such individuals (Parmeter, 2004:6). In many accounts of the group from the first half of the 19<sup>th</sup> century it is stressed that, although people of this group cannot be figured as human in its fullest form, they deserve compassion and help.

Some fifty years later, around the time of the turn of the century, a distinctively different view of intellectual disability had emerged. First, 'mental deficiency' had transformed into a 'threat', for all the reasons stressed in the previous chapter, linked to degeneration of the population and to various social problems. There was no longer a place for charity, pity, and optimism. Second, mental deficiency had come to be seen along the lines we recognise from today: as a medical condition that could be understood by means of modern medicine. The key organ, of course, was the brain (Maudsley, 1873:40; Mercier, 1905; Paton, 1905; Mott, 1914). Hence, when Penrose (1933: vii-viii) authoritatively formulated what would be a very influential view for the coming century – 'I consider the study of mental deficiency to be a branch of human biology' – he immediately followed up on this statement by adding that previous theories of mental deficiency needed to be revised provided this insight. This perspective indicated that the study of the abnormal mind was analogous to studying any other diseased part of the body. Viewed in this way, it was possible to connect the sociology of social problems with human biology in the quest to find the causality of 'inferior individuals' (Henderson, 1901:12-4). Still, as Paton (1905:230) noted in his introductory textbook on psychiatry, the pathology of mental deficiencies was, to a large extent, still an enigma. During the course of the 20<sup>th</sup> century, this would change.

It is important to note that the shift to a medical and biological understanding of intellectual disability was not primarily motivated by conclusive scientific findings, but by new theoretical assumptions concerning the way that deviancy was interpreted. Very few early medical accounts have anything substantial to say about biological correlates of 'mental deficiency', but they do not hesitate to assume that such biological markers must be present, only not yet discovered. The actual elaborations of the linkages between the brain and deficient intelligence appear to be clumsy and imprecise, deduced rather than scientifically proven. In this way, the recognition of deviancy came prior to detecting its causes, and the explanations were speculative rather than demonstrated. The emergence of biological explanations of intellectual disability was produced by a shift of belief-system rather than of scientific discoveries; only after deviancy was recognised did psychiatry set out to search for the causes of 'mental deficiency' in the materiality of the brain.

The linkages between deficient morality, social problems, and deficient intelligence that I discussed in the previous chapter were also present in

medical and psychiatric treatments of mental deficiency, as can be exemplified by Kraepelin's (1906:329) ideas on lacking intellect:

imbeciles are naturally unable to satisfy the more difficult demands of life. Sexual relations in the present case, and in other alcohol, bad example, or a propensity to idleness, are the reefs on which they are wrecked in consequence of their inadequate equipment for the battle of life.

Note how seamlessly the word 'naturally' figures here, referring to 'imbecility' as a phenomenon which naturally exists in the form of deficient biology. Also, note the influence of Darwinism, appearing in the analogy of life as a 'battle' where some are worse equipped than others. At the time, the deficits in question were, to a large extent, interpreted as hereditary, a view exemplified by Goddard's influential account of the Kallikak family. During the decades around the turn of the 20<sup>th</sup> century, the optimism and concern for the mentally deficient were replaced by biological determinism and a glum view of 'mental deficiency' as a motor of social unrest and degeneration. In concert, this re-conceptualisation was intertwined with governmental incentives. First, it became possible to design specific measures to target people with mental deficits, separating them from the insane and the generally poor. Secondly, as the hereditary stock of society was on the line, there was an urgent need to do something. And so prevention of 'mental deficiency' became a primary motivation of research as well as of policies targeting the group, driven by the eugenics movement and disseminated throughout the western world.

I argue that, in similar ways, the medicine and psychiatry of today are also organized around governmental rationalities, making certain responses to intellectual disability possible and taking certain ideals of what characterises 'normalcy' for granted. Furthermore, as we shall see below, some of the ideas emerging a century ago are still ingrained in how intellectual deficits are understood.

#### *What 'aetiology' does*

One of most important ideas which emerged during the latter half of the 19<sup>th</sup> century concerns the causation of deficient intelligence. Finding the causes of the condition has been a goal of researchers since the late 19<sup>th</sup> century and an explicit policy goal in the US, for example, since the 1960s (McDermott et al, 2007:4). What developed during the first decades of the 20<sup>th</sup> century was an ideology of origin, essentially formed around the seemingly trivial proposition that medical conditions are caused by something. This simple

idea, however, has played a significant role in how we have come to understand intellectual disability.

The contemporary clinical literature on intellectual disability may appear to a non-specialist as an odd mixture of psychiatry, psychology, genetics, and medicine. Since there are no necessary linkages between classificatory criteria and biophysical states of functioning, the task of mapping the causes is bound to be a monumental one. Any reason why one has failed at IQ-tests and been estimated as deficient in adaptive behaviour qualifies as a cause, which can include genetic and chromosomal aberrations, oxygen shortage during birth, gravely unfavourable circumstances during upbringing, or traumatic brain injury at any stage of development towards adulthood. Furthermore, as was stressed in the previous chapter, in a majority of people diagnosed with intellectual disability, the causes are not known and are therefore assumed rather than described.

The central concept here is 'aetiology'. In medical discourse this denotes the causes of pathology. Hence, Down's syndrome is an aetiological trait seen as leading to intellectual disability: the reason why some people have adaptive behaviour and intelligence deficits is that they have trisomy 21 – an extra chromosome in the 21st pairing which is associated with differing cognitive functions. Aetiology is central in clinical books on intellectual disability and all of the clinical publications examined here devote lengthy sections to various aetiological explanations. At the same time, they very rarely say anything about *why* this search for explanations is important and worthwhile. In this way, aetiology operates as convention and assumption, something which is presumed to enlighten our understanding of intellectual deficiency, but which only occasionally is motivated.

In his introductory book about intellectual disability, Harris (2006:43) provides the assertion that Bourneville 'established' the idea that intellectual disability 'results' from 'brain pathology'. This statement is interesting as it puts into words many of the assumptions that form the ideas of 'aetiology'. Harris' declaration is premised on two assumptions: *first* that every pathological state of functioning has an aetiological trait and, *second* that intellectual disability is, in itself, pathological. Thereby, an important step is taken, from the relative criteria of IQ and adaptive behaviour, to deficits in these being deemed 'diseased' and 'sick', which is the meaning of 'pathology'. This idea that intellectual disability results from 'brain pathology' is commonplace in the literature, although not always so clearly spelled out. Since aetiology denotes causes of pathology, the pervasive discourse on the importance of clarifying aetiologies implicitly constructs the

condition as such as ‘pathological’. In addition, as nature is always seen as prior to consciousness and behaviour, the material brain stands as origin and our behaviour as the result of its materiality. Hence, if we presume that all properties of our minds are caused by properties of our brain, then we can postulate that whatever we find strange in human action or behaviour should have a biophysical cause (see Altermark, 2014).

My argument here is that this manner of reasoning plays an important ideological function by displacing the political mechanics operating in the constitution of individuals as ‘intellectually disabled’. As was shown in the previous chapter, the diagnosis of intellectual disability is contingent on the judgement that certain ways of functioning are problematic. This judgement must be based on a normative yardstick with regards to the behaviours which are deemed to be so deviating or harmful that they require a societal response. What aetiology does is to make any correlates found in the brains of individuals masquerade as the real causes of the condition. For example, when we see how dendritic appendages of individuals with Down’s syndrome are notably different from those of ‘normal’ people, we believe we have found the ‘cause’ of their differing cognitive functions. But this requires that we neglect that the rendition of certain differing cognitive functions as ‘pathological’ underpins the whole exercise; pathology is already a matter of fact when the biological examinations enter to explain the causes of intellectual disability. Thus, when searching for explanations of certain ways of functioning in the brains of certain individuals, we will not find molecular size labels stating ‘pathology’. We cannot *see* or *discover* that some ways of functioning are ‘diseased’ or ‘disordered’. The construction of such labels always exceeds the biological ‘facts’ of the matter; they are always supplemented by a normative judgement of the examiner. This was the argument of Canguilhem’s (1991) analysis of the differentiation between the ‘normal’ and the ‘pathological’; that it must always be made on the backs of normative judgements; that it is always entangled with the values and ideals of a certain social order (see Vailly, 2008:2533). And therefore, we may very well believe that we have found a label of molecular size stating ‘pathology’ which we can attach to the notably shorter dendritic appendages of individuals with Down’s syndrome, whilst actually this label was there all along as a presumption.

Corresponding with a central argument from the previous chapter, the endeavour of finding the biological causes of ‘intellectual disability’ requires a prior norm concerning what appropriate brain functioning is and, just like in the previous chapter, there is also a history to this line of reasoning.

Consider, for example, how in a 1869 lecture Shettle starts off by stating that the definition of aberrant cognition requires a definition of 'health':

I would describe a healthy mind as that state of the brain, which, existing in any individual, enables him, by a free exercise of the will, to grasp some mental thought or idea; to study some subject which requires considerable exercise of the will of the imagination as well as of the reasoning of the understanding for a considerable time, without wearing its powers; and I would further add, a capability of fixing the attention upon any one subject, or turning it to another at will. (Shettle, 1869:2)

Only by comparison to this ideal is Shettle able to go on to define mental disease. In the next step, he postulates numerous biological correlates of the unhealthy mind. But these, of course, are not causes of 'mental deficiency'. Rather, the cause of this label is found in his own yardstick of the 'healthy' mind, without which the biological examinations of aberrations would not even be able to take off. Similarly, in 1905, Mercier stated that any recognition of mental deficiency originates in judgements of behaviour, 'for only by conduct can mind be known' (Mercier, 1905:103). Hence, before the recognition of any biological explanations, there is a recognition that someone has behaved strangely. In the next step of the argument, the causal force of this normative judgement is displaced and masked as biological causality: 'feeling and thoughts, mental states and mental processes, are but the shadows of or accompaniments of a nervous change' (103), leading to the conclusion that 'Whenever [...] there is disorder of mind, there must be disorder of nervous processes' (103). Although Mercier explicitly states that judgements of behaviour produce 'mental deficiency', biological scrutiny soon takes over the role of explaining what it is and how it is caused. This movement, from norms of proper and deviating behaviour to biological causes is possible because the value-judgement of sickness and disease is a presumption which is taken for granted.

The reason why Shettle and Mercier are worth looking into here is because of the apt correspondence to similar lines of reasoning present in current understandings of intellectual disability. Just like then, a judgement of inappropriate behaviour lies at the heart of a diagnosis. Like then, the idea that any behaviour corresponds to properties of the brain leads to the conclusion that there is a cause located in the neuronal organization of the individual. And like then, this neuronal explanation, whether known or postulated, replaces the normative judgement at the heart of a diagnosis in order to appear to be a neutral and scientific explanation. Following Butler's

(1993: xix-xx) analysis of the materialisation of bodies, the discursive ascription of ‘aetiology’ thus functions as a further extension of the brains it describes; beyond the reach of social factors, measurement errors, and the critical analysis of power, the blurriness and the historical and social nature of classification are transformed into a question of solid biophysical difference. This is how ‘aetiology’ naturalises and masks the political investments of the body.

Urla and Terry (1995:1) argue that the idea that social deviancy is expressed on the body is one which reoccurs in Western science and popular thought, from Aristotelian studies of moral expressions of bodies, onwards. As I suggested in the opening of this chapter, this idea works so as to safeguard the line of demarcation between ‘intellectual disability’ and ‘normalcy’, ultimately operating to protect the coherence and unity of humanist notions of subjectivity by asserting that it is not possible for just anyone to be ‘the other’ since otherness is biologically rooted. And so we forget that the biology of pathology is only searched for *after* deviance is detected, in both a temporal and logical sense; first comes the norm and then the thorough investigation that aims to locate difference in the materiality of the brains of deviating individuals.

#### *Nature and society in aetiology*

In this way, discourses of ‘aetiology’ perform the overarching task of projecting deviance onto the body. We shall now – admittedly only in short – turn to examine what happens when this concept is transferred from medical depictions of biological phenomena to understanding abnormal psychology.

The first thing to note here regards, on the one hand, the perceived stableness of intellectual disability and, on the other hand, the fluidity of what the classificatory definitions of the condition denote. Carlson (2010:36-40) shows that historically, mental deficiency has been seen both as a static and as a dynamic condition, depending on severity, type, and fluctuation over time. Of course, as concerns the present classificatory criteria, cognitive functioning is not static but changes when neuronal patterns are reconfigured in reflexive dialogue between the brain and its context (Malabou, 2008). Yet, aetiological traits are static; it does not matter that your behaviour and intellect may change, you are born and you die with Down’s syndrome. In this way, the shift from classificatory to aetiological definitions also implies a step from an implicitly dynamic to a static understanding. Again, following Carlson (2010:40-3), the concurrency of dynamic and static conceptions has been integral to how intellectual disability has been managed – as something

that can be improved and educated away and as a threat that primarily needs to be erased. Today, intellectual disability is often seen as dynamic *within* the group, where educational interventions and possibilities of development are often stressed. On the other hand, the clinical literature rarely views the category itself as changing within an individual, although the capacities that classification measures are. In this way, the clinical literature constitutes intellectual disability both as an object of knowledge that can be ameliorated, to some extent, and as a label that cannot be escaped.

A second thing to note here concerns what qualifies as a cause of intellectual disability. In medicine, ‘aetiology’ denotes biological causes of pathology. Hence, a common aetiology of having a cold is being infected by the rhinovirus. When this concept travels into psychological explanations of socially inappropriate behaviour, however, it transforms into something else, as the causes of having a low intelligence can be almost anything. This means that social and contextual factors are allowed to explain intellectual disability in a way that would be alien in medicine. For example, a doctor would not call ‘working at a pre-school in the winter months’ – where kids have colds all the time – an aetiology. But precisely such explanations are common in the literature on intellectual disability, where, for example, being under-stimulated and suffering from harsh socio-economic conditions are stressed as ‘risk-factors’. In turn, when the clinical literature emphasises environmental factors leading or contributing to intellectual disability as ‘aetiologies’, biophysical causes such as ‘chromosomal’ aberrations are put on par with suffering from malnutrition, domestic violence, or abandonment. Several of the clinical works analysed explicitly state that poverty is a ‘risk factor’ of intellectual disability (Carr & O’Reilly, 2007a:23; Glascoe, 2007:353-4; Landesman Ramey et al, 2007:447; McDermott et al, 2007:22;). It is important to note that since intellectual disability is a condition of deviant behaviour, this is distinctively different from saying that poverty, for example, increases the risk of developing asthma due to smoking being correlated with socio-economic factors; since here, we are dealing with a label of pathology consisting of adequacy of intellect and behaviour, the explanation boils down to ‘poor people are likely to behave inappropriately and think slowly’. Both the cause and what is to be explained are distinctively social in nature; no biophysical markers need to appear to link poverty with low intelligence. But as this chain of inferences is dressed up in the language of medicine, and since it is underpinned by the assumption that all behaviour is biologically rooted, it makes sense to explain intellectual disability by reference to poverty as aetiology.

When viewed like this, basically anything which contributes to individuals performing poorly on intelligence tests and to failing to behave appropriately qualifies as an ‘aetiological trait’. Obviously, a lot of causes will be found without identifiable biological mediators. It is hardly surprising, for example, that people whose parents fail to stimulate and to show affection towards them are more likely to turn out with considerable behavioural problems. This chain of inferences by itself hardly gives reason to label such individuals ‘diseased’ or, for that matter, to understand their predicament as a biological fact appearing prior to politics. Eventually, the discourse of aetiology in this context boils down to the trivial proposition that ‘everything has a cause, including intellectual disability’. At the same time, the terminology of ‘aetiology’ and ‘pathology’ removes intellectual disability from the political considerations and normative yardsticks that bring it into existence.

## **Biology and Government**

### *Aetiology as biopolitical tool*

Following Foucault, scientific knowledge, however neutral it presents itself as, is for power to act on and linked to the norms of its social and historical context. Besides the function of naturalising intellectual disability, this is to suggest that biological knowledge of intellectual disability also works as a more concrete tool for government. This function is what we turn to now.

The intertwinement of knowledge and government suggests that new knowledge regimes correspond to new methods of management. For example, when hegemonic depictions of intellectual disability presented the condition as caused by evil spirits, power acted through the exorcism of priests. As hegemonic knowledge constructed the condition as hereditary in nature, power was channelized through doctors sterilising disabled women. As amniocentesis for the last fifty years has offered means to discover conditions associated with intellectual disability through prenatal diagnosis, power has come to operate by letting expecting parents decide whether to continue with the pregnancy or not<sup>8</sup>. Thus, the succession of knowledge regimes has offered different ways of both constructing and responding to intellectual disability – indeed, this history shows that construction and

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<sup>8</sup> A sustained engagement with prenatal diagnosis as a system of government is presented in Chapter 9.

response are perpetually intertwined. However, as the observant reader notes, the historical examples just referred to simultaneously show a remarkable continuity as concerns the ultimate purpose – namely, that intellectual disability is produced as an object of knowledge to be erased (see Stiker, 1999). I argue that today's research on the biological origins of intellectual disability is also bound up with the promise of making the condition disappear. In order to see how this functions, I will take a closer look at the growing field of neuroscience research on intellectual disability (of which I have previously published a more extended examination) (see Altermark, 2014).

Neuroscience is often presented as revolutionising knowledge on our brains and selves, covering more or less every aspect of the relationship between our nervous system and our minds (Mountcastle, 2001; Changeux, 2004; Sandman & Kemp, 2007:129). It can be argued that neuroscience, genetics, and psychology, sometimes in collaboration, have come to provide the leading efforts to explain intellectual disability (Tartaglia et al, 2007:99). As a discipline, neuroscience stresses the fluidity of our cognitive capabilities, how our brains are changing through a constant dialogue with our environment, which is called brain plasticity, and how our minds are therefore constantly evolving (see Mountcastle 2001:7; Malabou 2008:17). This has led many neuroscientists, along with some philosophers, to reengage philosophical questions, such as the mind-body relationship, in light of new scientific findings (see Changeux, 2004; Jeannerod, 2008; Malabou, 2008). Since intellectual disability is thought to emanate from brain functioning, the 'revolution' of the science of the brain surely must have consequences for how we understand the condition.

Provided the inclination of some neuroscientists and science writers to pepper their descriptions of neuroscience with bombastic portrayals of the field's prospects, a sobering note on what neuroscience has actually achieved is here called for. As showed above, the abandonment of the mind/matter-dualism was already becoming apparent in the medical literature of mental deficiency produced in the later 19<sup>th</sup> century, and was present when the categorisation of 'mental deficiency' first emerged. To the extent that early brain scientists recognised that the mind could change, the notion of brain plasticity was also implied. Of course, the actual reorganization of neuronal patterns and the abilities of brains to compensate and heal themselves after injury – processes that neuroscientists of the last few decades have provided ground breaking insights into – are a radical development of the state of knowledge on brain functioning. But does that development alone constitute

a revolution in how brains are understood? Even though the basic assumptions of the relationship between matter and mind are left intact? I argue that neuroscience has not revolutionised how we think in this respect, but rather developed novel visualisation technologies to reliably trace a correspondence that was assumed over a century ago. As a point of historical comparison, consider Mercier's (1905:292-3) use of illustrations of the brain size of people with 'mental deficiency' as compared to 'normal' brains and how these are used to explain deficiency by reference to biological depictions. The accuracy and level of detail aside, there are no fundamental differences between this visual explanation of intellectual disability and the visualisations of fMRI scans depicting differing cognitive functions; they are both judgements of certain behaviours that are to be matched with correlating biological features. What has changed here is the scale of visualisation, not the basics of how the brain is linked to matter or how behavioural characteristics are explained. Therefore, I propose that what neuroscience revolutionises in this respect is the level of scrutiny, not the general understanding of how the biological brain is linked with the mind of the individual.

It is worth noting that the continuation in how deficient intellect is explained is paralleled by a continuation as concerns the normative assumptions. The subfield of neuroscience relevant here is 'neuropathology' (Kemp & Sandman, 2007:136), devoted to neuroscientific explanations of 'malfunctioning' minds. Compared to the general neuroscientific descriptions of the human mind, 'neuropathology' represents a sharp contrast. Although the notion of 'brain plasticity' seems to suggest that our intellect develops in tandem with environment, that our lived history is inscribed upon our neuronal organization, the neuropathology of intellectual disability instead ends up reproducing the construction of static pathology (see Altermark, 2014). Hence, the general category of 'intellectual disability' is almost always stated in the title, abstract and among the keywords, whilst the actual examination is preoccupied with a narrow set of aetiologically defined syndromes (see Choi et al, 2011; Levenga and Willemsen 2012). By doing this, we are stepping from classificatory criteria, which according to neuroscience denotes capacities that are fluid and the result of the interactions between brain and context, to a number of syndromes that people are born and die with. This is because 'neuropathology', as is indicated by its name, sets off from assumptions of disease and disorder. It follows that the neuroscience of intellectual disability is not occupied with *if* or *how* these brains function, but with tracing biological markers of mental abilities that

are already determined to be pathological. Thus, the assumption of pathology is more or less ubiquitous (see Levenga and Willemsen 2012; Pavlowsky et al, 2012; Troca-Marín et al, 2012, 268-270; Verpelli & Sala, 2012). In effect, whilst the general propositions of the plastic brain suggest that the characteristics measured by classification criteria are fluid and changing, the neuroscience of intellectual disability is preoccupied with the brains of static syndromes (see Walsh & Engle, 2010; Choi et al 2011; Pavlowsky et al, 2012; Troca-Marín et al, 2012; Verpelli & Sala, 2012). In this way, this research field merely adds a new level of scrutiny to what John Langdon Down had already understood as being a fact about people with ‘mental deficiencies’ at the end of the 19<sup>th</sup> century – namely, that their condition stems from disorganization or damage of properties of the brain (see Harris 2006:42-3).

A testament to how knowledge on intellectual disability is knowledge to act on often becomes evident in the sections ending neuroscience publications on intellectual disability, entitled ‘therapeutic prospects’ or similar (Walsh & Engle 2010; Choi et al 2011; Levenga and Willemsen 2012; Pavlowsky et al, 2012; Troca-Marín et al, 2012; Verpelli & Sala 2012). In these, the authors specify how research findings relate to the possibility of producing ‘cures’ that target the deficient cognitive functions detected. These ‘cures’, in turn, are discursively linked to a terminology of ‘disorder’, ‘illness’ and ‘defect’ and can, for example, consist of considerations regarding the prospects of producing pharmaceuticals targeting deficient neuronal functions (Troca-Marín et al, 2012:268-70; Verpelli & Sala 2012:530). Hence, oftentimes, erasure of intellectual disability stands as the ultimate end and justification of this research. Although we may well have an argument as to whether that would be good or not, we cannot ignore the fact that advocating ‘curing’ intellectual disability is based on a value judgement on the condition in question.

In this respect, there is a similarity between neuroscience, the genetic knowledge that goes into modern prenatal diagnosis, and the medieval exorcism of priests; they are ultimately bound up with the promise of eradication (see Stiker, 1999). What the example of neuroscience shows is that the search for aetiological explanations not only operates by separating normalcy from intellectual disability, but also suggests ways of how the latter can be reduced.

### *The undesirable biology*

Now, intellectual disability can only be perceived as something to ‘prevent’ or ‘cure’ provided the judgement of pathology: of disorder and of something that is best avoided. In the field of neuropathology and the clinical literature more generally, this presumption is integrated into how intellectual disability is described. In turn, these literatures constantly reconstitute the devaluation of the condition. Thus, it comes as no surprise that both biophysical and social factors understood as ‘aetiologies’ of intellectual disability are continually talked about in terms of ‘risk’ and ‘risk factors’ in the clinical literature (see Harris, 2006:79, 103, 116; Carr & O’Reilly, 2007a:23, 45; Carr & O’Reilly, 2007b:52-3; McDermott et al, 2007:7, 22). Sometimes, there are hints of substantiations of this language. It is, for example, commonly suggested that a disabled life contains a lot of suffering and that ‘risk’ therefore refers to the quality of life of the individual being labelled with the condition. In the clinical literature, this structure of reasoning takes the form of detailed lists of potential dangers, associated conditions, and a lack of capacities, which are related to the sub-syndromes of intellectual disability (see Bennet, 2006:342-4; Carr & O’Reilly, 2007b:72-4; AAIDD, 2010:154-5). Taken together, these constitute what social model analysis refers to as a ‘tragedy narrative’ of disability (Oliver, 1996:32), solely focusing on what people with intellectual disabilities lack and miss.

Rather than isolated mishaps, I argue that this language exposes the biopolitical rationalities underpinning knowledge production on intellectual disability. First, as stated already, conditions labelled ‘abnormal’ and ‘deficient’ can only exist when juxtaposed against a prior idea of normality. When constituted by reference to such an idea, intellectual disability holds a devalued position. Secondly, the ‘risk’ of deviating from this ‘norm’ constitutes an incentive to act, eugenically, neuroscientifically, or through social politics, depending on which historical epoch and setting we are looking at. Thus, although the science of intellectual disability has developed in terms of its efficiency and its ability to actually help people, there are also important continuities as concerns the dividing line between cognitive ability and disability and its promises of cure and prevention.

To once again return to the argument of Canguilhem (1991), my point here is that the language used to designate ‘risks’ is bound up with an implicit and presumed normative framework hierarchizing ways of being. The favoured existence of ‘normalcy’ and of ‘health’ – as opposed to ‘disability’ and ‘pathology’ – is today largely implicit, most often figuring as the abstraction that makes a language of ‘risk’ and ‘pathology’ possible. In the

clinical literature, it is never stated that it is better, more valued, more desirable, to have a 'normal' cognition. But without this presumption, it would not make sense to search for 'cures', to propagate 'preventative measures', or to formulate an increased likelihood of intellectual disability as 'risk factor'. Although, there may be answers worth consideration as to why intellectual disability, at least in some cases, should be prevented, for example through decreasing the prenatal alcohol use of pregnant women, the problem is that these questions are not even addressed as normative in the first place. In order to have meaningful discussions about such questions, we need to realise that they are imbued with concerns of government and ideals of how human beings should function.

## **Clinically Other**

In 1979, Michael Begab gave his presidential address to the IASSMD (at that time, the largest organization for researchers of intellectual disability), stating:

the implementation of knowledge goes well beyond the purview of science and service. Only as we make an impact on the political process and provide an empirical base for rational decision-making can significant inroads to the global and complex problem of mental retardation be expected. (Begab, 1979 in Parmeter, 2004:28)

There are two significant things to note in this statement. First, there is a separation, meant to be bridged, between the production of scientific knowledge and politics. Hence, science shall inform politics, ideally, but is not conceived of as 'political' in itself. Similar sentiments seeing scientific knowledge as separate from politics are very much present in the current discussion around disability policy and research (see Shakespeare, 2006:41-2; Holland, 2008; de Vries & Oliver, 2009; Holland, 2013). Secondly, Begab denotes 'mental retardation' as a 'problem' that science can help solve, which itself is an expression of the political stakes involved in scientific claims to describe the world. Here, the element of devaluation ('problem') and the element of government ('an empirical base for rational decision-making') are enmeshed. The first two chapters of this book can be read as an analysis of these two interrelated logics; on the one hand, a logic seeking to de-politicise intellectual disability, by means of scientific classifications systems and allegedly neutral depictions of the body, and, on the other hand, a logic of

knowledge production continuously being interrelated with government, leaning on the prior recognition of intellectual disability as pathology.

As I have argued, thus, these chapters have sought to show the primacy of politics and normativity. In both a temporal and logical sense, biological causes are only searched for *after* deviance is detected; it is always preceded by the recognition that there is something abnormal to explain. Hence, biological correlates or ‘causes’ of intellectual disability do not prove the natural and pre-political existence of the condition. Rather, they expose that certain ‘abnormal’ behaviours incite careful scrutiny of the genetic, cerebral, and neuronal features of individuals. Lennard Davis (1995:7) declares:

the manner in which this society defines disability in fact creates the category. Able-bodied (or temporarily able-bodied) people safely wall off severely disabled so that they cannot be seen as part of a continuum of physical differences, just as white culture isolates blackness as skin color so as not to account for degrees of melanin production.

As Davis argues, society constitutes disability with reference to norms of the able body and brain. It separates it and distinguishes it, and the process of biologisation that I have examined and discussed here is a central aspect to how this ‘walling off’, as Davis calls it, is achieved. At the same time, an array of differences and complexities to human cognitive functioning are slated over and sorted into the strict categories of ‘normal’ and ‘deviant’.

In Foucault’s analysis, like mine, ‘deviancy’ exists in a mutually constitutive relationship with what is considered ‘normal’. This division come to shape how we perceive, also our own, bodies. Lingering at the very heart of this is the dominating ideal of a humanist subject, characterised by reason, rationality, and independence. By projecting shortcomings with respect to this ideal onto the biology of deviants, a difference of sorts is established, a mark of otherness which cannot be escaped, which is natural and thus beyond questioning. For Foucault, this has to do with our desire for authoritative truth, provided by the science of the body that connects individual bodies (and brains, in this case) to modes of regulation, containment and incitements. In this way, biologisation is integral to the process of ‘making up people’ (Hacking, 1986; 2007), amassing knowledge on certain ways of being to consolidate these as ‘natural kinds’ that appear to exist independently of social organization. As was discussed in the introduction, the idea that norm-breaking behaviour is written onto the body is one which reoccurs within western science and popular thought (Urla & Terry, 1995:1). Hence, the body is designated as ‘origin’, as the materiality

that cannot be argued against, and as conveying manifest expressions of otherness. It is thereby ascribed a privileged status as source of evidence, understood as 'natural', 'real', and 'authentic'.

The separation of intellectual disability, however, leads to the threat of what Butler (1993:27) calls 'a terrifying return'; of divisions between otherness and normalcy collapsing, and of the political investiture in the separation between deviancy and normal becoming exposed. In her analysis of the suppression of queer subjects as a guarding mechanism of compulsory heterosexuality, Butler (1990:23-4) starts from the recognition that normalcy is founded on the separation of several excluded others (see Urla & Terry, 1995). To maintain a strict division between 'male' and 'female', desires that challenge this division must continually be kept at bay from what is considered normal, for example, by understanding them as 'diseased' or 'disordered'. Here, I have analysed a similar guarding mechanism, operating by the discursive structure of 'aetiology', which affirms that 'otherness' is a biological mark, separated from 'normal' cognitive functioning. This is to say that 'aetiology' operates to secure the idea of humanist subjectivity by linking together shortcomings with respect to its ideals with biological markers of the bodies of people seen as deviating.

In conclusion, taken together with the previous chapter, biological and classificatory knowledge productions are mutually reinforcing. Classification cannot detect biological properties, although such are assumed. The depictions analysed in this chapter purport to provide precisely this. Biological knowledge, in turn, is premised on a prior presumption of undesirable deviancy of precisely the kind that classification detects and which legitimises the search for causes in the body. The technologies used to segment the population by claiming to detect intellectual disability construct this group to be targeted by socio-political programs and interventions. Thereby, I suggest that the biophysical correlates of intellectual disability, generally understood as the origins of difference, are better regarded as effects of biopolitics and its inclination to locate deviancy in nature.

### 3. Politicisation

This chapter concludes the analysis of how questions concerning what intellectual disability is are answered. I will here discuss how disability came to be interpreted as, at least partly, a social phenomenon during the last decades of the 20<sup>th</sup> century. My main focus will be the formation of what have been labelled ‘social’ and ‘relational’ models of disability, which contested the medical focus of disability research and rearranged how disability was understood. Over the past forty years, the calls for reform of disability politics were substantially organized around new and alternative conceptions of disability itself and, today, some of these ideas have become integrated into disability policy and clinical science.

Before going on, I want to say a few things on the critical discussion that will follow. When looked at as a historical instance of resistance, there is no denying that the formation of a social analysis of disability (which will be presented in a moment) was important to the disability movement and contributed to the abandonment of institutionalisation. In this sense, I see the activists and scholars that developed these theoretical models as inspirations for how thinking beyond the dominating discourse is possible and how theory can spur resistance. Still, when looked at as a way of conceiving of what disability is, I will argue that their underlying template for politicising disability is problematic due to the assumption that the *biology* of impairment and the *politics* of disability are ontologically separated. This, however, is not to deny the advances that followed from the social model critique. Today, certain aspects of social model analysis have become institutionalised, written into legislations and national treaties. The clinical literature often commits to relational models of disability that were foregrounded by the introduction of a social analysis of disability. This must mean that these theories should be subjected to the same tools of criticism as medical understandings of disability. After discussing the pitfalls of the social and relational models of disability, I will end the chapter by proposing another way of politicising intellectual disability which begins with the proposition

that there can be no separation between the ‘nature’ of intellectual disability and intellectual disability politics.

## **Disability as ‘Social’**

During the 1960s and 70s, the second wave feminist movement, the civil rights movement, and the gay movement, along with a number of other solidarity campaigns, gave voice to a wide-range of critiques of capitalism, liberal democracy, and their associated norm systems. At roughly the same time, although paid significantly less attention, the disability movement emerged in Britain, Scandinavia, and North America, demanding the abandonment of institutionalisation, the need for societal integration, and citizenship status for people with disabilities. As it turned out, in terms of policy outcomes, the disability movement would become one of the most successful of the ‘new social movements’. Essential to its formation, the political demands that were raised, and its subsequent victories, was the social model of disability.

### *Social Models of Disability*

Although not as famous as his fellow activists in the UK, in 1968 the Swedish disability activist Vilhelm Ekensteen presented what, to my knowledge, is the first social model of disability in his book *In the Backyard of the Welfare State* [*På folkhemmets bakgård*]. In his analysis of the grim living conditions of people with disabilities, he made the claim that ‘disability’ was the result of discriminating social structures rather than of bodily impairment. Together with a number of activists in the southern university town of Lund, Ekensteen formed the organization Anti-Handikapp, which demanded deinstitutionalisation and criticised other disability organizations for basing their analysis on medical perspectives.

Roughly a decade later, a similar conception of disability emerged within the UK disability movement. In 1983, Mark Oliver coined this the ‘social model’ and it has served as a focal point in debates about disability since (Shakespeare, 2006:9). The foundation of the social model of disability is most often attributed to The Union of Physically Impaired Against Segregation (UPIAS), in the years 1976-80. This organization was only one among many to emerge in the UK during the 1970s. At roughly the same time, similar organizations surfaced in a number of other countries (Shakespeare, 2006:11). The UPIAS, however, was considered among the

more radical, and, like Anti-Handikapp in Sweden, Marxist in its ideological orientation. In 1976 the member Paul Hunt put together what has since been interpreted as the first formulation of the UPIAS social model:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. (UPIAS, 1976:3).

Like in Ekensteen's analysis, what we see here is a clear-cut distinction between impairment and disability that shifts focus away from the individual body and towards society as the cause of disability (see Barnes, 2012:18). Later in the same document the implications of this shift are spelled out:

We define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability 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. (UPIAS, 1976 in Oliver, 1996:22)

Worth noting is that the fundamental principle of the UPIAS' social model is that impairment and disability are not only separated, but understood as causally unrelated, as seen in the quote; disability is the result of social organization, not of impairments residing in the body. Within any population, there will be an array of differences as concerns bodily functions, but when some ways of functioning are not accounted for, we are dealing with discrimination rather than individual hardships stemming from unfortunate circumstances. The reason why society discriminates against certain bodily constitutions is the organization of the economy and its demand for able bodies to feed capitalist production. The overriding implication of this is that society has to change, not the individual. This analysis was possible to act on and form political demands from, as has been pointed out by Oliver (1996:37):

It is society that 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 or interventions provided by the medical or para-medical professions.

Until UPIAS and other organizations burst onto the scene of disability politics, disability had primarily been understood as an individual phenomenon made sense of by medicine and, in the case of intellectual disability, psychology (Oliver, 1996:31; Barnes, 2012). With the social model, an enemy was constructed: a ‘medical’ or ‘individual’ model in which disability is understood as a ‘personal tragedy’. The specification and naming of an oppressing ‘personal tragedy theory’ was instrumental to how the disability movement came to approach the existing attitudes towards disablement: the activists did not want compassion or pity, they wanted rights and an end to discrimination. Against the medical narrative of personal loss, still prevailing in biological and psychological depictions, disability was reinterpreted as a collective phenomenon, caused by structures in society discriminating against disabled people as a group. Hence, the analysis went, society is designed to accommodate for a hegemonic understanding of a normal body, a body whose value is tied to its usefulness in production. As the consequences of these social structures do not fall randomly on individuals, but on disabled people as a group, ‘disability’ becomes equal to a form of structural oppression directed against people with particular bodily constitutions.

Conceived of as caused by discrimination, disability could be contested and reversed by the removal of such structures – not a task for doctors, but for activists. In this way, social model analysis essentially introduced ‘disability’ as a field of politics. In this sense, this book is foregrounded by the efforts of this generation of activists and scholars. However, the first generation of social model analysis did not see the constitution of biological knowledge as political, it focused on social structures discriminating against certain bodies, but did not conceptualise impairment as a field of politics. In this sense, social model analysis differs from later critiques – including the one I have advanced – which sees the body and impairment as socially constituted. We will get back to the implications of this difference in a bit.

During the 1980s and early 90s, years which saw legal changes along with increased activism of the disability movements, a variety of analytical tools associated with or influenced by the UPIAS-social model developed. Many of these were formulated by what has been characterised as a ‘second wave’ of scholars theorising the social dimensions of disability (see Rapley, 2004:64). Whilst the first generation mainly focused on oppressing structures that emanated from socio-economic organization, the second generation was more receptive to post-structural insights, thereby highlighting discourses, culturally rooted structures of oppression, and norms and value systems

embedded in social organization. These scholars often accused the original social model of being overly simplistic and dualistic, reducing complexity to neat binary categories (see Rapley, 2004:64-6). Oppressive social structures were still understood as a central cause of disability, but these structures now included culturally rooted perceptions. Simultaneously, there was a growing sentiment that the original social model went too far in claiming that disability was *solely* a social phenomenon and that this analysis neglected embodied experiences of impairment.

In contrast to the original formulations of the social model, the second wave scholars sometimes picked up and devoted special attention to intellectual disability, which by the first generation had been understood as either un-problematically situated within the collective of impairment groups or simply overlooked. Interestingly, the argument was that this group exposed the opaqueness of the original social model. ‘How can this group’, the sentiment went, ‘with all of their hardships, solely be a result of social oppression?’ (see Goodley, 2001:211; Rapley, 2004:67) In this vein, Shakespeare and Watson (2001:18-9) rhetorically asked how a changing society could accommodate people with severe intellectual disabilities having equal opportunities on the labour market. The implicit answer, of course, was that it could not. Thus, intellectual disability was imagined as the materiality that the original social model was unable to provide an answer for. Quite paradoxically, the influence from post-structuralism over second generation social model analysis rarely extended to asking questions of how discourses on bodies and brains were involved in manufacturing what they named; while the first wave neglected intellectual disability, the second wave, despite their preference for discursive perspectives, used it as the material reality that proved the first generation wrong (see Rapley, 2004:67). In this way, intellectual disability has often figured as the group where politicisation meets its ultimate limits (Goodley, 2001:211). In parallel, it must be noted that people with intellectual disabilities have been excluded and seen as inferior within the disability movement, as well (Campbell & Taylor, 1996:97 in Goodley & Runswick-Cole, 2014:11), precisely by reference to their assumed deficient cognitive functions. As the disability movement mobilised the language of ‘citizenship’ in its struggle for equality, it neglected the fact that intellectual disability once originated as the others of this very concept.

As Shakespeare (2006: Chapter 1) has pointed out, parallel to the development of the social model(s), a number of related ways of politicising disability gained prominence, which were theorising it as a *relationship*

between biological impairment and environmental factors. One such account was provided by Thomas (1982:11 in Shakespeare, 2006:21):

The concept of disadvantage allows us to appreciate that disability should be perceived as a relationship. That impairments can lead to disabilities and handicaps is in part a function of a society which is organized and structured for and on behalf of the dominant able-bodied.

In this analysis, social factors and impairment produce disability by interaction. This way of understanding disability – often labelled ‘relational’ or ‘environmental’ – is important since it came to influence many official definitions at the end of the 20<sup>th</sup> century (see Parmeter, 2004:6; Barnes, 2012:20). For example, a relational understanding is referred to in the 1990 Americans with Disability Act of the US and in the legislations of the Scandinavian countries (Hejlskov Elvén et al, 2012:29), in the WHO (2011:4) *World Report on Disability*, where it is dubbed a ‘bio-psycho-social model of disability’, and advanced by UNESCO (Carlson, 2010:6). In classificatory practices this way of conceiving disability has also gained ground, evident for example by how the WHO complements its IDC-10 system with the ICF (see Hoskins, 2004:94), which includes social and environmental factors, and in how various editions of the AAIDD (and previously AAMR) conceptualise intellectual disability as an expression of the relationship between individual impairment and environment (Harris, 2006:5, 62; McDermott, 2007:6; Carlson, 2010:6).

Hence, the ‘truth’ of intellectual disability is no longer solely in the hands of medicine and psychology. Rather, the biophysical realities of impairment are comprehended as being socially situated in contexts that can add to or reduce disability. Arguably, relational understandings are ideologically linked to the original social model and are perhaps best conceived of as the result of a compromise with the perspectives of medicine and psychology, not discarding what are seen as the biophysical realities of impairment, but understanding them as socially situated (see Harris, 2006:63; WHO, 2011:4).

### *Models of naturalisation*

Despite their influence on important changes in the lives of disabled people, the social and relational understandings of disability also have significant limitations, primarily concerning their scope of critique and de-politicisation of the body. All of the dominating conceptions of disability – ‘social’, ‘relational’, and ‘medical’ – start from the assumption that the biology of

impairment and the social setting surrounding impaired bodies can be analytically separated. As I indicated above, this differs from my argument that the mobilisation of certain differences as grounds for classification and biological examination is inherently social, implying that every way of comprehending disabled bodies will be socially invested. In the social, medical, and relational models, to the contrary, the body is never seen as a field of politics. This presents us with two questions: first, what does it mean that these different ways of conceptualising disability share such a central presumption and, provided the analysis that I have presented in the previous two chapters, what critiques can be levelled against this separation?

Starting by considering the social model specifically, although questioning the medical authority over how people with disabilities should live, its conception of disability is unable to question the medical authority to define what impairments *are* – precisely because the bodily constitution is conceived of as prior to politics. Hence, as focus shifts to discriminatory social structures surrounding the impaired body, the norms that designate certain bodily constitutions as ‘disabled’ or ‘impaired’ are rendered outside the scope of criticism. The body is just as naturalised in the social model as it is from medical perspectives. It is just that the social model finds it irrelevant to the conception of ‘disability’ and to formulate political demands.

Here, it is worth looking at Butler’s intervention into feminist debates regarding the relationship between ‘sex’ and ‘gender’. Butler’s (1990:9-12; 1993: xii) argument in this context is that understanding ‘gender’ as layered on top of biological sex leads to a naturalisation of the sexed biology: what comes to matter in such analyses is the social construction that is inscribed upon biology, but this neglects the becoming of the body through social processes of normatively invested materialisations. Parallel to this, the original social model naturalises the impaired body by claiming its political irrelevance; when power enters in the form of discriminating social structures, the body is already there. In contrast, I suggest that the impaired/disabled brain, in its materiality, is not thinkable outside a regulative normativity which constitutes our perceptions of certain brains as, precisely, ‘impaired’ (see Butler, 1993: xii). Furthermore, and in contrast with recent formulations of some social model writers (see Barnes, 2012:22), these are not mere theoretical matters, removed from the lived realities of disability. On the contrary, if we approach the definition and understanding of intellectual disability as an instance of biopolitics, the specification of impairment is pivotal to making sense of social policy and thereby an integrated part of how disability politics is organized.

The problem of naturalising the body pertains to the relational model of disability as well: understanding disability as the result of an interaction between impairment and society still leaves out the norms, discourses, and institutions that shape what we understand as ‘impairment’. In this conception of disability, the body is primary and analytically separated from ‘the social’; it appears before social context and is therefore never seen as a field of politics. Here, society is context, interacting but never affecting, inscribing, or constructing the impaired biology. This reliance on pre-political impairment makes possible the same structures of naturalisation and de-politicisation of the body that we see in the clinical literature. It also explains why legislations which have been organized from this understanding can still rely on classificatory and medical depictions (see Barnes, 2012:23). It is sometimes suggested that the relational model of disability de-emphasises disability as pathology (Schalock, 2004:382), but what really happens is that it shifts the normative judgement, inherent to labelling something ‘pathological’, to the pre-political body.

Following Carlson (2010:7), despite the inroads of social perspectives on disability, intellectual disability is still firmly rooted in a biomedical and genetic discourse. One contributing reason for this is, I contend, that the models of disability that have dominated the critique of medicine and psychiatry still end up re-inscribing their ontological placement of human biology in the sphere of nature. Essentially, the on-going debates that revolve around the ‘models’ of disability are framed by the ‘nature-culture’-divide, where ‘nature’ stands for the biology of impairment and ‘culture’ for the conditions that can enable or disable the biological constitution of the individual. As one can see, this divide figures in numerous ways in intellectual disability discourse, but in the end the social boils down to being *after* biology and *after* impairment. The truth of disability is thereby thrown into a potentially endless oscillation between nature and culture, biology and social remedies, where both have to be accounted for and understood, but where one is always prior and the other always reactive to this primacy. In the end, the attempts to politicise disability by invoking an understanding of its relationship to social organization bring about a simultaneous *de*-politicisation since they are premised on the naturalisation of biology.

The presumption that the brains of people with intellectual disabilities exist prior to social organization restricts politics to questions regarding how to accommodate for the natural characteristics of these brains by effective and appropriate social services, as in relational and medical understandings, or to questions about identifying the discriminatory structures that disable

individuals, as in social model analysis. These theoretical perspectives may have been necessary to significantly change the pervasive oppression of the 20<sup>th</sup> century, but their underlying template is insufficient to address the construction of intellectual disability as biopolitics. Thus, rather than a relational or social understanding, my proposal is that we need a critique that starts from the proposition that the body is always already socially constituted.

## **Differences that Matter**

An overarching argument of these first three chapters has been that *descriptions* of intellectual disability *constitute* what intellectual disability is, that is, that the knowledge systems that I have analysed invent what they propose to represent. More than anything, this necessitates a critical approach to clinical and classificatory depictions in order to make explicit the stakes of ordering society along the lines of ‘normal’ and ‘pathological’ cognitive capacities. In the following, I will develop the analysis presented up to this point in order to elaborate on an alternative way of politicising intellectual disability that does not take the biology of deviance for granted.

### *Re-politicising intellectual disability*

In light of the ‘models’ of disability and how they operate to produce knowledge concerning what intellectual disability is, I argue that what we need is not so much another ‘model’ as a new epistemological approach to disability. As we shall see in the following pages, significant and important steps in this direction have already been taken by disability theorists starting from, or being influenced by, post-structural philosophy. Following Butler (1993) and disability theorists such as McRuer and Garland Thomson, I propose that, instead of examining the body *or* the social forces targeting the body, we need to understand how society, discourse, and governmental rationales, operate to produce our recognition of the biology of disability.

‘Intellectual disability’ is itself a discursive figure, loaded with history, value, and originating in ideals of ‘normal’ functioning. However, to recognise that intellectual disability emerges from a space where society and nature are indistinguishable is certainly not to deny the ‘reality’ of the condition. Rather than questioning the existence of intellectual disability, I have tried to discuss what it means for intellectual disability to exist and, by doing that, to thoroughly counter the presumption that its existence can be

hermetically separated from power, politics, and government. Hence, the idea is not that people with intellectual disabilities are like ‘normal’ people or that social constructions fool us into believing that the differences we perceive are chimeras clouding our sight. Rather, my analysis has sought to understand which differences come to matter and how governmental concerns are involved in this process. It follows that examinations of intellectual disability must recognise normativity; in this case concerning how ‘intelligence’ emerges in relation to the construct of the humanist subject, of how IQ-tests are designed to measure deficiencies with respect to this construct, and how these are turned into governmental tools, institutionalised within the state apparatus and ultimately motivated by the prospect of managing the population. These are ways of making intellectual disability exist in order to govern. As intellectual disability is bound up with some fundamental ideological propositions and ideals about what being human is, its existence is solid and very real, but never prior to politics.

In the introductory chapter, I stated that Crip theorisations of disability are relevant to these arguments since they propose an engagement with disability that starts from the recognition that politics and bodily compositions are always enmeshed (McRuer, 2006). In other words, and as I have argued, the constitution of disability is contingent on the ideal of a normal and fully functioning body, for example illustrated by how I showed that intellectual disability has been substantiated with reference to ‘normal’ cognitive functions. From a Crip perspective, the implicit or explicit yardstick of normalcy *produces* intellectual disability along the lines of ‘able’/‘disabled’, operating through a norm system that McRuer (2006:2) has dubbed an ideology of ‘able-bodieness’. In our society, able-bodieness operates as a non-identity, as the natural order of things, and hence as a presumption that does not need to be explicitly acknowledged (McRuer, 2006:1); it is the invisible ideal of how human bodies are supposed to function, instrumental for the formation of all categories defined by bodily and cognitive features. The invisibility of able-bodieness is why ‘normal’ cognitive functioning only occasionally is made explicit to define intellectual disability; for the most part, able-bodied ‘normalcy’ figure as a shared and taken-for-granted presumption. But it is against this backdrop that it becomes meaningful to discuss certain behaviours as ‘abnormal’ and to call them ‘disorders’. Whilst able-bodieness/able-brainness is institutionalised as the

invisible and normal order of things, disability is operating as its outside, detected, examined, categorised, and named<sup>9</sup>.

Now, as McRuer (2006:6) notes, almost everyone presumably wants to be 'normal' in the able-bodied/able-brained sense of the word – it is, after all, the incitement directed towards all of us by a culture privileging 'ability'. Along these lines, the terminology of 'risk' and 'pathology', frequently used in clinical depictions of intellectual disability, expresses that the valued position is that of the non-disabled. Furthermore, as the division between 'normal' and 'disabled' permeates Western societies, there can be no place for anyone outside the distinction between deficient and appropriate cognitive functioning. We are all situated in relation to this division and it is central to how we appear as subjects (although our relationship to it will only be made explicit once we fail to function as expected) (see Goodley, 2014:26). Running alongside Butler's (1990) analysis on heterosexuality as compulsory, McRuer (2006:7) concept 'compulsory able-bodieness' denotes how we are all impelled to fulfil the ideals of the able body and, I would add, the able brain. Even more closely related to the topic at hand, Clifford Simplican (2015:4) contends that the ideals of political belonging, of being a citizen and democratic subject, function in a similar way as an invisible and unattainable ideal that we are all measured against. In this way – provided that 'intellectual disability' ultimately consists of the failure to appear as a subject of reason and independence – this diagnosis can be seen as the result of a social ordering along the lines on inside/outside the ideals of humanist subjectivity that we are all becoming subjects in relation to.

In other words: the ideals of able-bodieness and full functionality compose an ontology of being human; an already existing pre-script as to how we see ourselves and to the ways societies are hierarchized (see Goodley & Runswick-Cole, 2014:4). My critique has targeted notions of intellectual disability that discard this pre-script, that fail to recognise that the knowledge of 'pure' bodies or brains is impossible to attain since it is produced within cultures and discourses that privilege the able brain. It is important to note that, following Butler's (1990: xxx-xxxii, 26-7) analysis of compulsory heterosexuality, able-bodieness, as an ideal, is ultimately unattainable. Since our functioning will fluctuate throughout life in ways that defy the strict division between 'able' and 'disabled', the perfectly able body, or the

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<sup>9</sup> As Goodley (2014:23) remarks, this resembles the ways that colonial knowledge is present as neutral and universal through the mobilisation of the vocabulary of humanism, philanthropy, and human rights.

perfectly functioning cognition, does not exist; the at-all-times-rational, reasoning, autonomous, and adaptable individual is a fiction that we are nevertheless compelled to accomplish and sustain throughout life. Essentially, this means that there is no identity position of ability in which disability is securely walled off and out of question; we must constantly strive to achieve able-bodieness and we must constantly re-inscribe our place in relation to the ability/disability divide through our behaviour (see Goodley, 2014:26). Therefore, the ideal of the able brain is bound to be endlessly repeated, on both individual and societal levels. Such repetition is performed through every stage of early detection of deficient cognition: in the milestones-checklists that parents judge their kids by, when the pre-school or school's psychologists are called in because something 'seems to be wrong', in the 'information talks' provided for parents 'unlucky' enough to have a kid with Down's syndrome, and so on. It is also repeated on an individual level as our behaviour is geared towards confirming our proper mental abilities. Thus, when Butler (1993: ix) asserts that the materiality of the body – sexed bodies in her analyses, cognitively disabled bodies in mine – is constructed through the ritualised repetition of norms, this is what she has in mind; biological constitutions come to matter as 'disabled' through reiterations of certain ways of being as desirable and others as unfavourable that are repeated throughout society and in the behaviour of individuals. In this way, the social and historical processes that have singled out certain characteristics as ordering our understanding of humanity – through the creation of categorisations, taxonomies, but also of lay knowledge and folklore – provide the scene of recognition of some people as 'intellectually disabled' and others as 'normal'. The intellectually disabled brain could not exist without such social and discursive formations (see Lloyd, 2005:24).

Parsed in a more densely-theoretical way: irrationality, lunacy, idiocy, foolishness, and so on, all figure as the constitutive outside of the 'reason' and 'rationality' of the humanist subject; it is *that* which must be dispelled for 'rationality' and 'reason' to appear as possible. By the same discursive gesture, however, the constitutive outside of reason also appears *within* the dominating normativity, precisely by being its condition of possibility (see Butler, 1993: xiii-xx). As was discussed in the introductory theory section, the outside of cognitive malfunction is latently inside in the form of an unfulfilled possibility figured as threat. The 'threat of a terrifying return', read this way, is the result of intellectual disability simultaneously being the opposition of, and the necessary precondition for, the appearance of 'normal' cognitive functioning. The efforts to name, classify, and inscribe the

judgement of deviance upon the materiality of the brain are all efforts to enclose otherness, to render it less of a threat, to safely contain it and project it onto the bodies of specific individuals who can be distanced from the humanist subject.

As totalising – and perhaps pessimistic – as this analysis may seem, a line of reasoning often emphasised in theoretical attempts of ‘cripping’ disability concerns its potential to trouble our conceptions of ‘normalcy’ (see McRuer, 2006:10; Goodley & Runswick-Cole, 2014:4). That is, the very instability of the system of signification, formed around ‘otherness’ and ‘norm’, implies that there is always room for contestation, resistance, and rethinking. This is what Butler (1993:25) calls the task of refiguring the necessary outside as a future horizon, in which the violence of exclusion is constantly in the process of being overcome. Viewed in this way, the instability of the category of ‘disability’ can be seen as a resource for critique (see Garland Thomson, 2012), as Goodley and Runswick-Cole (2014:14) points out: to the extent that ‘able-bodiness’ operates as a taken-for-granted discursive system of power, disability may very well serve, not just as the otherness of this ideal, but also as a site of contestation (Goodley & Runswick-Cole, 2014). Like Butler (1990) analysed ‘gender trouble’, thus, we may follow McRuer (2006:10) asking about the extent to which we are living in a society equally haunted by ‘ability trouble’. Indeed, that the construction of intellectual disability requires a continuous process of reiterating a prior devaluation suggests that the biopolitical regime which produces knowledge on this condition is haunted by its own inability to reach systemic closure; the will to normalise, as Garland Thomson (2006:262) calls it, can never be satisfied. We shall return to this discussion, regarding discursive openings and disruptions as possibilities of resistance, in the last three chapters of this book.

Now, this elaboration on intellectual disability and performativity calls for a clarification regarding the place that ‘biopolitics’ holds in the attempts to ‘crip’ intellectual disability, or, in other words, how ‘biopolitics’ and ‘performativity’ blend together in my analysis. On the most basic level, of course, biopolitics as elaborated on by Foucault, is the governing of the population, whilst the primary inspiration I have drawn from Butler (and her theoretical heirs) has been related to understanding the relationship between bodies and politics. For Foucault, biopolitics is fuelled by the need to manage the population. His is an analysis of the concerns of government and the productiveness of power. For Butler, and some Crip writers, performativity stems from the need to consolidate identity. This is why the domain of

‘abject’ beings returns to haunt normalcy: theirs are analyses of how the productiveness of power has come to shape the becoming of subjects, through performativity and what Butler calls ‘materialisation’. Thus, ‘biopolitics’ has helped us recognise that classification and clinical knowledge are preceded by the recognition that there is a group of people in society that needs to be separated and targeted by government. The analysis of the relationship between biology and politics, on the other hand, proposes that the differences of people with intellectual disabilities are dependent on the prior recognitions of deviancies from the same humanist ideals that incite governmental action. In other words, the societal reproduction of ideas which makes certain differences matter are the same processes that government act on. And in this way, biopolitics helps us explain the rationalities of government, whilst Butler’s performativity helps us understand the constitution and consolidation of biological differences.

In summary, thus, the constitution of intellectual disability meant a redistribution in the discursive structure underpinning the humanist subject. The invention of this diagnosis, during the first decades of the 20<sup>th</sup> century, as the opposite of ideals of ‘reason’ and ‘independence’ also meant handling the threat and spectral nature of a constitutive outside. By being inserted into a binary of norm/deviancy, unreason was meant to be enclosed and governed as a way of rendering it less of a threat. Thus, from being an unnameable and unspecified outside, figuring only as a defining absence of the humanist subject, ‘intellectual disability’ came into being as ‘otherness’, named and specified in order to be properly excluded and separated from human reason. However, as I have shown, constituting the ‘other’ of the humanist subject produced new problems, related to the knowledge technologies of use and the boundary between the normal human being and their abnormal ‘other’. The ritualised repetition of norms of reason, separating this group again and again, thus serves to uphold the status of people with intellectual disabilities as ‘others’.

#### *Internalisation, performativity, and looping-effects*

A final point that I want to briefly discuss regards the internalisation of intellectual disability by individuals labelled as such. As part of his theory of ‘dynamic nominalism’, Hacking coined (2007:285-6) the term ‘looping effects’ to denote how classifications come to interact with the persons classified. He argues:

We think of these kinds of people as given, as definite classes defined by definite properties. As we get to know more about these properties, we will be able to control, to help, to change, or to emulate them better. But it is not quite like that. They are moving targets because our investigations interact with the targets themselves, and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved. This is the looping effect. Sometimes our sciences create kinds of people that in a certain sense did not exist before. That is making up people. (Hacking, 2007:293)

Following this, the constitution of intellectual disability, around a century ago, ‘made up’ people who had not previously existed. It shaped how people were perceived and, by extension, how people perceived themselves. The looping effect, in turn, concerns how members of this group came to inhabit this role, how it shaped their way of existing and understanding themselves and how it thereby affected their behaviour. Here, I agree with Carlson (2010:95) that Hacking’s description captures something of the interaction between the label and the people labelled with ‘intellectual disability’. Although Hacking’s account starts from meta-theoretical presumptions which differ from mine – most notably as concerns his neglect of the constitutive force of discourse and his reliance on an ontological split between social constructions and ‘reality’ (see Hacking, 2007:294-5, 300, 303-4)<sup>10</sup> – his analysis directs attention to internalisation of socially constituted identities. Of course, Butler’s performativity is itself a theory of internalisation, transferred to this context about how the ideals of ‘compulsory able-bodiedness’ requires all of us to enact the division between ‘able’ and ‘disabled’. Thus, as I have argued, to exist as ‘intellectually disabled’ is to exist in relation to a socially mediated normativity of ‘normal intelligence’; it is to exist in a discourse where it is pre-established that one’s brain embodies differences that matter. Now, just as the ideal of ‘intelligence’ incites us to behave in certain ways, so does the associated category of ‘otherness’. Goodey (2011:1-2) argues that the label of ‘intellectual disability’ often means that these people have been targeted by social interventions since their infancy. Their personal characteristics are reinterpreted as ‘psychological objects’, ameliorated by pedagogical methods, which may well help them, but as history has shown, this is very often not the case. It is not far-fetched to say that many people with intellectual disabilities, perhaps most, live their

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<sup>10</sup> Corresponding to his neglect of the constitutive force of language, Hacking is himself prone to speak of disability as a ‘problem’ and in terms of ‘abnormality’ – choices of words that I would say contribute to constitute these phenomena as undesirable.

lives embedded by various services that are specially tailored for this specific group and this has consequences for how people belonging to this category understand themselves and their existence. Hacking (2007:296) jokingly refers to 'split bars' for people with split personalities to point towards how people with split personalities consolidated as a specific group. As most people who have worked within disability services know, not only are there bar nights for people with intellectual disabilities, but dances, football teams, recreational camps, and, in my hometown of Malmö, Sweden, a part of the coastline called 'the handicap shore'. The sum of the effect on the individual, of all such treatments targeting people in their capacity as 'intellectually disabled', is the looping effect.

Regardless of whether one is referencing Hacking or Butler, the process of internalisation is not primarily described as conscious adjustments or performances. In Butler's analysis, sex is not performed by individuals actively choosing to enact 'femininity' or 'masculinity', but is rather to be conceived of as a response to a psychological loss, stemming from the impossibility to reach identity closure with respect to the unattainable ideals of a fixed gender identity. Likewise, for Hacking, the process of internalising classificatory categories is made through how individuals respond to the ways institutions target them; it is an analysis of the creation of identity with regards to how one is socially situated and related to. In both cases, identities are based upon self-understandings shaped in dialogue with our surroundings. Worth noting is that this means that the identity categories that we come to inhabit and relate to, like 'sex', 'ability', or 'race', are prior to our appearance as subjects (see Mitchell & Snyder, 2012:45). Since these categories are embedded in so many aspects of our everyday lives, they will form the preconditions for how we can emerge as subjects and provide the language in which we can understand ourselves (see Butler, 2005:22-4).

Again, this is not suggesting a totalising societal and discursive determinism, where subjectivity is straightforwardly moulded from dominating ideals. Indeed, precisely because identity categories exist prior to our becoming, they will never fully fit. As Butler puts it (2005:35-7), the language that we possess to describe ourselves will always, to some extent, misrepresent us and hence establish an incomplete subject. This incompleteness is what impels us to reiterate prior norms of sex or of ability, but it also provides opportunities to critically reconsider how we emerged as subjects provided precisely these categories and ideals. Thus, questioning one's own ontological status, as 'male' and 'able-brained' in my case, or as 'intellectually disabled' in the cases of those diagnosed, opens up spaces

from which the assumptions concerning who one is and how one should act become possible to re-examine. In other words: internalisation is also a place of agency. We will return to this in Chapter 8, wherein activists labelled with intellectual disability engage in a far-reaching contestation of their identity as ‘intellectually disabled’.

Before the final section on resistance and the possibility to rethink intellectual disability, the next three chapters will focus on the main issue of this book: what happens *after* people with intellectual disabilities are formally included as citizens? As we shall see, the otherness which is established and anchored through medical and classificatory knowledge will serve as an essential background to understanding how people of this group are simultaneously included and excluded.



## *Part II: Citizenship*

There is a door. The door opens, in comes the Outside, even inside he remains the outside, the Outside in person, that which I do not know, who strikes me very hard and loves me, thinks Tsvetaeva, the women who loves the devils who carry her away.

HÉLÈNE CIXOUS  
*Stigmata*

The very factors that propel such a wide range of theorists to make appeal to 'citizenship' as a common status which might provide a framework for a just and peaceful coexistence also seem to expose citizenship as an impossible and even oppressive discourse.

JUDITH SQUIRES  
The State in (and of) Feminist Visions of Political Citizenship

## 4. Philosophy

Up to this point, the overarching argument has been that scientific knowledge systems of intellectual disability construct the condition as biologically anchored otherness for the purpose of making the population governable. The three chapters included in this second section examine what happens when people of such otherness are to be included into the citizenry.

Throughout this and the coming chapters, we will encounter a recurring structure: in fundamental ways, intellectual disability causes *disruptions* to common notions of that which defines human beings. Disruption means that schemes of justice, morality, or politics are destabilised when faced with a group that is presumed to be different with respect to what is understood as characterising a human being. This is to say that whenever a political project takes reason and autonomy as its basic ontological presumptions, and as long as intellectual disability is seen as lacking in these respects, the resulting disruptions must be resolved by some sort of *supplement* in order to deal with this condition. Supplements can consist of, for example, charity or segregation, but also of special attempts to include the group without reconsidering the humanist subject; a supplement is an extra principle necessary to deal with what falls outside of the ordinary.

In other words, attempts to include people with intellectual disabilities are destined to repeat exclusion as long as they are founded on the same ontology of human beings which produced the otherness of the condition in the first place; such attempts will be entrenched by the structure of disruption and supplementation, where intellectual disability disrupts the general idea of inclusion and hence must be supplemented with ways of treating the group that re-inscribe their status as outsiders of full belonging. It is important to remember here how the notions of human reason put forward by Locke and Kant went directly into early conceptions of intelligence, IQ-testing, and the emerging field of psychology, all dedicated to identifying this group as falling outside the scope of 'normal' humanity. Today, notions of citizenship that are ingrained by the very same tradition of humanist philosophy are meant to include this group. The effect of this is that contemporary politics of

intellectual disability both govern by including and by re-inscribing exclusion; it is a dual way of managing that both seeks to create a new included citizen-subject whilst upholding otherness through maintaining the marginalisation and restrained agency of people with this condition. The concurrency of these two modes of government defines the post-institutionalisation era.

This argument breaks with the common narrative that describes disability politics as a succession from oppressive rule that has given way to citizenship, but which is sometimes stalled by implementation failures. First, when the politics of inclusion operates as intended, it also moulds subjectivity and creates citizen-subjects (see Cruikshank, 1999). Hence, 'inclusion' is also a means of government, an instance of biopolitics that works through 'the conduct of conduct' (Foucault, 2000:341; 2007). As my analysis will show, particularly in Chapter 6, the absence of force and coercion does not mean the absence of power. Policy commitments to 'citizenship' and 'inclusion' does not imply the withdrawal of government. Secondly, government by inclusion is parallel to and intertwined with systematised and structural exclusions. This is an expression of how intellectual disability remains the constitutive outside of citizenship ideals, after the advent of politics of inclusion. Indeed, efforts to include by these ideals reinforce the ideological framework that rendered the group other in the first place. By these two rationalities of government, the politics of inclusion has transformed the biopolitical rule of intellectual disability rather than ended or moved power from a paternal state to people with intellectual disabilities; it has converted government into a regime of simultaneous inclusion/exclusion. In other words, the disruptions of politics of inclusion caused by intellectual disability is supplemented by efforts that maintain their exclusion.

As we shall see, the three chapters of this part make use of different methods in order to understand the politics of post-institutionalisation. This chapter is a political theoretical critique in which I engage with the arguments of a number of prominent philosophers. The next chapter is a discourse analysis of a number of treaties and international policy documents in which I analyse their presumptions and discursive implications. The last chapter of this section, Chapter 6, is based on an interview study in which I analyse how support workers describe their job in order to understand the group home as a place where citizens with intellectual disability are both produced and constrained. All of the chapters are sorted under the rubric of 'Citizenship'. This is because they all deal with the inclusion of people with intellectual

disabilities into community belonging. Presently, and in the actual policies targeting this group, ‘citizenship’ is a dominating way of describing political efforts to include people with disability. These efforts, however, have a history; they are founded on conceptions of ‘independence’, ‘autonomy’ and ‘participation’ which have been central to Western political thought. In order to understand the politics of post-institutionalisation, it is therefore necessary to look at why people with intellectual disabilities became outsiders in the first place. This will be the principle task of this chapter. Although not all philosophers discussed theorise explicitly in terms of ‘citizenship’, they have all informed the political imaginary that the contemporary politics of inclusion has emerged from.

The exclusion of people marked by deficient intelligence from political philosophy will be examined in two analytical steps: *first*, I will investigate how such individuals disrupt philosophical notions of societal belonging. *Secondly*, I will show how efforts to include people with intellectual disabilities often re-inscribe exclusion as they are based on ontological presumptions similar to the ones that caused the exclusion in the first place. In my analysis, I will engage with John Locke’s *Two Treatises of Government* (1988 [1690]) and *An Essay Concerning Human Understanding* ([1690] i.e. ‘Essay’) (in the latter case building largely on Clifford Simplican’s [2015] analysis), David Hume’s *An Enquiry Concerning the Principles of Morals* (1957 [1751] i.e. ‘2:d Enquiry’), John Stuart Mill’s and Harriet Taylor’s *On Liberty* (2003[1899]), and the moral philosophy of Immanuel Kant, primarily as developed in *Groundwork of the Metaphysic of Morals* (2002[1785]). The selection of these works is purposely diverse: my argument is that ‘deficient intelligence’ has figured in similar ways across Western political thinking. Furthermore, as my argument will be that this is more than mere historical prejudice, I will conclude the first analytical step by discussing John Rawls’s (1971) theory of ‘justice as fairness’, which explicitly discards people with cognitive deficits from the conception of justice. In the second step, analysing philosophical efforts to include, I will first analyse Charles Taylor’s notion of a politics of recognition and thereafter Martha Nussbaum’s capabilities approach. Whilst Taylor’s treatment of intellectual disability has a minor place in his theory (half a page in ‘Politics of Recognition’ [1995]), one of the main purposes of Nussbaum’s (2006) *Frontiers of Justice* is to include people with disabilities into liberal

conceptions of justice. Nussbaum and Taylor are both chosen because they explicitly address inclusion of people with intellectual disabilities<sup>11</sup>.

## **Excluding Lack of Reason**

To start with: if we take ‘citizenship’ to denote the relationship between the individual and the political community, it becomes evident that certain classes of people, specified by their inferior minds, reoccur throughout the history of philosophy as the constitutive outside of societal belonging. Consider the examples below.

The *Second Treatise of Government* contains an intriguing critique of Filmer’s notion of absolute patriarchal hierarchy and rule, whereas John Locke (1988) uses the potential for reason in children as grounds for contesting the absoluteness of patriarchal rule. Since children have this potential, the authority over them is not absolute, but restricted until ‘reason’ has developed. Locke then goes on to contrast the temporary control of children with the rule of people suffering from a permanent lack of reason (Locke, 1988:308); the ‘lunatics’ and ‘ideots’ who by merit of their deficient minds cannot be part of the social contract. In other words, and as we shall get back to in a moment, lack of reason *disrupts* Locke’s theory of the contract, which requires a *supplement* consisting of ‘permanent patriarchal rule’ of the permanently deficient. This shows how deficient rational capacities mark the limits of inclusion for Locke’s social contract.

David Hume, in the 2:d Inquiry (1957), differentiates between a government of justice and a government of a principle of charity, explicitly stating that those of ‘inferior strength, both of body and mind’ shall be subjected to the principle of ‘gentle usage’ rather than to a ‘government of justice’. Hume bases his conception of justice on what he calls ‘rough equality’, which means that people must have similar powers for situations of societal co-operation – and hence justice – to arise (see Nussbaum, 2006:47, 61-2). He calls the conditions for such cooperation ‘circumstances of justice’ and the gist of his argument is that men will only work out principles to govern themselves if they believe that others have similar capacities. Although Hume does not base his theory on the idea of a social contract, his ‘circumstances of

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<sup>11</sup> This is also why I will not discuss related approaches, as for example the concept of ‘recognition’ in Honneth’s thinking or the capabilities-approach of Amartya Sen.

justice' resemble the structure of Locke's motivations for excluding people who fail to meet the ideals of mental capacity.

Finally, in their ardent defence of diversity and tolerance in *On Liberty*, John Stuart Mill and Harriet Taylor (Mill, 2003 [1899])<sup>12</sup> exempt from their principles of liberty people who lack reason. Their discussion of the perpetual tension between the sovereignty of the individual and the oppression of the state concludes with a defence of the absolute independence of each in matters which only concern themselves (Mill, 2003:81). This principle, however, is disrupted a few lines later by people not 'in the maturity of their faculties' for whom such individual freedom does not apply (Mill, 2003:81). Not only are Mill and Taylor talking about children and legal minors in this context, but also about those who need to be taken care of by others due to their lack of reason (Mill, 2003:81). Thus, dependency and mental inferiority are here intertwined. Accordingly, the principles of freedom and individual sovereignty can only be granted for *all* if simultaneously held back from *some*, illustrating how tolerance and diversity, so central to Mill's and Taylor's account, are demarcated by a presumed set of capacities that not all people possess. Echoing Locke and Hume, the capacity of reason operates both as an underlying ontology of humanity and as a dividing line between what is inside and what is outside of the sphere of inclusion.

It might be suggested that these examples, at least to a degree, are the result of the historical settings of these philosophers. In a trivial sense, this is certainly correct. However, for my purposes it is also beside the point. I am not interested in charging a bunch of historical figures with 'ableism'. Rather, in order to historicise our present, I want to explore how the Western history of political thinking is structured by an ontology of human beings which produces exclusions; I am interested in how humanism, as a way of seeking to define human existence by singling out certain characteristics, has always been bounded. This history is inscribed onto our present: the paradoxical simultaneity of inclusion and exclusion that characterises present intellectual disability politics must be understood against the backdrop of how our conceptions of belonging have been premised on excluding people who are assumed to lack reason.

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<sup>12</sup> Today, it is widely accepted that Mill and Taylor co-authored *On Liberty*. As I follow prevailing reference standards, only Mill's name appear in references, but I want to credit both with authorship in the actual text.

### *Reason and exclusion*

The exclusion of persons ‘lacking reason’ from notions of belonging is founded on a specific understanding of society and on a related conception of the subject. To illustrate this, I will turn to two of the most influential philosophers on each area: John Locke and his idea of society as founded on a social contract, and the subject of Immanuel Kant’s moral philosophy. Although not all Western political theories of modernity are contractual and not all notions of subjectivity are Kantian, I do believe that these two are helpful for our present purposes.

The above reference to Locke’s justification of patriarchal rule serves as an illustration of his more general treatment of intellectual disability. In what I consider to be the best analysis of intellectual disability and the history of Western political philosophy, Clifford Simplican (2015) argues that Locke’s exclusion of ‘mental deficiency’ is pivotal to his overarching political project. Following her argument, the social contract establishes an ideal, which is also deeply ingrained in present societies, concerning what political participation requires. Thus, when Locke argues that people ‘born [...] to the use of the same faculties’ should be equal in regards to the state, he sets a precedent for how political philosophy, within and outside the contract tradition, has premised political rights and duties on certain capacities (see Clifford Simplican, 2015:26). In turn, this implies that some people, on these grounds, are excluded. Locke frequently uses ‘idiots’, along with other denotations of ‘mental deficiency’, to limit the sphere of political membership (Clifford Simplican, 2015:25-7). In his argument, such people serves the purpose of characterising ‘normal’ personhood by exemplifying abnormality. Through a close reading of Locke’s *Essay*, Clifford Simplican (2015:33) convincingly argues that impediments of reason are vital to Locke’s political theory, whose notion of humanity is ultimately anchored in the idea that reason is the faculty that comes closest to God’s imperfectability. In turn, she therefore argues that an understanding of Locke’s social contract requires that we acknowledge how it is premised on an implicit ‘capacity contract’ that states that membership in society hinges on the rational capacities of individuals (Clifford Simplican, 2015:40-1). By the capacity contract, ‘reason’ operates as an implicit justification of political subordination and, in this way, Locke can justify political rule on the grounds of the mental faculties of those subjected to government (see Clifford Simplican, 2015:40).

Although Clifford Simplican’s argument has much more nuance, arguing that the ‘capacity contract’ also stresses a form of human vulnerability that can be mobilised for the purposes of solidarity, it is the

exclusion of unreason and the supplementary addition of patriarchal rule that is important for my purposes. People need to be removed from political membership in order for Locke's political theory and notion of personhood to take off. Now, if the social contract were to offer a story of society whose main actor is a subject characterised by rational capacities, Immanuel Kant could be seen as the central philosopher who developed this notion of subjectivity by making it the basis of his moral philosophy<sup>13</sup>. Understanding the prerequisites of being included into Kant's conception of 'moral autonomy' can thus help us to understand the primacy of reason in modern philosophy more generally.

For Kant, individual autonomy means consolidation with a universal moral law: we can all be moral in the same way since our individual rationality leads us down the same path of reason. Thus, autonomy and reason are tightly knit together. An important component of this argument is that 'reason' should be conceived of as functioning *a priori*, that is, as prior and separate from any experiences, senses, and observations (Kant, 2002:4-5); the moral law is established by turning inwards and seeking out principles by means of pure rationality, an exercise that discards our sensory impressions and social ties from moral deliberation. This means that, although reason will provide all moral agents the same answers, the exercise of deriving the moral law is strictly individual.

Kant's (2002:46-7) most famous moral dictum is found in his second formulation of the categorical imperative, stating that we should never treat others as mere instruments, but also always as ends in themselves. This principle has been central to liberal philosophy, for example seen in Rawls's notion of justice, in Nussbaum's capabilities approach, and in various charges against utilitarianism. For Kant, this principle means that we should acknowledge that the rational wills of others can be in agreement with ours and be able to contain in themselves the ends of our actions (2002:47-8). Thus, the principle effectively ties the universality of individual reason to a set of moral requirements towards others. Kant deduces from this that respect for other human beings, in the strongest sense of the word 'respect', is a respect for their capacity to be moral – it is to acknowledge in others a

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<sup>13</sup> I believe that a very similar analysis to the one advanced here could be made from Kant's political philosophy, which is strongly connected to his moral philosophy (Reiss, 1991). However, as the relationship between Kant's politics and morals is complex and continuously debated, and as his politics also is built on a social contract that is similar to Locke's (see Nussbaum, 2006:50-1), I will here focus on the subject as it appears in Kant's writing on morals.

morality that is guided by reason. Since we cannot force our moral views upon others, and since actions that are forced do not qualify as ‘moral’, the notion of the universality of reason serves to derive communality in a world inhabited by autonomous selves. What makes actions moral is that they are anchored in the exercise of individual deliberation. Hence, Kant’s moral philosophy is deontological, which means that consequences are irrelevant to moral evaluations of actions (Kant, 2002:16). It follows that there is a distinction between acting from *one’s own recognition* of moral laws and *in accordance* with moral laws (for example due to custom or legislation) even though the actual course of action may be the same. Motivation, rather than results, is what makes actions right or wrong. For Kant, the enforcement of judicial laws serves the purpose of ensuring that the actions of individuals conform to what is morally required even in the absence of a moral motivation. However, only human rationality can render actions moral, which means that behaviour conforming to moral principles, but produced by custom or legal measures, does not deserve the respect and dignity reserved for behaviour derived by *a priori* deliberation (see Honig, 1993:26). Therefore, those who lack the will of the moral law – i.e. who lack ‘reason’ – are excluded from the moral community and figure in society purely as subjects of laws that serve to protect the circumstances of moral reasoning for the fully rational part of the population.

Hence, a precondition for being respected by others as an autonomous moral agent is that one possesses the capacity to derive the moral law by reason (Kant, 2002:17). Of course, reason is not the only characteristic of human beings, but it is the characteristic which sets us apart from other living things: although humans also have needs, desires, and instincts, being moral is about raising ourselves above these by establishing laws for our own actions (see Nussbaum, 2006:131). In this way, Kant depicts a subject split between ‘animality’ and ‘rationality’, where being moral consists of taming the former by the latter. Through doing this, Kant locates those failing to meet his rigorous standards of reason outside the sphere of moral capacity and in this way, the formation of a grounds for belonging – here, to a moral community – produces a simultaneous set of exclusions, (see Honig, 1993:18-9, 38-41).

To summarise, the architecture of exclusion in Kant corresponds to Locke’s ‘permanent patriarchal rule’ and Hume’s above mentioned principle of ‘gentle usage’. The motivation behind Locke’s subjection of individuals seen as cognitively inferior to ‘patriarchal rule’ is that these fail to meet the requirements of what is distinctively human. Likewise, in Hume, those

inferior in ‘body and mind’ cannot be subjects of justice precisely because they fail to conform to the idea of what it is being fully human – here, the principle of ‘gentle usage’ works as the supplement answering to disruption. In Kant, the judicial law, enforcing moral behaviour without the moral motivation of reason, supplements how people lacking deliberative rationality disrupt his conception of personhood. Obviously, the designation of reason and rationality as what characterises humans take different forms in Kant, Locke, and Hume. However, all of them share such ontological commitments to human nature that correspondingly constitutes certain individuals as ‘others’.

### *Rawls's Justice as Fairness*

It is important to note that the relationship between reason and exclusion is much more than a historical artefact, but rather a structure that recurs in political thinking that starts from a definition of personhood as reason, autonomy, or deliberation. In the below I will discuss the structure of disruption and supplement in the philosophy of John Rawls, who for similar reasons as Locke, Kant, and Hume, explicitly excludes people with intellectual disabilities from his conception of justice. I shall start by reviewing the reasons why people of this group are excluded and thereafter go on to elaborate on the significance of this exclusion by engaging Honig's (1993: Chapter 5) reading of Rawls's theory of justice as fairness.

Rawls's *A Theory of Justice* (1971) is arguably one of the most influential books of political philosophy of the 20<sup>th</sup> century, reconceptualising social contract theory and building on Kant's moral philosophy and Hume's ‘circumstances of justice’. Rawls exclusion of people with deficient cognitive capacities follows from his assertion that the ‘sense of justice’ is a mental capacity involving the exercise of thought (1971:11). Although a contract theory, Rawls differs from classical contractarian thinking in that he does not figure a state of nature from where the contracting parties create political order. Instead, his original position is to be conceived of as a fictive situation that works as a procedural legitimisation of principles of justice. The only assumptions made about the characteristics of the contracting parties in the situation where the contract is agreed upon – what he calls the ‘original position’ – are that their intellectual abilities lie within the ‘normal range’ and that they are acting out of self-interest (Rawls, 1971:10, 83-4). Hence, rather than deriving the principles of justice from characteristics of the individuals that enter into the contract or from pre-societal natural rights, a set of restrictions of the contracting situation itself is what produces his principles

of justice. The gist of his argument is that, in a situation in which individuals do not know what kind of person they will become and what kind of life they will live in an unknown future society – that is behind a ‘veil of ignorance’ – two principles will be chosen to govern society: (1) that each person has an equal right to the most extensive liberty that is compatible with a similar liberty for others and that (2) the only tolerable inequalities deviating from equal distribution are of such a nature that the least well off in society gains from them (Rawls, 1971:53, 266-7).

The question here is why Rawls needs to exclude people falling outside the normal range of abilities from the contracting situation. A first reason is his assumption that contracting parties are motivated by mutual advantage. Following Rawls’s assumptions, for a solely self-interested person there would be no purpose in making a contract with people who are unlikely to contribute to the common good. Hence, provided this assumption, Rawls deduces that people who are likely to demand extensive care and leave few contributions would be unwelcome behind the veil of ignorance (see Nussbaum, 2006:104, 117). At this stage of his argument, Rawls (1971:109-10) leans heavily on Hume’s ‘circumstances of justice’, mentioned above, which hold that concerns of justice emerge between people of roughly equal capacities in a world of scarce resources. As contracting parties are not allowed to be motivated by benevolence<sup>14</sup>, people with disabilities are left out of the contracting situation. The non-contribution of people with disabilities is thus taken for granted in Rawls’s argument. A related motif here, pointed out by Nussbaum (2006:114), is that adding functional limitations to the characteristics of contracting parties would complicate measurements of whether individuals are more or less well-off in the future society. For example, two people, one with and one without a disability can be of similar rank and have similar income, but it would still be hard to say that their situations are comparable. From Rawls viewpoint, this is problematic considering the second principle of justice, called the ‘difference principle’, which requires that questions concerning who is more or less well-off can be clearly answered. Excluding disability thus means keeping issues of who gains and does not purposefully simple.

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<sup>14</sup> Rawls is well aware that this is a simplified picture of the actual motivation of individuals. However, his argument is that benevolence and the concerns of others are served for by the veil of ignorance in his theory, whilst the subjects assumed to choose the principles of justice are purposely kept one-dimensional. Thus, accusations of Rawls’s simplifying and reducing human motivations somewhat miss their target.

More fundamentally, I believe, Rawls's notion of personhood draws heavily on the rationalism of Kant, with its emphasis on the deliberative capacities of individuals. Indeed, the exercise of deriving principles of justice by discarding one's social roles behind a veil of ignorance can be seen as parallel to the Kantian moral requirements of *a priori* moral reasoning: in both cases, principles of justice or morals are reached by the intellectual exercise of stripping oneself of one's social belongings. The subject projected behind the 'veil of ignorance' functions by deliberative rationality, a subject assumed to be able to turn their back against society to find out what to do and who they want to be: it is a coherent, autonomous, and rational self that reaffirms the principles of justice. The rational subject, in turn, is a guarantee that the contracting parties really choose rational principles from the original position and thereby the exclusion of intellectual disability is central to ensure the linkage between Rawls's original position and the principles of justice.

Thus, intellectual disability disrupts Rawls's notions of personhood and mutual advantage, which, in turn, means that the handling of this group requires a supplement. Like other contract philosophers, Rawls assumes that those who decides on the principles of the contract and those that these principles apply to are the same: as people with intellectual disabilities are left out of the contracting situation, they are not targeted by its outcome (see Nussbaum, 2006:16). Rawls's solution is to postpone the treatment of people with intellectual disabilities until after the contracting parties have agreed upon the principles of justice, that is, their situation should be handled *ad hoc* through legal arrangements outside the scope of justice. This exclusion is repeated throughout Rawls's work; for example in the postulation that the contracting parties know that their 'native endowments' all lay within 'the normal range' (Rawls, 1971:83-4); in the statement that the principle aim of the theory is 'to specify the fair terms of cooperation among persons' within a 'normal span of native endowments' (Rawls, 1993:183); and in the assumption that 'persons as citizens have all the capacities that enable them to be cooperating members of society' (Rawls, 1993:20). However, as Clifford Simplican (2015:73, 84) argues, accepting Rawls's own description of this as a mere 'postponement' underplays the perpetual definitional work performed by intellectual disability in his theory of justice. Rawls frequently uses people of inferior intellect – described as subjects of pity and unfortunate circumstances – to demarcate political subjectivity in ways resembling how Locke used 'idiocy' to construct a definition of personhood. Only by

discarding certain ways of being can the rational subject be designated as the agent that agrees on the principles of the just society.

Now, in addition, I want to extend my analysis by considering the above discussion in light of Honig's (1993: Chapter 5) reading of Rawls. Her engagement begins with the acknowledgement that justice as fairness supposes a pluralism of ideals in democratic societies governed by the principles of justice, a plurality being the result of human reason exerted under liberty. According to Rawls, justifications of political ends should be acceptable to all and not just to particular groups, which, in turn, implies that public reason corresponds to a specific type of subjectivity; namely, the morally autonomous and deliberating subject that we recognise from Kant (Honig, 1993:127). Thus, in Honig's reading, the focus is shifted from the procedural legitimation of justice towards Rawls's envisioning of a just society, thereby emphasising that the rational subject not only serves the purpose of guaranteeing that a certain set of principles is chosen, but also that the resulting society is harmonious and free from conflicts. How is such harmony and pluralism treated in Rawls's writings? Honig (1993:126-8) argues that the peaceful coexistence of Rawls's just society is premised on the exclusion of certain situations and certain people that she calls 'remainders'. The 'remainders' are those that threaten the consensus around the principles of justice and, more generally, the homogeneity and coherence of Rawls's political theory. To understand how Rawls guarantees a minimum of value conflicts, it is important to remember that self-interested individuals acting behind a veil of ignorance will always arrive at the same principles of justice. Rationality itself is thereby seen as leading to homogeneity of conceptions of justice. Here, Honig notes how Rawls uses the 'veil of ignorance', not only as a hypothetical and procedural guarantee of just outcomes, but also as a mental exercise that people can make use of in order to remind themselves of what justice entails (see Rawls, 1971:120). In turn, this constitutes a process of self-ordering that produces conformity on the principles of justice (Honig, 1993:132-3)<sup>15</sup>. Thus, when faced with difficult situations that actualise questions of justice, Rawls urges us to consider what our route of action would be if choosing from behind a veil of ignorance (note here that this does not concern situations involving people with

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<sup>15</sup> Although beside the point for the argument I am making here, for Honig (1993), precisely the moments of eruptions and clashes surrounding the fundamental principles of social order constitute the very moments in which politics can emerge. Discarding these moments essentially means displacing the politics of political theory.

intellectual disabilities, who are not considered subjects of justice at all). As long as we possess the proper rational capacities, this procedure will provide the same result. Lastly, Honig (1993:134-6) stresses that Rawls devotes a lot of attention to how to deal with individuals who, nevertheless, fail to conform to the principles of justice; regarding whether they can be legitimately punished and concerning how to persuade them of the advantages of Rawls's principles.

Rawls's sustained attention towards non-conformity testifies to a lack of reliance concerning the capacity of a just society to produce subjects complying with its guiding principles (see Honig, 1993:127). Thus, Rawls seeks to discard situations of potential conflict from his theory. As can be seen, Rawls projects that deliberative rationality produces flourishing pluralistic societies because all rational and self-interested individuals will choose the same principles of justice. Therefore, people that might not be rational in this way pose a major threat to the homogeneity of the just society, which ultimately explains their exclusion from the original position. And in this way, Rawls continues the tradition of excluding people not conforming to the humanist ideals of reasons since they disrupt the humanist ontology of personhood that I examined earlier.

### **Including Otherness**

To understand the politics of post-institutionalisation, knowing that people with intellectual disabilities have been excluded is not nearly as important as knowing *why* they have been. This is so for reasons already discussed; the efforts to include by citizenship seem to repeat the exclusion of intellectual disability. In other words, the humanist notion of reason and rationality as grounding personhood is both the origin of and cure to exclusion. As we shall see, this also pertains to some prominent theoretical efforts to include intellectual disability. Below, I will argue that both Taylor and Nussbaum repeat exclusion because they still, in important senses, commit to the humanism and universalism that constituted the otherness of people with intellectual disabilities in the first place; they found their notions of what characterises humanity in qualities which, at the same time, they assume that (at least some) people with intellectual disabilities lack.

### *Recognising intellectual disability*

The politics of recognition is one of the prime contenders to liberalism and social contract theory, challenging both assumptions of an autonomous and rational subject and substantial political ideals of liberal justice. It may therefore seem as though Taylor's attempt to include intellectual disability has the potential to lead beyond the above-discussed problems. However, as I will show, this is not the case.

The origin of Taylor's argument is found in Hegel's idea of humans as becoming through mutual recognition. This proposition was largely formulated in opposition to the atomism and pre-social individuals of Kant's moral philosophy. It is also from Hegel's notion of recognition that some of the most piercing criticisms of liberalism have been developed. In his essay 'The Politics of Recognition' (1995) Taylor advances the argument that minority cultures ought to be acknowledged as valuable by the dominant culture in dialogical processes of recognition. Theorising colonial practices of subjugation, he argues that a recurring tool in the history of oppression consists of the imposition of negative self-images on the colonised (see Taylor, 1995:65-6). The politics of recognition, therefore, starts with transforming how people view themselves by building mutual respect between different groups and individuals. It follows that, for Taylor, the relationship between individuals and the community is essentially dialogical, whereas other individuals, and groups of individuals, are preconditions of our self-images and self-understanding. Rather than the self-constituting individual of liberalism, Taylor's proposal focuses on how societies can enable processes of mutual recognition in order to shape identity.

Taylor confronts the otherness of intellectual disability when he seeks to provide a basis for what it is that should be recognised in others. He writes:

this [universal human] potential, rather than anything a person may have made of it, is what ensures that each person deserves respect. Our sense of the importance of this potentiality reaches so far that we extend it even to people who through some circumstance that has befallen them are incapable of realizing their potential in the normal way – handicapped people, or those in coma, for instance. (1995: 41-2, italics added)

As Taylor presents his argument, he suggests that 'handicapped people', itself a pejorative term, are to be recognised, not for what they are, but for what they 'potentially' could have been (see Arneil, 2009). Unfulfilled potential, in turn, is the result of special circumstances that 'befall' individuals, meaning that they cannot realise their potential in a 'normal

way'. Thus, what makes it possible to include 'handicapped' people in the sphere of recognition is a shift: from an *actual* ability to realise one's potential to having a *potential* for this, although something has prevented it from developing. The word 'even' is important here, indicating that the invocation of 'potential' enables the inclusion of an unlikely candidate. Furthermore, the argument hinges on a differentiation between 'normal' and 'abnormal' ways of realising one's potential, where it is clear that the former is preferable. From this we can conclude that people with intellectual disabilities (together with people in comas) represents something that requires a special measure in order to accomplish inclusion by recognition; although the overarching ethos of the politics of recognition is that it grants respect for individuals based on what they truly are, this principle does not apply to people with intellectual disabilities who should instead be respected for what they *are not*, but once had the potential to become.

To understand how Taylor reaches this conclusion, it is necessary to examine his indebtedness to the Kantian notion of respect. Taylor develops his concept of recognition from Hegel, but it is the influences of Kant that explain the problems with this particular argument. As Taylor (1995:41) notes on the page before the section quoted above, and as I discussed a few pages back, for Kant (2002:16-7) it is the capacity to derive moral laws by the faculties of reason that commands from us a sense of respect. What is important here is the shift that Taylor (1995:41) makes when going from Kantian respect of 'reason' to his own proposition of respect of 'potential of reason'. By making this shift, Taylor shows that he believes that he is able to extend recognition 'even' to people with disabilities, which would have been impossible if one used Kant as a jumping off point. In other words, disability disrupts a notion of respect of rationality, which requires that Taylor adds to this notion by switching to 'potential' for this characteristic. In doing this, Taylor produces a new division, this time between those that can be recognised as moral subjects and those that only are recognised as holding the unfulfilled potential of being moral subjects. An unspoken normativity is thereby operating, in which the actual realisation of Kantian reason is the norm and starting point, while potential as grounds for recognition is the supplementary tool which enables the marginal case to be included. This normativity is made explicit as Taylor states that people with disabilities cannot reach their potential 'the normal way'. Hence, in his efforts to produce a grounds for recognition that includes 'even handicapped people', he simultaneously produces a new line of demarcation between rational subjects

and people who merely have the potential to be rational. This way the exclusion of Kant is both handled whilst also being reproduced.

To fully grasp the implications of this, I want to broaden the perspective to discuss Taylor's reasoning on disability in light of his overarching project. Markell (2003) has interpreted the politics of recognition as grounded in an idea of sovereignty as temporality, ultimately seeking to secure the future of one's identity. Similarly, Fareld (2008:163-8) argues that Taylor's reading of Hegel ultimately seeks to confirm an already-there stable and coherent identity that is to be re-valued rather than challenged or transformed. This limits the constitutive force of 'recognition' that, at first glance, appears to be central to Taylor's viewpoint (and that certainly was for Hegel). In fact, Taylor presents us with a rather conservative reading of Hegel which ends up close to the assumptions of a true inner identity and of a subject exercising self-mastery which he seeks to challenge. Fareld (2008:156-7) goes on to argue that Taylor thus places the identity of self on a collective level that becomes as un-reflected and taken-for-granted, as the liberal atomistic individual he seeks to escape. What differentiates recognition from misrecognition in Taylor's argument is that the former makes the return to a true self that enables different identities to live together in harmonious coexistence possible. In this way, the figuring of a unified identity is very important for Taylor's larger project of advancing a conception of the value of diversity. Taylor understands differences as being constitutive parts of a united whole and, as long as people are respected and recognised for who they really are, such differences can coexist, nourish each other, and allow citizens to live together peacefully. Diversity thereby translates into the richness of humanity, which means that we all have an interest in the difference of others since such differences complement our own restricted share of what it means to be human (see Taylor, 1995:72-3). Thus, we all need to be recognised, not to become subjects in the first place, but to live in peace together (Fareld, 2008:160).

Brought to bear on intellectual disability, by Taylor's argument, this group can be seen as a difference that enriches the whole of humanity, which, in turn, serves as a source of their recognition. However, as it is their *potential* for being rational that should be respected, this simultaneously means that the differences of this group are simultaneously neglected. The logic of Taylor's argument is that disparities of identity are underpinned by a notion of sameness consisting of the common humanity that diversity provides value to. And it is precisely here, I argue, that we have come full circle and are faced, once again, with Kantian respect for persons as respect

for their rational capacities. In the end, this is what Taylor (1995:41) uses to knit diversity together into a united whole, the ‘universally human’ that his theory of recognition cannot do without and which serves as a grounds for the enriching differences of humanity to be layered upon. By ascribing a *potential* of being respected for one’s reason to the intellectually disabled, however, Taylor’s insistence on an underlying sameness comes at the price of re-inscribing difference, conceived of in a way that looks very much like his own conception of misrecognition. And in this way, Taylor’s lingering commitment to a notion of rationality as defining humanity – fulfilled or as potential – both includes and excludes intellectual disability.

### *The Capabilities-approach*

Whilst Taylor explicitly contests liberal conceptions of membership in political community, Martha Nussbaum (2006:3) proposes her capabilities approach as part of political liberalism and as close to, although criticising, Rawls’s theory of justice. She first developed her version of the capabilities approach in *Women and Human Development* (2000), where she argues that basic requirements of justice consist of guaranteeing a minimum level of ten capabilities which are central to a dignified human life, and the book analysed here – *Frontiers of Justice* (2006) – essentially develops from this earlier work. Among philosophers of disability, Nussbaum provides one of the leading efforts to formulate a grounds for inclusion of intellectual disability. I will therefore present a rather extended and detailed treatment of her argument.

Among Nussbaum’s capabilities we find being able to live ‘a human life of normal length’, being able to have ‘good health’, being able to ‘live towards and with others’, and ‘being able to form a conception of the good’ (Nussbaum, 2006:76-8). As is clear from her formulation of capabilities, it is what people are actually able to do which is important in matters of justice (Nussbaum, 2006:70). The capabilities are understood as un-exchangeable and intrinsically desirable, which means that an increased level of one capability cannot compensate for the lack of any other (175). Government therefore needs to make sure that every citizen reaches a minimum level of each capability or they have failed to meet basic requirements of justice. As soon as all threshold levels are met, the capabilities approach does not address further issues of distribution and, in this sense, Nussbaum only offers a limited account of justice. While *Women and Human Development* argues against utilitarianism, slanted in the tradition of economics, *Frontiers of Justice* discusses, adds to, and intensely criticises Rawls’s theory of justice.

The book reproaches three significant problems of Rawls's theory: its inability to address justice for people with disabilities, global justice, and the justice of non-human animals, stating that the capabilities approach is better suited to deal with all of these. The treatment of justice for people with disabilities will be the focus here.

First, I want to point out that I believe that Nussbaum is correct: her approach certainly appears to be a better account of justice for people with disabilities than 'justice as fairness'. In addition, as a grounds for formulating political demands on disability politics, Nussbaum provides many appealing suggestions that avoid some of the dangers of the social contract tradition. Thus, the following discussion should not be read as a rejection of the capabilities approach as a practical tool to raise political demands. Rather, my treatment of Nussbaum relates to the overarching argument of this chapter, proposing that the inclusion achieved by the capabilities approach, despite its strengths, simultaneously re-inscribes exclusion.

Nussbaum's criticism of Rawls is similar to mine (although she parses her argument in the crisp and seductively clear language of analytical Anglo-Saxon philosophy): the theory of justice excludes 'mental impairment' because it starts from a narrow conception of mutual advantage and because it takes for granted a Kantian notion of personhood as grounded in rationality. I have no major objections here. However, her positioning of the capabilities approach in relation to Rawls is notoriously ambiguous in what I believe to be an analytically significant way. At the opening of the book, she states that justice as fairness suffers from structural problems and that we must rethink what a citizen is and could be in light of her capabilities approach (2006:1-2). She later argues that Rawls is constrained by his adherence to theories of the social contract (57), that the flaw of not being able to handle (intellectual) disability goes directly into the architecture of Rawlsian justice (1, 98), and that these are not merely problems of incompleteness, but that they misdirect his basic concerns of justice (4, 139-40). These (and other) formulations suggest a thorough criticism of Rawls and contract theory. On the other hand, Nussbaum continuously points out that she does not intend to dismiss Rawls, nor the social contract, and that she sees justice as fairness and her own approach as allied theories of political liberalism (Nussbaum, 2006:24, 94-5). In her most thoroughly developed formulations, Nussbaum states that the capabilities approach is an extension of Rawls but starts from similar intuitions (120) and that her conception of capabilities take us further within the three specific areas that her book focuses on (69, 94-5), implying that she believes that justice as fairness

provides satisfying answers in other areas. This interpretation is also supported by her repeated statements that Rawls offers the strongest theory of justice that we have. All of this suggests that at least one way of reading *Frontiers of Justice* is as a supplement to *A Theory of Justice*. Viewed in this way, disability – and particularly ‘mental impairment’, as Nussbaum frequently stresses – figures as a special case that requires *ad hoc* solutions to an otherwise adequate notion of justice. Her general reluctance to see Rawls’s reliance on Kantian personhood as founded upon the exclusion of intellectual disability downplays the problematic treatment of disability in Rawls’s writings and reifies the impression that intellectual disability falls outside the scope of justice by ordinary theoretical means (see Clifford Simplican, 2015:84). Hence, as compared to my own analysis, which approaches disruptions of justice as fairness as being spaces of politicisation of the ontological underpinnings of contract thinking, Nussbaum seeks to reach closure by providing the answers that Rawls fails to deliver.

More important than its indistinct relationship to Rawls, is that there are some internal and structural problems with the capabilities approach as well. Nussbaum states that her theory proposes a route to ‘inclusion’ for people with disabilities (2). She elaborates on two basic arguments as to why the capabilities approach performs better than justice as fairness in this regard. First, it does not ground justice in mutual advantage (156-7). Nussbaum’s theory is not contractarian, which means that she does not need to postulate self-directed motivations for individuals seeking out principles governing society (158). The capabilities approach, on the contrary, starts from the reasonableness of the list of capabilities itself; it is in Nussbaum’s words a theory of the good that is ‘ethical all the way down’ (388). As compared to procedural notions of justice, the appeal of her argument is derived from the attractiveness of the list of capabilities itself, as it lacks a metaphysical anchoring (Nussbaum, 2006:79). Hence, it may be true that, at times, individuals are motivated by mutual advantage, Nussbaum (156) states, but they are also motivated by benevolence and the love of justice itself. This means that she can rid her theory of the correspondence between those who create the contract and those who its principles apply to (15-6); the capabilities list concerns all, including those who cannot take part in formulating principles of justice or contribute to mutual advantage. This argument stems directly from Nussbaum’s indebtedness to Aristotle, who famously described human beings as ‘political animals’. In the capabilities approach, individuals are social creatures, naturally motivated towards others. This, in turn, provides her with a second argument against Rawls, challenging

the rationalistic and atomistic subject he inherits from Kant. The 'political animal' gives Nussbaum (2006:92) a source of human dignity outside of Kant's and Rawls's shared ideal of a rational subject: human beings are not only defined by capacities of reason, but also by needs and vulnerabilities, dependence on others, and by how our lives are intertwined with the lives of our fellow human beings (158). Whilst Kant, as argued a few pages back, sees human dignity in the capacity to raise ourselves over our animal nature by means of reason, Nussbaum sees the split between our neediness and our rational capacities as providing dignity to human lives. Consequently, she argues that although some lives are marked by diminished reason, such lives are still worthy of our deepest respect as they are expressions of human vulnerability and expose our shared dependency.

One way of seeing Nussbaum's list of capabilities is as expanding on a narrow focus of reason and rationality, adding dependence, emotional ties, and a social human nature, as sources of human dignity. Nevertheless, she still commits to a universal understanding of what constitutes the dignified human life, and it is precisely because of this that she runs into problems. It is important to remember that Nussbaum's argument designates minimum requirements as concerns each capability and that these are non-interchangeable (175). According to Nussbaum – and this is a vital point for the argument that I wish to make – the minimum threshold of each capability designates the level needed to live a dignified human life (Nussbaum, 2006:70-1). Nussbaum states that beneath the threshold level 'truly human functioning is not available to citizens' (2006:71); that a life of human dignity, at least in part, is constituted by having the capabilities on the list (162); that the capabilities are fundamental for citizens (166); and that the evaluative notion of human nature operating in the capabilities approach designates normatively central aspects of humanity without which we are not living with full human dignity (179-81). As is clear from this, the notion of 'human dignity' is absolutely central to Nussbaum's conception of justice. Since each individual is regarded as an end in themselves, this means that governments are obliged to do as much as they possibly can to raise every individual to meet the threshold levels of each capability. According to Nussbaum, the threshold levels of each capability can be specified if we imagine what a life without the capability in question would be like; a kind of mental exercise that can help establish a cross-cultural overlapping consensus concerning a minimum conception of justice (Nussbaum, 2006:161-3).

For Nussbaum's argument, all of this is important to be able to include intellectual disability: regardless of whether they can be characterised as fully

rational or not, all people have a claim of justice on governments in providing them with a minimum of the capabilities (2006:98-9). All people are subjects of justice. However, in several instances, Nussbaum states or takes for granted that (primarily intellectual) disability may have the consequence that individuals will be naturally unable to develop all capabilities to a sufficient degree, for example when arguing that not even the best care in the world can raise all people to meet the threshold level of all capabilities (188) and that not all capabilities of people with impairment can be remedied by social action (222). She seems to think that this is especially pertinent with respect to people with what she calls ‘severe mental impairments’ (177) (a condition not defined beyond a conceptual linkage to failing to meet Kantian standards of reason). Nussbaum’s point here is that such people are still subjects of justice as they have other capabilities for which governments have a responsibility. At the same time, these assumptions hold implications for the valuation of the inherent human dignity of such lives. As we can see, Nussbaum believes that lives below the thresholds level of any capability cannot be considered fully dignified *and* that meeting threshold levels will be impossible for some. Although still subjects of justice, people who lack any of the capabilities are not considered to be living fully dignified human lives; her inclusion of disability is paralleled with the exclusion of some people with disabilities from her conception of human dignity.

As a consequence, Nussbaum is forced to abandon her language of ‘full human dignity’ when speaking of people with disabilities that she presumes fall short with respect to any of the capabilities. Instead, she introduces a terminology of ‘human flourishing’ to specify what is attainable for people with severe disabilities (186-8). I believe that this shift of language is intentional and significant: in using the premises set up by her argument, Nussbaum is prevented from stating that people with disabilities who cannot meet all threshold levels have lives of equal human dignity – one could say that people with such disabilities disrupt her notion of the ‘dignified human life’ – and hence the language of ‘human flourishing’ is introduced as a supplement; as a new term for the state of existence that is possible in the wake of Nussbaum’s simultaneous inclusion and exclusion. It shall be noted that Nussbaum (38), at one instance and only in passing, argues that she actually does grant all people born of human parents full and equal human dignity. However, this is not backed up by the actual content in her argument, and is later explicitly contradicted in the discussion of people in vegetative states (who she states do not have human lives at all, regardless of their parents being human) (181-2).

To be able to say something of the seriousness of the charge here, it is necessary to try to make clear what this exclusion excludes *from*: what does full human dignity stand for, where does it come from, and what does it mean to not have it? To start with, this is no small matter for Nussbaum: the concept of ‘dignity’ is central to her notion of justice; ultimately, it is what a fair society has a responsibility to provide to its citizens. At the same time, and as Claassen (2014) notes, ‘dignity’ is not clearly defined in the theory. What Nussbaum says is that capabilities can be viewed as ways of realising a life of human dignity (Nussbaum, 2006:161). Capabilities and human dignity thus appear as intertwined (2011:32) and, in a sense, the capabilities list can be read as a practical operationalization of ‘human dignity’. Thus, human ‘dignity’ is ultimately anchored in a conception of human nature, or, more specifically, a conception of what it is in human beings that should be protected and nourished. As Bernardini (2010:46) puts it, the notion of human dignity ‘refers to a quality inherent in human nature which ennobles and renders one’s life precious’. Similarly, Gheaus (2007) states that Nussbaum ultimately sees ‘dignity’ as that which inspires spontaneous wonders and awe in our recognition of other beings. Excluding people with ‘severe’ disabilities from this essentially means that we cannot be in awe of these people as human beings to the same degree as those who possess all capabilities<sup>16</sup>. Revisiting the list from this perspective, it is important to remember that the capabilities have a clear functionalist slant. Thus, for example, Nussbaum (2006:77) specifies the capability of ‘practical reason’ by referring to its manifestations; as being able to form a conception of the good and being able to plan one’s life (see Bernardino, 2010:49). This turns problematic as the individuals of the group she seeks to reconsider as subjects of justice – people with disabilities – are defined by functional loss. It follows that unequivocal inclusion is only possible for people who do not have functional losses in what Nussbaum considers to be central capabilities. Bernardino (2010:49) has made a related point, arguing that, for Nussbaum, the inherent dignity of human beings is possible to lose – as Nussbaum herself clearly states with respect to individuals in vegetative states (181-2) – since it is something that one has by merit of capacity. In this way, human dignity is not

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<sup>16</sup> In later discussions of ‘dignity’, Nussbaum (2011) argues that the potential for certain capabilities is the foundation of dignity. First, this effectively undoes her prior idea that it is ‘what individuals are actually able to do’ that matters for justice. Secondly, the problems discussed above on Taylor’s potentiality applies here as well; living a dignified life by merit of a capacity that one is defined as lacking hardly seems to be a convincing ascription of dignity. In *Frontiers of Justice*, however, no such admissions of potentiality are clearly made.

inalienable, it is not regardless, but bound up with a set of functional characteristics. To be excluded from full human dignity thus means to be excluded from Nussbaum's humanism. This is not suggesting that Nussbaum does not value disabled lives, that she disregards them, or neglects their moral significance. But it is saying that an ideal conception of human life operates in her theory as a universal yardstick, which she simultaneously assumes that some people with disabilities fail to meet.

A related point here concerns the role played by intuition in Nussbaum's argument. While seeking to forestall charges from perspectives of procedural justice, Nussbaum repeatedly makes the claim that the intuitive and flexible nature of the capabilities list is a great strength of the approach. Its intuitive appeal, it is argued, suggests that it can be agreed upon across a broad cultural spectrum (Nussbaum, 2006:163). On the other hand, this appears to be suspicious provided her exclusion of some people with 'severe mental impairment' from human dignity – because, in the end, it means that her argument boils down to 'intuitively, we recognise that these people are not living as dignified lives as people with all capabilities', or something along these lines; her theory essentially confirms the 'ableism' deeply ingrained in contemporary Western societies, verifying that something is not there, that these lives may flourish, but that some essential elements of what make human lives worthwhile are missing. Hence, her inclusion does not question the normativity that renders people with intellectual disabilities, in particular, perpetual outsiders – it merely seeks to find a new way to care for them as part of a conception of 'justice'. It is therefore not surprising that Nussbaum – akin to what critical disability scholars have long called a 'tragedy narrative' of disability – states that the lives of people with 'severe mental impairment' are 'unfortunate' (192) and that she calls the birth of impaired children 'accidents' (102). Such formulations reveal the normative and exclusionary side of the overarching effort to include; it testifies to the power of the capabilities approach to constitute certain disabled lives as worse off than 'normal'.

I want to make a concluding point here in reference to the presumed viewpoint of the capabilities approach. The fact is that this theory is not attainable to all subjects it claims to have authority to speak to. Indeed, Nussbaum presumes that planning one's life along a conception of what makes life good may be impossible for some of the people she uses as examples of disability. This also means that they will not have access to the capabilities approach as a theoretical tool. In this way, Nussbaum discards the agency of such individuals in having a say on their own life provided the

capabilities approach. How life appears from their viewpoint, what they strive for, and what they experience as worthwhile, is irrelevant to the estimation of their dignity. As such, the capabilities approach rests on a 'severe' intellectual inequality, where the philosopher formulates the lesser good of a group which is simultaneously presumed to be unable to have a say on their own dignity as human beings. This theoretical manoeuvre itself deprives the people whose interests it claims to speak for, of dignity.

## **Reason and Citizenship Belonging**

I have proposed two things in this chapter: (1) that the humanist focus on 'reason' and 'rationality' as defining characteristics of humanity operates as a mechanism of exclusion in formulations of political and societal belonging and (2) that efforts to include people with intellectual disabilities that do not address this ontology will retain exclusion, resulting in situations of simultaneous inclusion/exclusion. Another way of saying this is that the disruption of intellectual disability will be reprised in many efforts to include.

I want to conclude here by adding a few things to these propositions. First, although I stated at the opening of this chapter that this second part of the book would deal with the politics of post-institutionalisation, it must be noted that the humanist subject was central to the ideological landscape in which 'intellectual disability' first emerged; it was in contrast with the ideals of a rational subject that 'mental deficiency' could be specified as a problem requiring government responses and scientific explanations, as I discussed in Chapter 1. Thus, the primacy of reason, exemplified by Locke, Kant, Hume, and Mill, was instrumental to the emergence of intellectual disability and is today instrumental to how their inclusion is to be provided for. This also means that I am not suggesting that the branch of humanism that I have criticised here is disrupted because there is an inherent lack of people with intellectual disabilities, but because this branch of humanism became possible due to the exclusion of intellectual disability. Hence, both the ideals of humanism and the lack of people with intellectual disabilities are socially constituted, as inside and outside, with respect to the humanist normativity.

Secondly, I want to stress again that the above arguments are not meant to be read as an engagement with a number of theorists who suffer from more or less obvious prejudices against people with disability. Rather, these philosophers expose a common structure of much political thinking that I believe has become integral to how we conceive of citizenship and which is

central to how we understand the deficits that define intellectual disability. The latent tension between ideas of *sameness* with respect to what all citizens share, and *difference* with respect to what the intellectually disabled lack, will reappear in the next two chapters to explain the policy discourses and the policy practice that surrounds intellectual disability. Thus, in a sense, the arguments presented in this chapter illustrate Butler's (1993:xiii) proposition that any designation of a norm – in this case concerning what defines humans – will create a necessary outside of abject beings. However, the outside of reason, by being the condition of possibility for the norm itself, will always threaten the unity and homogeneity of the sphere of inclusion. The reason why deficient intelligence re-emerges, again and again, throughout the history of philosophy, is precisely that such threats must be put to rest by having their otherness re-inscribed.

Ultimately, this ties back to how any universal depiction of 'human nature' requires a constitutive outside that makes this depiction possible in the first place. Therefore, attempts to formulate new, universal, grounds for inclusion by singling out some characteristic to be elevated as 'what we are' will end up drawing a new line of demarcation between inside and outside. Therefore, I do not propose that the solution to the problems here analysed is to seek an unproblematic inclusion of people with intellectual disabilities by continuing the search for universal grounds of societal belonging (as both Taylor and Nussbaum do). Instead, inspired by Honig (1993), I propose that precisely the disruptions caused when the sameness of citizenship confronts the difference of the intellectually disabled are resources for politicisation. When the universals, unavoidably as Butler (2005:5-6) argues, fail to include all, this very failure can serve as a starting point to critically examine the universals as such.

In the following two chapters, we shall continue to trace this play of inclusion/exclusion by focusing on the failures of universals to include all, looking at the actual governmental and biopolitical efforts to include intellectual disability. Thus, we shall go on to examine how the politics of post-institutionalisation operates both by moulding intellectually disabled subjects to become citizens and by excluding intellectually disabled subjects with the consequence of retaining their status as the outside of human reason.

## 5. Disruption

The advent of citizenship inclusion in disability politics was both a break with and a continuation of the philosophical tradition examined in the previous chapter. In sharp contrast to a history of exclusion, governments and international organizations for the first time started to see people with cognitive deficits as entitled to equal individual rights. At the same time, this was also a continuation of the liberal and humanist philosophical tradition that equates ‘citizenship’ with emancipation, thus re-inscribing the humanist subject as the agent to be liberated. Since intellectual disability itself is a designation of otherness to this subject – exemplified in the philosophies of Locke, Hume, and Rawls and by the history of measuring intelligence – people with this condition are both citizenship’s constitutive outside and target. In this chapter I will argue that the same structure of ‘disruption’ and ‘supplement’ that we saw at work in the history of philosophy operates in the global policy discourse: in international treatises and policies, attempts at inclusion are upset by the otherness of intellectual disability, which means that inclusion is only possible by simultaneously preserving exclusion.

Now, as I will argue, within the global politics of intellectual disability, two concurrent and conflicting discursive constructions operate: first, the intellectually disabled citizen-subject is constituted as self-ruling, independent, and as worthy of inclusion. This is not the absence of power, but power operating by constructing what emancipation and freedom are and what excluded subjects are expected to strive for (see Cruikshank, 1999; Rose, 1999). At the same time, exclusion lingers in the global policy discourse as the inclusion of people with intellectual disabilities is questioned, warranting exceptions, or calling for special premises to be met. This is power operating by upholding and re-inscribing otherness, after inclusion. Consequently, in congruence with the conclusions of the previous chapter, the global disability discourse appears as premised on an ideal-subject from which the intellectually disabled subject remains omitted. To handle this specific group, the commitment to inclusion must be

supplemented by special measures which effectively contradicts the overarching inclusive ambitions.

As concerns the methods and material of the analysis, the global discourse that will be discussed was established during the last three decades by a number of international organizations and inter-state agreements committing to ideals of deinstitutionalisation, independent living and societal participation. I will continue to call this a 'global discourse' since it is upheld by a number of international organizations whose efforts span the globe. On the other hand, it must be pointed out that the content of this discourse is Western in origin and linked to the humanism and Enlightenment thinking that emerged in European Modernity. This discourse is most often framed in terms of human rights, although citizenship is integrated into this approach rather than a rival perspective (see Council of Europe, 2006:9). I will primarily devote attention to the UN, the WHO, the EU, and the Council of Europe. Although these organizations may differ in numerous respects as concerns their respective disability policies, they share a strong commitment to the ideas of politics of inclusion. My main focus will be on what characterises the politics of post-institutionalisation from a theoretical perspective. This means that I will not bother with the political processes leading up to certain international policy agreements or their implementation; the problem examined is how the discursive architecture of the intellectually disabled citizen-subject is constructed. Furthermore, the analytical work essentially consists of a discourse analysis examining how the citizenship of people with intellectual disabilities is constructed. Throughout, I have been guided by the overarching question of how members of this group are conceived of as citizens.

The actual material that I have worked with consists of policy documents, treatises and agreements, primarily of the above organizations. As concerns the UN, *the Convention on the Rights of Persons with Disabilities* (CRPD) is central. This document can be seen as an overriding framework encompassing an ideology which had come to increasingly dominate the work of various international organizations during at least the two decades before its ratification. Within the EU, the most important norm source (beside the CRPD) is the Charter of Fundamental Rights, implemented by the European Union Agency for Fundamental Rights (FRA). Hence, reports and policy statements of the FRA are important to pin down EU disability policy. Within the Council of Europe, furthermore, there has been an on-going work with disability that is relevant in the context of this chapter, often related to the work of the European Court of Human Rights

(ECtHR). Lastly, the work and standpoints of the WHO are most clearly summarised in their 2011 *World Report on Disability*. During the past decade, its European branch has taken a special interest in the inclusion of intellectual disability, for example seen in the *European Declaration of the Health of Children and Young People with Intellectual Disabilities and their Families*. Reviewing this material, it is important to note that intellectual disability figures both as incorporated within the wider group of disabled people and as a sub-group specifically addressed by particular policy initiatives (see European Intellectual Disability Research Network [EIDRN], 2003:5). The structure of how different policy documents organize and premise citizenship inclusion, with respect to people with intellectual disabilities, specifically, and disabled people, in general, is both complex and sometimes analytically significant. Hence, throughout the chapter, I will stress this division when it appears as relevant for the analysis.

The chapter will proceed in two steps: first I want to pin down how the global policy discourse constructs an ideal disabled citizen-subject. Thereafter, I will show how this discourse is disrupted and hence requires supplementary amendments that are external to the original commitments to inclusion. As a last note of clarification, and despite the critical discussion that will follow, I recognise the important role of the CRPD, along with other international treaties and agreements, to facilitate and propagate demands that improve the living conditions of people with intellectual disabilities. My purpose here is therefore certainly not to argue for their immediate abandonment. Rather, I will examine what they might teach us about how people of this group are constituted and targeted by politics.

### **The Discursive Means of Inclusion**

The ideas of deinstitutionalisation, self-determination, and participation emerged in the international arena during the same period as the gradual changes of national legislations and policies that brought us into the era of post-institutionalisation. In human rights frameworks, up until around 1970, disability had been largely invisible. The 1971 *Declaration on the Rights of Mentally Retarded Persons* and the 1975 *Declaration on the Rights of Disabled Persons*, were both attempts to remedy this (Schulze, 2010:16). In 1993, furthermore, the UN issued the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, which promoted equal rights and opportunities for the group (WHO, 2011:147). However, the commitments of

the international community were still spread out over a considerable number of different texts and the advent of the CRPD can be interpreted as a response to this. As such, the UN convention came to summarise a global politics of inclusion which, to some extent, was already in place. Today, the convention is frequently referred to in policy commitments of more or less all NGOs and international organizations. For example, the WHO world report on disability explicitly states that its purpose is to facilitate the implementation of the CRPD and the FRA continuously refer to it in all of their recent publications on intellectual disability. Despite the fact that much of the content of the convention had been previously expressed, the CRPD is often described as signalling a shift of paradigms (Council of Europe, 2006:8; FRA, 2010), in which people with disabilities, and people with intellectual disabilities, in particular, were no longer seen as unable to play an active and participating role in society. Furthermore, in addition to being a Human Rights Framework, the CRPD is designed as a development instrument that is meant to be implemented and to guide the disability politics of ratifying countries (Schulze, 2010:22).

The main idea of the CRPD is to make explicit that the universal declaration of human rights applies to people with disabilities, as well (see CRPD, Article 4; WHO, 2011:9). The necessity of clarifying this reads as an oxymoron, as the declaration of human rights would not really be universal if not already applying universally. However, as we shall see, the proposed universality of such grand claims frequently comes into question within disability politics when faced with certain sub-groups. In the context of the convention, the reliance on universal human rights means that its guiding principles (in Article 3) stress individual autonomy, independence, and the rights of persons with disabilities to make choices. It also commits to non-discrimination, accessibility, and respect for the differences of members of this group and it promotes their full and effective participation and inclusion in society. Ratifying states are obliged to undertake all necessary measures to meet these ideals, including adopting existing legislation and taking into account the situation of people with disabilities when adopting new legislations and governmental programmes (CRPD, Article 4). As concerns people with intellectual disabilities, specifically, the 19<sup>th</sup> article stresses deinstitutionalisation, independent living, the right to decide where and with whom to live, along with ending all forms of segregated living.

The direction set out by the CRPD is often described in terms of the 'empowerment' of people with disabilities to control their own lives (see Council of Europe, 2006:9, WHO Europe, 2010:12), by granting access to

meaningful choices (FRA, 2012:3). These descriptions hold for the general initiatives targeting all disabled people as well as the initiatives targeting those with intellectual disability, specifically. An important part of this consists of ‘mainstreaming’ disability, which essentially means phasing out segregated services, such as sheltered employment and special education (see WHO, 2011:264). This is to be achieved by the removal of ‘barriers’ that are seen as hindrances to participation (remember here the relational model of disability discussed in Chapter 3). The focus on barriers is especially prominent in the publications of the WHO, whose World Report is presented as a guide to remove barriers to full inclusion and thereby to implement the CRPD (WHO, 2011: xi). Thus, the WHO depicts a sphere of ‘inclusion’ not accessible to people with disability due to social structures and mechanisms that lock them into a corresponding sphere of exclusion. In substance, the goal is to replace segregated and institutionalising services with person-centred support, understood as a means to preserve ‘dignity’, to enable ‘individual autonomy’, and to achieve ‘social inclusion’ (WHO, 2011:137-8), which links back to Article 19 and 28 in the CRPD. The overarching goal set out in the WHO world report is that people with disabilities should be ‘empowered to live in the community and participate in work and other activities, rather than be marginalized or left fully dependent on family support or social protection’ (WHO, 2011:137).

As concerns intellectual disability, the European Intellectual Disability Research Network ([EIDRN] 2003:9), even before the ratification of the CRPD, had described the emergence of a new global policy direction as ‘an ideological shift towards ideas of citizenship, personal control and equal access to community’. The perception of a paradigmatic shift is tightly linked to the process of deinstitutionalisation, for example also stressed by WHO Europe (2010:5; 2012) and the Council of Europe (2006:8, 21). WHO Europe’s declaration exemplifies this line of reasoning:

the new approach marks a paradigm shift in attitudes and approaches towards people with disabilities from viewing them as objects of charity, health care and social protection towards viewing them as subjects with rights who are capable of claiming those rights and making decisions for their lives. (WHO Europe, 2012:3)

This perception of a ‘new’ direction appears to be fundamental to the global disability discourse and is therefore worth having a closer look at. In this quote, like in the material more generally, the politics of inclusion becomes understandable in contrast to institutional care and paternalism. The same

way as in much social scientific disability research, thus, the promotion of intellectual disability citizenship is contrasted against the repressive politics of the past. Drawing upon this – and throughout the material of WHO Europe, the Council of Europe, and the FRA – European states are described as being on a ‘journey’ towards more individualised support, where present policies have moved from seeing intellectually disabled as ‘non-contributing patients’ in need of care to ‘citizens who need hindrances to active participation removed’ (EIDRN, 2003:6). In this way ‘progression’ is central to the narrative of the global politics of inclusion, where the break between ‘past’ and ‘present’ constitute a normative step forward in which old attitudes are being replaced by better ones, institutionalisation is transformed into community living, and oppression gives way to citizenship. This furthermore makes it possible to describe countries that still have a substantial amount of institutional care settings as ‘not having come as far’, since they are supposedly on the same, predestined, journey towards the ‘new’ paradigm (see EIDRN, 2003:6). This indicates that the ‘new’ ideology of disability at times comes close to being depicted as a historical necessity.

I argue that this narrative de-politicises present policies, which are presumed to be inherently good, in the best interests of people with disabilities, and far removed from an old paradigm of repression. As I discussed in the introductory chapter, here, power is securely placed in the past, as something we have left behind but which occasionally haunts us (see Brown, 1995:8). The references to a ‘paradigmatic shift’ and the existence of ‘old’ versus ‘new’ ideas, elevate the ideology of the present as a set of self-evident starting points for political reasoning, un-contestable and deeply anchored in an all-embracing humanism. The still considerable problems of disability services are thereby understood as remnants of the past, and power over people with disabilities is conceived of as in the process of being replaced by individual freedom. Here, Foucault’s analysis of government suggests otherwise: rather than self-evident assumptions or statements of fact, the ideology that pervades present global disability politics is manufactured in a certain historical epoch and functions by designating certain ways of ‘being free’, ‘emancipated’, and ‘empowered’. It carries assumptions concerning what constitutes a good life and what liberation entails. From this perspective, the new paradigm can be seen as dictating that people with disabilities should live along a certain conception of freedom and provided a certain set of presumed capabilities. This is to say that, along with the ‘new’ disability politics, comes a ‘new’ subject (see Cruikshank, 1999).

Closely tied to the 'present' and 'past' of disability ideology is the ideal of an 'active' disabled citizen, understood in contrast to the 'passive' roles that pervaded under institutionalisation. The 'activeness' of disability citizenship is most clearly associated with 'participation'; in one's service planning, in political processes surrounding the group, in mainstream education, on the labour market, and in cultural life (see Council of Europe, 2006:12-13; WHO, 2011:137). Although the content given to these ideas tends to shift depending on which organization we are looking at, there is an overarching discursive consensus on the value of 'activeness' rather than passivity (see Council of Europe, 2006; WHO Europe, 2010). Hence, the global discourse stipulates a citizen-subject that is integrated in society by means of working on the regular labour market, participating in mainstream education, and engaging in civil society. People with disabilities are, to a large extent, supposed to achieve this role provided the removal of 'barriers' to inclusion. Thus, the will to be active and to participate is understood to be an inherent feature for all individuals. It has been pointed out by several scholars that precisely such ideals of participation and activeness constitute a key foundation of contemporary discourses on citizenship, and on democracy, more generally (see McKinnon & Hampsher-Monk, 2000; Hvinden & Johansson, 2007), emerging towards the end on the 20<sup>th</sup> century and branded as an alternative to a welfare state considered too big and too clumsy, said to make citizens 'passive' service recipients (see Rose, 1999:16-8, 141; Moriarity & Dew, 2012:684-685). In fact, inherent to this description is precisely the insight that modes of governing shape subjectivity: an extensive welfare state that provides a high rate of coverage produces 'passive' citizens and the task of 'activation' thus becomes to create an active and self-caring citizenry instead. In attempting to do this, the politics of activation can be seen as integral to contemporary biopolitics.

I argue that the will to be active and to participate is better conceived of as an ideological construct than a given characteristic of human beings. Following Foucault's (2007) analysis of modern government, Cruikshank (1999) has argued that contemporary schemes of 'participation' and 'activation' work by a rationality of people being governed by governing themselves. Such government operates by constructing ideas of citizens as 'capable', 'independent', and 'responsible for their own good fortunes', which are, in turn, internalised by citizen-subjects. Within this mode of politics, the role of the state is not to help the disenfranchised but to foster the conditions so that they can help themselves, by, for example, removing hindrances to their participation. At the same time, the power of

manufacturing precisely these ideals as designations of what citizenship should be is effectively veiled. From this perspective, the global discourse of disability politics does not contain a set of evident policy goals that discard the powers that have oppressed people with disabilities, but is an expression of how power operates by constructing an ideal citizen-subject that effaces its own ideology by depicting power as something only belonging with the repression of the past.

Parallel to the constitution of ‘activeness’ as an overarching ideal is the construction of citizen-subjects as ‘independent’. As seen above, this goal is explicitly stated in the CRPD and frequently referred to by all international organizations that are included in the material. To provide just a few examples: ‘independence’ is one of the fundamental principles guiding the Council of Europe Disability Action Plan (2006:10); The High Level Disability Group of the EU, which consists of bureaucrats from the member states, continuously refers to the importance of independence as ‘choice-making’; and the FRA’s (2012) work on intellectual disability continuously emphasises this concept as a central component of quality of life. In the WHO world report, independence as choice-making occasionally amounts to an empowered consumer role (70-1, 152-3, 158). Hence, a general feature seems to be that this concept is related to decision-making, for example regarding where and how to live, how services should be implemented, and in the daily interactions between disabled service-users and public officials. This can also be linked to the above mentioned shift in welfare politics, where the decline of extensive welfare states has been accompanied by a re-conceptualisation of the main problem of social services, from ‘poverty’ to ‘dependency’ (see Fraser & Gordon, 1997; Rose, 1999:159). As Verstraete (2007:58-9) points out, the frequency of descriptions of self-determination and choice as instrumental to an improved quality of life for people with disabilities is hardly surprising, but reflects our present place in history where precisely these ideals come forth as central to conceptions of what a good life entails (see Rose, 1999:87). Ideals of independence, furthermore, are deeply anchored in the tradition of the humanist subject. Hence, the global citizenship discourse expresses the idea that people with disability shall serve for their own needs, make decisions about their own lives, and be protected from external influences while doing so. It follows that the idea of citizenship requires a subject capable of making decisions, preferably good ones. As was shown in the previous chapter, precisely the failure to conform to this was what provoked Locke, Hume, and Rawls to exclude people distinguished by their lack of reason from their respective notions of full societal belonging. In

other words: if the biopolitics of activation and independence constitutes ‘the conduct of conduct’ it hinges on subjects being able to conduce in a proper way – a question which has historically and philosophically been followed by underlined question marks when it comes to people conceived of as intellectually deficient.

Thus, the move from ‘past’ to ‘present’ is disability politics is depicted as a break between ‘oppression’ and ‘independence’. But power may take the form not only of the brute clenching of freedom that dominated the history of institutionalisation, it can also operate by promoting *a certain kind* of freedom, in this case as ‘activation’ and ‘independence’. As Rose (1999:4) notes, the distinction between domination and governing is that the former attempts to crush the freedom of individuals whilst the latter acts on it, promotes it as an overriding ideal, and utilises it for some certain purpose. As concerns the global policy discourse, power is not only what infringes upon our liberty, but also what makes us believe that a certain conception of liberty is central to living a full human life.

### **Failed Promises of Inclusion**

In the previous chapter, I discussed how groups that are seen as manifesting a lack of what is required to be a subject of justice, of freedom, or of moral reasoning, disrupt theorisations of societal belonging. Therefore, such philosophical notions need to be supplemented by special measures external to the general principles of citizenship. The global policies that are analysed in this chapter are themselves attempts to remedy the exclusion of people with (intellectual) disabilities from societal belonging. But as the cure is premised on the same ontology of subjectivity that caused the exclusion of the group in the first place, we here see a similar play of disruption and supplementation – in how special conditions are set up with respect to when and how ‘universal’ human rights should be respected, in how exceptions are formulated, and in the ways people with intellectual disabilities can thus only be targets of inclusion by having their otherness re-inscribed. We shall examine this by considering a few instances in the global policy discourse where such disruptions surface, where inclusion is withheld, and where the content of the human rights discourse is established as an ideal that cannot be met by all people with disabilities.

### *Inclusive education*

As was noted above, a key element of the global discourse on disability rights is the active and participating disabled citizen-subject. A special area of integration, continuously stressed in the material, concerns the education of people with disabilities. The Council of Europe's (2006:16) statements on the access to mainstream and integrated education illustrates the point I want to make here. Its general commitment to inclusive education reads:

to ensure that all persons, irrespective of the nature and degree of their impairment, have equal access to education, and develop their personality, talents, creativity and their intellectual and physical abilities to their full potential. (Council of Europe, 2006:16)

Note here that the equal access to education pertains to 'all' persons, no matter the type or severity of their impairment. In line with the overriding focus on discriminatory barriers, this entails that member states actively work with legislative measures, planning, and policies to prevent segregated education. The underlying ethos is that disabled people should be an integrated and actively participating part of society. In this context, 'equal access' translates into being provided with the same opportunities to get an education as anyone else. However, the spectre of otherness appears only a few sections later:

in exceptional circumstances, where their professionally-assessed special education needs are not met within the mainstream education system, member states will ensure that effective alternative support measures are provided consistent with the goal of full participation (Council of Europe, 2006:16)

Hence, there are subjects whose participation comes into question even without barriers, people who cannot be the integrated citizens that the overriding policies postulate. As seen in the previous chapter, disruptions require supplements, here consisting of the allowance of segregation which is consistent with 'full participation' due to 'exceptional circumstances'. Hence, the sphere of 'all persons, irrespective of the nature and degree of their impairment' is not as inclusive as it seems; there are exceptional circumstances that break up the totality of 'all persons' and hence underhandedly constitute 'some persons' that the general principle of integrated education does not hold for. In Europe, 2.3% of all pupils are educated in a segregated settings (WHO, 2011:210) and it is very likely that many or most of these have intellectual or learning disabilities, as special schooling systems often target children and adolescents with cognitive limitations more or less exclusively. It therefore

seems reasonable that the 'exceptional circumstances' denote intellectual disability, to a large extent.

This example is situated in a wider discussion of integrated versus segregated education. WHO (2011:209) states that there are two definitions of what inclusive education entails: (1) that schooling of people with disabilities should be an issue of education politics rather than of social policy, and that (2) a stronger requirement of integration means that people with disabilities attend regular classes and/or have their education at the same schools as other children. If following the first definition, countries can maintain separation of people with disabilities whilst still claim that education is 'inclusive', as long as special schooling falls under the responsibilities of the education ministry. Here, inclusion merely becomes a matter of the organization of state administration and it is perfectly possible to go through a whole life of such 'inclusive' education without ever setting foot in the same school buildings as non-disabled peers. The stance of the CRPD seems to conform to this view, stating precisely that inclusive education of people with disabilities requires that education authorities are responsible (see CRPD, Article 24; WHO, 2011:217). The WHO also leaves considerable room for interpretation by recommending that no new segregated schools should be built, however at the same time refusing to reproach keeping people with intellectual disabilities in separate schools. The World Report states: 'In practice, however, it is difficult to ensure the full inclusion of all children with disabilities, even though this is the ultimate goal' (WHO, 2011:210). Similar to the Council of Europe statements above, the WHO thereby establishes an ideal that it also attaches with a clear reservation, consisting of the difficulties arising 'in practice'. Of course, in a document presented as an implementation guide to the CRPD, it is hard not to read this as a retraction from the ideal that segregated schooling should be ended for all people with disabilities.

My argument here is that these ambiguities answer to the disruption of intellectual disability. The formulation of two senses of inclusive education, allowing segregated schooling to continue under 'exceptional circumstances', and the differentiation between inclusion as the 'ultimate goal' and 'in practice', are all to be considered as supplements provoked by the otherness of certain disabled people who are seen as unable to meet the general goals of independence and integration. As education is seen to be central to inclusion, this means that the global policy discourse is tormented with lingering exclusion. When considered on the policy level, this may not seem very upsetting; people with disabilities should be granted mainstream education

and when that is not possible other measures directed towards the same goal shall be provided. However, what is important for my purposes is that the phenomenon of intellectual disability figures as the special case that requires extraordinary means that are external to the general goals in question. This is the logic of the supplement, where the basic principle – in this case of integrated schooling – needs to be added to because there is a group understood as requiring special treatments. In other words, this is how the universalism of citizenship as full participation in all areas of society clashes with the particularity of cognitive deficit.

#### *Independent living and dependency on others*

I have already discussed the centrality of ‘independence’ of the CRPD (Article 3) and how it recurs as a reference point, for example used to specify the content of rights related to accessibility, socially integrated living, and personal mobility (Article 9, 19, 20). More generally, this is arguably a key concept of the global disability politics discourse.

Again, I want to start by looking at a specific example. In its 2006-2015 strategy, the Council of Europe (2006:10) declared that ‘independence’ was one of its fundamental principles, later substantiating it as ‘dignity and individual autonomy including the freedom to make one’s own choices’. One of the domains where this principle has the most influence concerns where and how people with disabilities should live, which is also emphasised in Article 19 of the CRPD. On this matter, the Council of Europe (2006:20-1) action plan states:

This action line focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where to live. This requires strategic policies which support the move from institutional care to community based settings.

In this quote, ‘independence’ has gone from being a general guiding principle to becoming a continuum that can vary in degree, as is seen in the proposition that individuals should be as independent ‘as possible’. This also suggests that the guiding principle of independence cannot be fully met in all cases, otherwise the specification ‘as independently as possible’ would have been phrased ‘to live independently’ proper. The assumption that full independence is unreachable in some cases is made explicit a few sentences later:

Full independent living may not be possible or a choice for all individuals. In exceptional cases, care in small, quality structures should be encouraged as an alternative to living in an institution. (Council of Europe, 2006:21)

The document does not specify what it means that ‘full independent living’ may not be a ‘choice’. It seems reasonable that it relates to the ‘independent living’-movement of people with disabilities demanding to get appropriate support in their homes so that they can live independently. What we can infer from the quote, however, is that ‘care in small, quality structures’ is not seen as conforming to ‘full independent living’ as it is proposed as an alternative when this is impossible. Similarly to ‘fully integrated education’, the motivation for sidestepping the general principle is the existence of ‘exceptional cases’. Considering that smaller services, such as group homes and apartments with nearby support if needed, are common among people with intellectual disabilities, it is again reasonable to assume that the ‘exceptional circumstances’ in question, at least to some extent, refer to people with this diagnosis. Thus, what we see here is how a general principle of ‘independence’ is both established and circumvented in ‘exceptional cases’, which means that the ‘universal’ principle is not really universal. An implicit division is again made within the population of people with disabilities, between individuals where goals of independent living are applicable, and those who are characterised as ‘exceptional cases’ and with respect to whom these goals are sometimes impossible to fulfil. In turn, this means that there is a need for a supplement, here appearing in the form of ‘care in small, quality structures’, which is a measure added outside the general envisioning of how people with disabilities should be living.

Ultimately, this connects with the dichotomous relationship between ‘independence’ and ‘dependence’. Consider the WHO’s (2011:263) statement that reliance on institutional care, a lack of community living, and segregation are all problems that leave people with disabilities ‘dependent on others and isolated from mainstream social, cultural, and political opportunities’ (263). Here, ‘dependent on others’ is juxtaposed with the general goal of ‘independence’ and is clearly seen as something that contributes to the exclusion of people with disabilities. This has implications: if ‘dependence on others’ contradicts ‘independence’, more or less all attempts to promote ‘independent living’ will fall short as they leave the individual reliant on other people; in granting access, removing barriers, providing quality services, and so on. Admittedly, the authors surely do not mean to imply that. What is important here, though, is the structure of the relationship between ‘independence’ and ‘dependence’ that comes to the fore, not the intentions

behind the wording. In the introductory chapter, I discussed the implosion of the inside/outside structure, as these poles simultaneously provide each other with meaning by merit of being opposites *and* incorporating each other; a firm and stable separation of these is impossible as 'exclusion' will haunt 'inclusion' by being its condition of possibility. The notion of 'independence', and the efforts to formulate policies which promote this ideal, can serve as an example of how this plays out in policy discourse. The basic logic of how 'independence' operates in the context of the policy discourse is that disabled people should become independent through the help of certain policies granting them autonomy, choice, and self-reliance. But if disabled people are to be independent only given certain policies, they are concurrently dependent on these policies to become the independent citizen-subjects prescribed. In other words, if you are independent only by being recognised as such, then your independency simultaneously reinstates your dependence on such recognition.

There is an enlightening parallel here to the peculiar double-bind of summons to 'be free' (see Royle, 2003:31). When facing this particular demand, one can ignore it and hence continue to be 'un-free', as seen from the perspective of the interlocutor. If one, on the other hand, conforms to this call one will only 'be free' by the demand of an external authority, simply obeying command, and therefore still failing to be free. Hence, when we are called upon and follow the challenge to 'be free', or to be 'independent', we are simultaneously adhering to an external authority which either sets the terms of our freedom or which incites our independence. Now, if people with intellectual disabilities were constructed as equally 'independent' as everyone else, then there would be no need for the goal in the first place, the same way that there is no need to summon people that are already 'free' to 'be free'. Paradoxically, thus, the 'dependency' that the policies aim to remove is at the same time reprised, as the intellectually disabled subject is constituted as 'dependent' on policies that prevent them from being dependent. In this way, 'independence' is perpetually haunted by its constitutive outside.

In summary, the re-conceptualisation of the intellectually disabled – from being 'dependent' to becoming 'independent' – simultaneously reinscribes dependency at the points where the new goal is understood as unreachable. My suggestion is that this bears witness to a recurring and inherent tension between the content given to citizenship in the global policy documents and the construction of the condition of intellectual disability. As it appears, there are very few ways of understanding the present politics of intellectual disability outside these pre-set frames of interpretation; there is

no language of citizenship inclusion that is able to fully incorporate its constitutive otherness. The general instability of discourses on independence – teaching us that policies that promote independence construct their targets as dependent on such policies – is detectable within this policy area precisely because intellectual disability is the constitutive outside of ideals of autonomy and independence.

*‘Full’ inclusion and constitutive lack*

I want to point out a final contradiction in the global policy discourse which similarly directs attention towards the structure of disruption and supplement, this time relating to the more general issue of how people with intellectual disabilities are seen as lacking with respect to what is considered a full human life.

Consider the right of citizens to vote in general elections. Of course, equality of political participation is fundamental to any contemporary conception of citizenship and it seems contradictory to claim that individuals prohibited from voting have acquired this status. Nevertheless, this sometimes seems to be precisely the situation for people with intellectual disabilities. Full inclusion and participation in political life is central to the CRPD and integral to the work of the FRA, the WHO, and to ratifying countries. At the same time, the FRA (2010:10) states that in human rights law, the right to vote is not absolute, but can be restricted, among other things, on merit of mental incapacity. In accordance, prohibition of voting rights is subjected to conditioning throughout the material. For example, The European Court of Human Rights (ECtHR), which is the legal body of the Council of Europe, in the case of *Alejos Kiss v. Hungary* (2010:13), declared that ‘the curtailment of their rights must be subject to strict scrutiny’. The FRA (2010:11) states that some restriction of this right can be legitimate if certain procedures and conditions are met (although it is not clear from the context of this statement whether this refers to their own position or to an established general consensus within human rights law), thereafter going on to state that it is not clear whether the CRPD prohibits restrictions of voting rights or not, calling for clearer guidelines on this issue (FRA, 2010:12). These statements have in common the fact that they do not acknowledge the contradiction of proposing both ‘full’ and ‘equal’ political participation whilst considering retractions of voting rights as legitimate for certain disabled people due to cognitive limitations. Thus, on the one hand we have a set of clearly stated commitments to equal political rights of people with disabilities and, on the other hand, a recurring suggestion that restrictions of the right to vote may be

legitimate on the grounds of intellectual disability. The reason why the prohibition of voting rights on these grounds can appear to be legitimate is that intellectual disability disrupts notions of what is required for political participation. The resulting supplements consist of safeguards surrounding their retraction, stating that they must be subject to careful scrutiny and should not fall on people with intellectual disabilities as a collective (FRA, 2010:10-11; WHO, 2011:171). But this is only added *after* the general goal of full and equal participation has been established. In this way, the general idea that the CRPD guarantee people with disabilities ‘unconditional’ human rights is haunted by the actual conditioning of certain human rights (see Schulze, 2010:13).

Another instance where the tension between the presumed capabilities of inclusion and the construction of intellectual disability as ‘otherness’ surfaces is in the context of ‘legal capacity’, specified in Article 12 of the CRPD. The right to be recognised as a legal subject is central since it spans different policy areas and hence affects more or less the whole life of the individual (WHO, 2010:10, 15). Ultimately, being granted equal legal standing means being seen and treated as an individual competent to make decisions in all areas of life, concerning one’s living arrangements, health care, and services. To grasp what is at stake here, it is instructive to start off with a closer look at the relevant sections of the CRPD. The first three sections of the twelfth article guarantee that ‘disabled people have the right to recognition everywhere as persons before the law’ (UN, 2006). Furthermore, it is assured that ‘persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. Yet, in the fourth section there is a shift of tone and focus:

State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity 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. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

The quoted section deals with the rights of those who are in need of legal guardians, hence, with those who are not recognised as legal subjects, after all. However, the fact that we are reading about guardianship is not made

explicit in the actual text; it is an assumption that underpins the quote, a quote which would seem superfluous if the prior statement, that *all* disabled people actually were recognized as enjoying equal legal capacity and were recognised as people before the law, was really seen as unconditional. In fact, the extracted text only makes sense provided that all people are *not* recognised as having equal legal capacity, after all.

Legal capacity and guardianship was much debated in the process leading up to the CRPD. The debate concerned whether all disabled persons could be said to have a legal capacity and the outcome of the actual convention is often described as a manifestation of a paradigmatic shift from ‘substituted’ to ‘supported’ decision-making (see Schulze, 2010:86-8; WHO, 2011:138; FRA, 2013:7). In substance, this means that individuals lacking the capacity to make choices are to be supported, rather than having their decision-making transferred to someone else. Both the FRA (2013:55) and WHO (2011:137-8) advocate supported-decision-making. Hence, in the texts analysed, the safeguards surrounding guardianship and supported-decision-making are juxtaposed with simply declaring some people to be legally incompetent. But by doing this, the fact that supported-decision-making itself is an expression of a lack of legal capacity is concealed. Thereby, the global policy discourse can both uphold the idea of the universal recognition of people with disabilities as legal subjects *and* recognise that some people lack the capabilities necessary. And in this way, the shift from ‘transferred’ to ‘supported’ decision-making supplements the disruption of people who fall short concerning the capacities required to be a subject before the law.

Now, this is not a legal analysis and many of these things may well be explained in light of the intricacies of international human rights law. Neither is this a normative analysis, arguing that guardianship or supported decision-making is necessarily bad. Again, the point I want to make is that the ‘otherness’ of intellectual disability requires that the general commitments to ‘legal capacity’ are provisionally suspended. In discourse, the construction of citizenship inclusion for people with intellectual disabilities simultaneously re-inscribes a recurring lack of capacities with respect to the ideals of citizenship. When the goals of inclusion were formulated by the disability movement, they pertained to people with disabilities, in general. At the same time, the specific group of people with intellectual disabilities is understood as defined by a lack of reason and this is why this condition repeatedly appears to be an extraordinary phenomenon that requires citizenship ideals to be added to, in both political philosophy and in policy. Intellectual disability serves as the exception which cannot be incorporated into the universalism

that underpins notions of citizenship and hence the defining incompleteness of the group comes to exist in tension with ‘full’ citizenship and inclusion in human rights frameworks.

### **Politics of Inclusion/Exclusion**

In essence, the above analysis has established two things: how a regulative ideal of citizenship is established to achieve inclusion, and how this requires re-inscription of exclusion through supplements that answer to disruptions of intellectual disability. Hence, breaches of principles of inclusion are necessary when the idea of equality for *all* clashes with the lack of reason of *some*. Furthermore, when a lack of capacities is understood as a pre-political biological phenomenon, it composes a residual difference that policy can neither remedy nor incorporate. These are traces of imploding systems of signification which stretch into the organization of services and support (as we shall see more clearly in the next chapter). The failure to include the constitutive outside establishes a situation in which ‘otherness’ must both be removed and reconstituted, *post* institutionalisation. Thus, perhaps we should not be all that surprised when the ideals of independence and self-determination for people with intellectual disabilities fail to materialise, as the discourses manufacturing these ideals cannot grant the citizenship proclaimed without simultaneously withdrawing it.

Spivak (in Morton, 2003:28-9) has aptly captured the disciplining functions of the humanist subject by pointing out how its internalisation appears to be a pre-condition of becoming fully human. Considering the ‘lack’ that citizenship politics both answers to and reinstates, Spivak’s analysis also illuminates the effect of global citizenship discourses on intellectual disability. Indeed, this group is defined as lacking in the characteristics which are commonly seen as defining humanity, made measureable by classification, and so it is to be regulated by an ideal that always seems to require its own contravention. Just as Derrida’s (1997:144-6) ‘supplement’ highlights the incompleteness of the linguistic sign, ‘intellectual disability’ highlights the incompleteness of discourses of ‘citizenship inclusion’. This, again, points to why this particular kind of disability is central to understand citizenship and inclusion, in general. In a way, what has been analysed here is the failure to reach closure; the failure to integrate otherness, precisely because such integration threatens the system of signification that citizenship is founded upon in the first place. Including the

constitutive outside of what creates our sense of 'normal' subjectivity also means putting the very normality of this subjectivity into question. In this way, the policy promises made on a discursive level are always already broken; the failure to include, often noted and criticised by disability scholarship as an anomaly, should rather be approached as a feature of a system which can already be detected when examining how the goals of inclusion are given their discursive shape. This is not to say that citizenship politics is not called for, or that it just constitutes more of the same in relation to institutional care. Rather, it is to say that we are mistaken when suggesting that citizenship discourse is unequivocally inclusive. Now, in the next chapter, we will see how this structure – of simultaneously crafting intellectually disabled citizen-subjects and excluding them from citizenship – transforms into technologies of government applied in services where the intellectually disabled citizen-subject is supposed to materialise.

## 6. Control

In this chapter, I will show how disability services both foster citizenship and effectuate constraints on citizenship rights. Hence, contrary to the common frame of interpretation, the emergence of politics of inclusion did not reallocate power from state representatives to disabled individuals; it transformed how power governs the individuals targeted. On the one hand, in disability services, power has come to operate by moulding citizens and manufacturing ideals of self-determination, participation, and independence. On the other hand, individuals with intellectual disability are constantly subjected to paternalism and enforcements in case their behaviour does not conform to the ideals of citizenship. Both of these are effectuated through specific techniques and routines of support workers in their everyday work. Together, the dual logics of manufacturing and restricting citizenship define the service provision of post-institutionalisation.

In most social scientific and philosophical studies of this concept, citizenship is usually linked to equality of civil, political, and social rights, conceptualising it as a *status* (Marshall, 1950). On the contrary, my analysis starts from the proposition that ideas of ‘citizenship’ produce subjects (see Cruikshank, 1999). Hence, citizenship will be understood as an institutionalised construct that establishes ideals for the relationship between the individual, the state, and the community, shaping how individuals come to relate to the community that they live in (see Yuval-Davis, 2007). Therefore, while the standard narrative of disability politics primarily understands power as an intrusion on citizenship, I will also analyse how power operates as a precondition that shapes what individuals aspire to and how they understand themselves as ‘citizens’ (see Cruikshank, 1999).

As was stressed in the introductory chapter, disability services that are supposed to promote inclusion have often failed to meet the ambitions of policy commitments. Thus, the overriding conclusion of Beadle-Brown et al (2007 in Clement & Bigby, 2010), that deinstitutionalisation is ridden with remnants of the institutional era that constrain the possibility of independence and self-determination, seems to capture a global tendency in residential and

community-care for the intellectually disabled (see Galvin, 2004). Still, as I discussed in the introduction, the standard interpretations of the situation are blunt and misrepresent the problems: rather than implementation failures or remnants of institutionalisation, I will argue that we are dealing with a new regime of government that is defined by inclusion *and* exclusion. I will build this argument by showing that two concurrent rationalities underpin actual work in intellectual disability services. Both of these are integral to the present biopolitical regime. First, service provision operates by ‘governmentality’ (Foucault, 2007:107-10, 115-23); a mode of government geared to create self-ruling subjects by nurturing capacities seen as necessary to function as a citizen. Second, service provision operates using technologies of discipline, restriction, and straightforward coercion, which constrain the freedoms associated with citizenship. Together, these parallel modes of government create a decentralised system of control, constantly monitoring whether people with intellectual disabilities are fit to make judgements regarding their own lives. Furthermore, this new regime of government operates in and through relationships formed at the lowest levels of policy implementation. Although not the analytical focus of this chapter, it follows that the support workers are also subjects of government and that power limits their fields of action. Hence, my ambition here is not to depict this group as malicious rulers; they are also acting within certain constraints and discourses, often underpaid in a low-status job, often facing impossible situations, and often, despite this, doing a very good job given the circumstances.

A few words need to be said about the methodological considerations that have guided this specific chapter. In essence, this is a case study of Swedish intellectual disability services. There are strategic reasons to pinpoint Sweden in order to grasp the politics of inclusion. As stated already, for the past thirty years policies targeting individuals with intellectual disabilities have undergone significant shifts in large parts of Europe and North America, from the paternalism of institutional confinement to policies focusing on citizenship and socially integrated living. In this context, the Swedish legislation, called the Law of Support and Service for Certain People with Disabilities (LSS), can be seen as a forerunner (see Hollander, 1999:409-10; Race, 2007:32). More generally, Sweden is renowned in the international disability community for its ambitious goals of societal integration and its strong focus on individual self-determination (see Kristiansen, 1999; Kristiansen et al, 1999; EIDRN, 2003:5-9, 51-60; Race, 2007:23-5, WHO, 2011:148, 156). Therefore, Sweden is an exemplary case

to theorise the government of intellectual disability after deinstitutionalisation.

I will draw on two sources of material: official documents and evaluations of intellectual disability services, and interviews, with support workers and activists diagnosed with intellectual disability. The interview material is made up of 33 interviews with support workers and bureaucrats, whereof 26 are with staff working at the street-level, in direct contact with people with intellectual disabilities, and the rest with first-line managers and bureaucrats. Swedish disability policy is primarily implemented on the municipal level and 17 of the interviews were conducted as a case study of one such large Swedish municipality in 2009-2010. In 2013-2016 a second set of 13 interviews were conducted in three other municipalities, differing in size, political rule, and with respect to the organization of services, along with an additional three interviews in the municipality of the case study. Since the conclusions that will be presented appear to hold over time and across municipal borders, there is no need to differentiate between the initial case study and the follow-ups in the actual text. In addition, I have interviewed five members of the self-advocacy organization Grunden who have first-hand experience of Swedish disability services in several different municipalities. This took the form of a group interview (that will be more thoroughly presented in Chapter 8). Finally, the focus has been on one specific service, namely supported living, which is most often organised as group home living or as satellite apartments (we will get back to what these entail in a moment). The group home is the most common form of accommodation in the wake of deinstitutionalisation, in Sweden and elsewhere, being singled out by Tøssebro (2005) as the emblematic form of integrated community living. Furthermore, supported living is central to the politics of inclusion and its break with institutionalisation. Still, in order to ensure that I did not examine a culture isolated to this specific service, I also carried out three interviews with staffers at sheltered employment centres and with managers who have been in charge of other LSS services. An overview of the material and of how it has been coded is presented in Appendix 1.

## **The Citizen-Subject of Swedish Disability Politics**

Turning to Sweden as the empirical lens through which the inner workings of citizenship politics will be explored, two significant legislative changes are of vast importance to understand the present regulations. The first is the

Omsorgslag ('the Care-law') of 1985, characterised by its focus on citizenship and self-determination. The second is the subsequent introduction of the LSS in 1994, which replaced the 1985 care-law and established disability services as rights. The LSS strengthened the idea of citizenship as encompassing 'independence', 'self-determination' and 'societal integration' and was warmly welcomed by the disability movement as well as by all parties in the Swedish Parliament. Representatives of various disability organizations had been highly involved in the process leading up to the reform. A direct result of the new law was that the remaining institutions were closed down and replaced by socially integrated living and, in doing so, Sweden became one of the first countries to fully deinstitutionalise disability support (Tideman, 2005; WHO, 2011:147). In the narrative of Swedish disability politics, the LSS marks a shift of paradigms in which people with intellectual disabilities were finally recognised as equal citizens. Although Swedish policy has undergone several changes since the emergence of the LSS, the direction set out by the 1994 reform has been maintained<sup>17</sup>.

The LSS states that public services for people with intellectual disabilities aim to make the targeted individuals independent and participating members of society (7 § LSS; Prop. 1992/93:159) and the law is structured around ten services which are designed to accomplish this (9 § LSS). Supported living, which will be the main focus here, is, for example, accompanied by day-care sheltered employment and personal assistance<sup>18</sup>. Furthermore, LSS is a law of rights, which means that individuals deemed to be in need of support and who have a diagnosis which makes them eligible, have a legal claim that the municipality of residence provide them with services. In this way, the LSS is regulated by the state, but financed and implemented by local governments.

The overall intention of the 'handicap reform' was to move power from the state to individuals with disabilities (see Grassman et al, 2009:45). An important means to achieve this movement can be found in the strong emphasis on protecting the 'self-determination' and 'autonomy' of

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<sup>17</sup> The past two or three years have seen some worrying tendencies linked to politics of austerity. At the time of finishing this book, the costs of disability services were being debated and a public commission had been appointed to evaluate the functioning of the LSS. The disability movement is very critical of and worried about this development.

<sup>18</sup> When the LSS was introduced, personal assistance was most the service getting most popular attention, not least because it was strongly advocated by the disability movement and emerged from the ideology of 'independent living'. The reason why it is not studied here is that supported living is far more common for people with intellectual disabilities.

individuals with disabilities (6 § LSS). These formulations must be understood against the backdrop of paternalistic institutional confinement, which was depicted as the main problem throughout the public commissions that led up to the 1994 reform (SOU 1990:19; SOU 1991:46; SOU 1992:52). These reports frequently stress the risk that public officials decide over or influence the decision-making of people with disabilities and declare that the idea that people with disabilities does not know what is best for themselves is a violation of the integrity of the individual (see SOU 1991:46, p. 126). Along these lines, Swedish disability politics is designed to establish a sphere of individual integrity and autonomy that is protected against state intrusions and paternalism of the kind that was commonplace during the 20<sup>th</sup> century. As such, the politics of inclusion, and the LSS more specifically, are tightly connected to the main tenets of the liberal and humanist conceptions of citizenship; by their emphasis on rights, by the perceived conflict between state and individual, and by the weight given to ‘self-determination’ and ‘independence’ as central goals.

Before turning to what happens when these ideals are to be implemented, it is instructive to first draw attention to some structural features of the Swedish policy discourse. In the law text it is stated that the goal of disability politics is for people with disabilities to ‘live as others’ (5 § LSS), that is, as the non-disabled part of the population. Although open for interpretation, this is usually seen as a guarantee of certain standards concerning accommodation and as specifying the ambition that people with disabilities should be fully integrated in society. In other policy documents, a similar figure of reasoning is expressed by the ambition that people with intellectual disabilities should live as ‘normal’ lives as possible (Prop. 1999/2000:79, p. 25-6). Historically, an important source of inspiration for Swedish disability regulations has been the ‘normalisation theory’ (see Nirje, 2003; Yates et al, 2008:247), which originated in Scandinavia in the sixties and stated that people with intellectual disabilities should be able to live according to ‘normal’ living patterns<sup>19</sup>.

I want to pause for a bit and look at the ideas of ‘normal living patterns’ here. It is important to note that the ideas of ‘normalisation’ presume abnormality since only people who are not already ‘normal’ can become ‘normalised’; only groups that in some way exceed the norm call for services that state ‘normality’ as their objective. Taken by itself, this may not be very

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<sup>19</sup> A similar ambition of ‘ordinary’ housing leading to ‘ordinary’ living patterns was prominent in the deinstitutionalisation of the UK (Felce & Perry, 1995 in Clement & Bigby, 2010:123).

controversial: the living patterns of people with intellectual disabilities have historically been far from normal and being granted the same rights as everyone else would certainly seem to be a 'normalisation'. Still, this is important since it exposes how disability services must function by *transforming* its targets; it must do something to the people it supports in order to bridge the gap between what they should *become* and what they *are*. In other words, it exposes that 'citizenship' does not mean that the state withdraws, but that it organizes services that *make* citizens. The existence of a gap, between how people with disability live and how they should live, is revealed in the nouns frequenting Swedish disability policy, of 'normalisation' and 'activation' (SOU 2008:77, p. 265), which in turn require verbs that designate what disability services should accomplish; they should 'normalise' and 'activate'. This presupposes subjects for these verbs to take aim at – and, as already shown, only 'abnormal' and 'inactive' subjects can be targeted by policies of 'normalisation' and 'activation'.

On the one hand, the general goals of Swedish disability policy can be seen as forming the contours of a self-determined and independent subject, making their own way in life while being protected by rights. This is the idea of a transfer of power – from state representatives to disabled individuals. On the other hand, however, there is also an implicit division between people with intellectual disabilities and the 'normal' people who provide a model for what citizenship should be for those with this diagnosis. Next, we shall turn to how support work seeks to accomplish this model of a 'normal' and 'activated' citizen.

## **Making and Failing Citizens**

The nature of work in supported living can look very different, for example between group homes and satellite apartments (apartments where individuals do not have access to constant support and which are most often integrated into regular housing estates), between different group homes, but also between individuals living at the same group home. Some individuals only need help with structuring their daily routines while getting by independently in most other respects. Others need help with personal hygiene, eating, dressing themselves and leaving the home. Despite such differences, the goals of self-determination and participation in society apply, although the legislation states that these goals should be interpreted with respect to the needs of the individual (2 § LSS). Among the support workers I have

interviewed, the whole range of service-needs and severity of disability are covered.

In the typical Swedish group home – the dominant way of organizing supported living – 5-7 apartments are bundled together along with larger rooms that are shared between all tenants<sup>20</sup>. Sometimes, staff is also responsible for one or a few satellite apartments where people with less hands-on support needs live. The extent to which staffers help out with cleaning, bathing, brushing teeth, and cooking in the individual apartments varies based on the needs of the individual and workplace routines. In a sense, thus, supported living can be characterised as state regulated and financed work in private homes. Group homes are usually located in either suburban residential areas of self-contained houses, where the group home is often visibly separated from other houses in the neighbourhood, or in regular housing estates. Many people with intellectual disabilities spend a large part of their of their life within the confines of the group home, perhaps going to sheltered-employment centres for work and leaving for day-trips together with other tenants during the weekends, living patterns that appear to be quite far-removed from the goals of ‘full participation in society’. But there are also individuals who go out on their own, have friends, activities, and so on.

In the following, we shall start by seeing how support workers actively strive to cultivate citizens. Thereafter we shall consider the concurrent technologies of constraining the freedom and independence of people with intellectual disabilities.

### *Producing citizens*

The purpose of supported living is to provide the individual with support so that they are granted citizenship and full participation in society. As was showed above with reference to the LSS and its associated policies, this implies that services take on a productive role; they must make citizens out of people that previously, or in the absence of such services, would not be.

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<sup>20</sup> Other studies, notably Clement & Bigby (2010), have other models for differentiating between forms of supported living, for example separating group homes from individual apartments where individuals are not renting their apartments from the same organization that provides services. The reason why such distinctions are not made here is that the Swedish system has both pure group homes (although the persons living in them are ‘tenants’ legally speaking), ‘stairwell living-units’ without shared areas, and satellite apartments tied to nearby personal units. Oftentimes, staff are both responsible for a group as well as for a few satellite apartments, which renders it difficult to distinguish between these different service forms in the interviews.

An overview of the material shows that there is a general awareness and commitment to the goals of the LSS among personnel working in supported living. All of the interviewees have expressed that they value the general intention of the LSS to enable people with disabilities to live independently and by their own choices. The commitment to the goals of 'independence', 'participation', and 'self-determination', however, far from implies that the interviewees are neutral with respect to how the people they work with live. To the contrary, they continuously seek to encourage certain ways of being, develop certain capacities, and teach certain lessons on how to get by in society. It is clear that the people interviewed see it as their task to facilitate the individuals they work with to *become* citizens. Furthermore, as has been discussed with reference to the history of political philosophy and policy discourse, citizenship is frequently described as premised on certain capacities that are actively nurtured and promoted; one needs to be able to make choices, to move around society, and to reflect on the consequences of one's actions. Much of what goes on in the group home is geared towards creating such individuals, capable of being independent. This focus is often already evident when the interviewees answer a first general question about the overriding purpose of their work:

The whole point of our workplace is to make the people living here as able to participate as possible. They cannot be totally independent, but to make them as able to participate as possible in different decisions concerning their lives. (AP7)

The idea is to make them more independent. So I work to make myself redundant. You want as little support for them as possible. But, they live here for a reason, so it's not possible to make them accomplish what people such as you and I can do. But you can make them less dependent on support. (CP1)

Depending on the service needs of the individuals one works with, 'independence' might mean being able to choose what to eat or getting the newspaper out of the post-box, whilst for other individuals with disability it could mean being able to walk to and from the sheltered-employment centre or being able to go out and eat on one's own at a restaurant. It is continuously stressed that such development is a process, in which tenants in the group home gradually learn how to manage their lives.

Taken together, the interviews establish the impression that the discursive construction of the subject found in the regulation of Swedish disability politics incites processes of shaping individuals to become citizens. One of the interviewees describes this:

It's both them and us that see the need for developing skills. We talk to them and ask "would you like to do this?", for example. And then we'll have to wait and see what the response is. Sometimes, you have to ask and ask and as and ask, for three months, ask and ask and then ask again, before they are ready. Then, we discuss how to do it, how they can learn. So that discussion is always there, these are really long processes. (CP3)

The quote is typical in how it describes staffers as initiators and highly active in nurturing capacities. In several interviews, the processes of developing skills of independence and participation are described as developing through carefully managed progression, where staff teaches individuals with intellectual disability how to improve skills understood as required to be participating and self-determined community members. One of the support workers gives an example of this:

One of the persons living here could not walk by herself to her day-care centre, despite it being just a kilometre away. Her parents said that she had to take the taxi. But we decided that we would work with her, so we started to walk with her, gradually letting her walk more of the way by herself. We planned, step by step, how she could learn how to walk to and from work. (CP4)

This quote illustrates the general tendency that people with intellectual disabilities are not seen as already possessing the necessary capabilities of citizenship. This picture is mirrored in previous research on the implementation of citizenship politics in other countries. Consider, for example, the description provided by Gilbert (2003:40) of how self-management and citizenship are actively promoted and developed by the UK public officials who he interviews. Similarly, Schelly (2008), describes the actual experience of working as a personal assistant implementing policies of self-determination as a process of cultivating capacities. In these accounts, making one's own decisions, taking responsibility, and communicating one's desires are skills that are taught rather than skills that people with intellectual disabilities have. Rather than 'empowerment', this can be seen as a reinforcement and practical application of what Clifford Simplican calls the 'capacity contract': processes aiming to instil in the individual the prerequisites of societal belonging. This is what Cruikshank (see Cruikshank, 1999) calls processes of crafting 'citizen-subjects'.

Since developing skillsets necessary for citizenship is seen as integral to working at the group home, there is a need to coordinate and plan how these processes are managed. A common way of doing this is to discuss tenants at

monthly staff meetings. These are more or less ubiquitous in group homes and are very often devoted to discussing how the development and behaviour of each individual should be handled. A related tool to coordinate citizen-production is the report book, where what has happened during the day (or night) is written down. These often function as logs of activities, visits, and similar – but sometimes they also map the moods of tenants, whether they have requested certain things, whether they have demanded help with certain tasks, or whether they have showered, brushed their teeth, or eaten. The report book appears to be central to the working routines of supported living, keeping track of matters such as personal hygiene, mental states, or when and for which reason, tenants have left their apartments. The activists of Grunden share the impression that report books are central to the organization of supported living. They are well aware that they are being reported about and are talking points at meetings in their absence, which they describe as paternalistic and derogatory. One of the activists recalls how she contested such practices, demanding to see what was reported about her and to be present when talked about, but these requests were denied by staff. As described in my conversation with Grunden, in these cases, the efforts to plan and coordinate measures to produce citizens could not extend to involve the citizens-to-be in the process.

Far from a withdrawal of state representatives, thus, the nurturing of citizenship functions by planned and coordinated processes where staffers see it as their role to cultivate capacities which are understood as being necessary for citizenship. A recurring theme here concerns capabilities of decision-making. There is a widespread idea among the support workers that people diagnosed with intellectual disability have difficulties making choices, which becomes problematic considering the weight of self-determination and independence in the LSS. Basically, this is the disruption of ‘intellectual disability’ to conceptions of reason as a qualification for citizenship that I have discussed in the previous two chapters. Note that the perceived lack on behalf of individuals granted support is not described as pertaining to making choices in general, but to making ‘good’ choices. However, since the interviewees interpret the LSS as a hindrance against making decisions on behalf of the individuals they work with, they often set out to find courses of action that do not violate their interpretation of the law. In this context, all interviewees state that ‘motivational work’ is central to their jobs. The selection of quotes below illustrate what this can mean:

All we can do is to work through motivating. It is the same problem as with what they eat, for example. If they want to eat kebab seven days a week, then we are not allowed to force them not to. (BP2)

Very much depends on the individual. We have people living here with mild disabilities, many of which have gone to regular schools and have a good understanding of things... with them it is continuous motivational work, where they have a very clear awareness of their rights. With young people, there is a lot of motivational work. People with more severe disabilities are not aware of their rights in the same way, although relatives might be. But that cannot mean that you just ignore their wishes. After all, it's always about motivation. (AP6)

I believe that respect for the individual is central, that you try to avoid infringements. You have to use your common sense. If they want to sleep 'til 1pm we cannot stop them, and then they'll sleep 'til 1pm. We have to motivate them against doing these things if we believe that they're not good for them. (AP10)

As it appears, motivation occurs when there is a conflict between what support workers and individuals believe is best in a certain situation. Thus, the 'lacking' decision-making capacity which is referred to essentially consists of not agreeing with the judgement of support workers. The interviewees thus presume that their own viewpoint is superior. In this way, motivation functions by directly intervening in the individual's field of action, not by constraining or forcing, but by seeking to convince and win over. The technology is applied to choices concerning a number of different things, such as what clothes to wear, what to eat, how to use one's money, how many cups of coffee to drink, or less mundane matters such as how to handle a relationship or what assistance tools to use. There are also great differences concerning how 'motivation' is carried out:

Some people, we can talk to. One person here, if she had been investigated today, she would probably not have ended up in the LSS. You can joke with her. So, with her, you can say "you won't feel well if we go there, let's do something else instead". There is another person here where it's much harder [when he wants to go somewhere that makes him feel ill]. I have tried to explain to him that "you are older now, you don't think that it is comfortable to go there... Shouldn't we stay home and have coffee and cookies instead?" You only have sweets and biscuits to use, that's what's left if they cannot use their hands. (AP4)

You constantly need to guide them in their self-determination and decisions. It is about informing and pointing out why certain things are important [to think about when choosing]. Sometimes, it is not possible, but oftentimes you can argue with them. It is never about forcing, because we are not allowed to do that. (AP10)

If you're accompanying them buying clothes, then you have to steer a little and say "don't you think this shirt is nicer?" On the other hand, you have to step back if they insist. We have a man living here who does not want to clean up his room, so we have to go in to him. But he can still say that we have to leave, and in that case, we have to. So you often think "should he just sit there in his mess?" But if someone came in and told me to go somewhere or do something, I would become really pissed off. (AP1)

Thus, motivation can entail verbal persuasion, elaborate arguing, providing information, reminding of consequences, bribing with sweets, making suggestions, among other things. Many interviewees stress that verbal communication is their primary working tool, especially when it comes to motivational work. It is common that support workers describe elaborate discursive techniques that make certain choices appear to be more favourable and attractive, as is exemplified in the above question 'don't you think this shirt looks nicer?' In several interviews, it is also stressed that tenants with intellectual disability view the support workers as authorities. Thus, prior to motivation is a hierarchical relationship, which suggests that we are not dealing with regular advise-giving like you would find in most relationships between friends or siblings. Motivation is not presented as input into the decision-making process of people with intellectual disabilities, but as a measure that seeks to produce the *correct* decisions.

Motivational work is also described in my conversation with the activists of Grunden, who see it as a recurring annoyance in their everyday lives. All of them have stories about being 'advised' and, as they see it, protected from negative consequences, for example regarding not having their partners staying overnight, not being out too late, and not drinking alcohol. The extent and frequency of references to 'motivation' in the material presents it as an ever-present dimension of how people with intellectual disabilities are communicated with by group home staffers. Thus, motivation is a technology of micro scale management that can be seen as arriving both *before* and *after* citizenship: on the one hand, it is a response to citizenship, to the perceived gap between the rights of freedom and the perceived incapacity to make wise use of it. On the other hand, considering the extent and ubiquitous nature of its use, it must also be seen as a

continuing project of crafting citizen-subjects, not only responding to, but shaping individuals to be able to act as good decision-makers. As such, motivation supplements the disruption caused by people with intellectual disabilities and their incapacity of making good decisions.

As a technology of power, motivation arises in the context of post-institutionalisation, when collectivism and rules give way to individualism and freedom of choice. This is aptly captured in the below quote:

When we started with individualised meals and they were allowed to decide what to have, they gained weight, of course. But I am not allowed to say “no”. I am allowed to explain that it isn’t good to have pizza seven days a week. But if she still wants it, then I am in no position to decide over them. So, we try, like, saying that “you had pizza the other day, wouldn’t it be nice with a salad?” (CP3)

This quote illustrates how the abandonment of collective rules and restrictions produces a new set of perceived problems facing support workers. Motivation arises in this context as a technology applied to manage tenant behaviour in situations where the freedom of the individual risks leading to bad decisions. This is power transformed, from collectively enforced rules to individual management. For example, to restrict ‘bad’ eating habits, motivation works by seeking to convince each individual of the consequences of being overweight, of the dangers of diabetes, of the vitamins the body needs to function, and so on. In turn, the lives of individuals become embedded in these discourses, constituting a landscape where considerations of health effects of eating habits become incorporated into how people with intellectual disabilities practice their right to live by self-determination. This corresponds to Foucault’s notion of government as the ‘conduct of conduct’; instead of deciding what people with intellectual disabilities eat, the technology of government described here seeks to make individuals internalise health considerations into their individual decisions, that is, to achieve a subject that conduces in the favoured way.

Two features of the technology of motivation stand out. First, motivational work always takes the individual as its target and it is described as requiring a deep knowledge and bond of commitment between tenant and staffer. Secondly, motivational work presumes a hierarchy, where the support worker doing the motivating perceives their own viewpoint as superior. Otherwise, motivation would not be needed and could not be justified. For the motivation to function efficiently, furthermore, it is necessary that the recipient of motivation also perceives the knowledge of support workers as

authoritative. Otherwise, they will not listen. In one of the group homes where I conducted interviews, the hierarchy of knowledge regarding decision-making was made explicit:

Here, we work with providing them with 'good' and 'bad' choices, where we explain that if you do this, it will have bad consequences, but if you do that, you will gain from it long term. If you choose the bad course of action, then you have to live with the consequences. It is not about punishing them, but about building on what's positive. (CP3)

This is a technology of redesigning the field of action of the individual, attaching a discourse of valuation to courses of action. Like motivational work more generally, this is described as a tool to increase and allow for self-determination, as the individual remains in control of whether the 'good' or 'bad' alternative is chosen. Of course, in all motivational work, such valuation is implied by the fact that motivation is seen as required and possible to justify. What happens when courses of action are explicitly named this way is that the taken-for-granted authority of knowing what is best is made explicit.

In conclusion, the reality of group home work ties well into what Rose (1993:285) has deemed a prominent feature of contemporary government, namely the decentralised management of the choices of individual citizens. The technologies of citizen-production described here, furthermore, reveal that such micro-management occurs no matter the severity of disability: nurturing capacities may mean teaching individuals how to post a letter or how to develop information gathering skills in preparation for the general election, depending on the individual targeted. In this way, implementing the goals of the LSS, designed to foster independence and self-determination, paradoxically appears as an intensification of state involvement in the lives of people with intellectual disabilities. This is a transformation of the relationship between the state and the individual, where government no longer confronts people with intellectual disabilities as a collective, denied rights and subjected to paternal decision-making, but constantly manages and promotes the capacity of individuals to become self-ruling citizens. The power inherent to such shaping is blatantly obvious to the activists of Grunden, as it permeates their everyday lives. They tell me about constant tensions with staff, about recurring reminders, advice, and a sense of being controlled and watched over.

In this way, the politics of post-institutionalisation is characterised by management of the individual, guided by how support workers interpret the

LSS and what capabilities they perceive as necessary to function as a citizen. Thus, the active moulding of citizens supplements the tensions that arise when people with intellectual disabilities are seen as deficient in necessary capacities of citizenship. In the following, we shall see how post-institutionalisation is characterized by another type of supplement, where the discrepancy between citizenship ideals and intellectual disability instead give rise to restrictions that clearly violate the legislation and its ethos of inclusion.

### *Failed citizens*

A common rhetorical figure, reappearing in more or less all contexts in which LSS-services are managed, is that people with intellectual disabilities ‘...after all are living here for a reason...’ This figure of expression usually accompanies the idea that the LSS cannot be adhered to at all times and indicates that there are characteristics of intellectual disability which conflict with the idea of citizenship. A number of my questions encourage the interviewees to put into words what they feel is difficult with respect to the LSS. The answers suggest that there is a widespread perception of a conflict between the right of self-determination and the very reason why people with intellectual disabilities are entitled to support, namely their intellectual deficiencies. All but a few care workers explicitly state that people with intellectual disabilities sometimes do not know what is best for them, which means that the self-determination of members of this group is being called into question:

They cannot see the consequences of their actions. Sometimes, self-determination is not what is best for them. Within LSS, there are not many that can do that. So in the end, you often end up with how the staff view things, I don’t think that can be avoided. You try to do what is best for the person in question. (AP4)

In pure intellectual terms, they are at the level of minors. That’s how it is. Although they are formally viewed as adults. (CP1)

Conflicts between what’s best for them and what they want are very much a part of our daily work. They don’t have full capacity, that’s why they live here. And I think that they should have a right to being cared for, rather than decide everything. They cannot be responsible for all their choices and that’s when things becomes strange with a law stating that they have a very strong right for self-determination. (BP2)

As exemplified in these quotes, the lack of ability ascribed to people with intellectual disabilities is seen as inherent to why these people need support in the first place; ‘they live here for a reason’ and that reason is that they are deficient in some way. This resembles how, among staff members, Gilbert (2003:40) has pointed towards a widespread lack of belief in the capabilities of people with intellectual disabilities. Furthermore, it suggests that individuals with intellectual disability are not only understood to be ‘citizens in the making’, but also ‘failed citizens’, unable to exercise all of the rights granted by the LSS because of their impairment (see Clement & Bigby, 2010:128). This idea reappears in all but a few interviews. Consequently, many care workers express an overt frustration with the focus on self-determination and individual choice of the legislation:

I have no education, so I have never read the complete law. But I have been informed about it. And I do feel constrained. Many times, I have been in conflict with the LSS when I have felt that things I have done have violated the law. But if I had not acted as I did, it would have been wrong. It does feel awful, really, it sure does. [...] But, sometimes it is right to violate the law. Hopefully people have enough sense to see what’s wrong and right. (AP1)

It sounds really nice that all should be participating and equal, but it does not work... They destroy much more than they heal. Sometimes when I get home, I want to vomit on all of these laws and regulations. (AP8)

They cannot see consequences but we are really not allowed to do anything until it is a life-threatening situation. It is really upsetting that you can only look... after all, you are a fellow human as well. (BP1)

Similar frustrations are described in research of other national disability support systems as well. Consider for example Clement and Bigby’s (2010:98, 128) description of how UK care workers argue that the goal of autonomy and independence ‘does not take disability into account’ since this kind of goal ignores the lacking intellectual capacities of the targeted group. Implicit here, and throughout my interviews, is precisely that goals of autonomy and independence are premised on capacities of reason and rationality that individuals with intellectual disability allegedly lack. In my material, furthermore, such sentiments are expressed frequently, by staffers who also make overarching statements of commitment to politics of inclusion.

The perception that disability is not taken into account by policies protecting self-determination and independence easily slips into a paternalistic style of reasoning:

You try to work with as much self-determination as possible. But I can say as much, the guy that I take care of, if we are out buying clothes, we buy what I like. Otherwise, he would look really strange and, I mean, you don't have to make them stand out even more. Beanies in particular, for this poor guy... there probably is not a thing to put on that head that he looks good in. You don't have to make it wackier than it already is. (AP4)

Under the previous heading, a similar situation spurred another interviewee to motivate the individual. Here, this staffer rather describes herself as an 'intervener'. This kind of steering, deciding over and forcing, reoccurs in the material with respect to very different kinds of situations:

According to the law, they are allowed to decide everything. You think a lot about that in certain situations. Sometimes it feels as if they do not know what is best for them. So you have to step in a little. We have a person living here that prefers to stay inside, all the time, but if she does come out she is really happy. But she can't see that while inside. So sometimes you just say to her "now, put on your shoes so we can take a walk". But I am not allowed to do that. I have to ask. But if I ask she says "no". Still, when she is out, she is so happy, while inside she has outbursts and gets angry. So in such situations, I do the wrong thing, but is it really wrong to make her happy? (AP1)

If some people want to eat ice cream all the time, then you have to steer them. I mean, you see that all the time with your own kids at home, they are not allowed to eat candy and sweets all day. Myself, I might prefer to have chips instead of sausages with mashed potatoes, but I have an insight that this is not good for me. (AP8)

Steering is ever-present and can be about something like care-workers believing that it's silly that Muslims don't eat pork. That has happened, a care worker serving pork to an unaware disabled Muslim woman. That is just one example of where personnel and tenants can have completely different views. (AP12)

The second quote is particularly interesting in this context, since it highlights how non-disabled individuals, like the interviewee herself, also make poor choices. Indeed, people without disabilities can smoke a lot of cigarettes, drink a lot of alcohol, be really overweight, get diabetes as a result, and numerous other things that disabled people are described as being prevented

from doing. The difference is that non-disabled individuals are depicted as acting against their better judgement, whilst people with intellectual disabilities, in these situations, are described as being incapable of incorporating consequences into their deliberations on how to act. There is a presupposed difference of sorts between the presumably oblivious behaviours of people with intellectual disabilities and the harmful actions against better judgement of non-disabled people. In turn, this leads to the paradox that ideas of normality become more restrictive for people with disabilities than for the non-disabled; people with intellectual disabilities are not allowed to wear beanies that make them stand out, to pick an example from the quotes above, even though people without this condition wear them. The difference is that individuals without this label supposedly know that they look silly, whilst people with intellectual disabilities are seen as lacking this self-reflexive capacity. Similarly, in many group homes, there are restrictions concerning how many cups of coffee tenants are allowed to have, what days they are permitted to eat sweets, what kinds of stuff they are allowed to spend their money on – all in clear conflict with the ethos of Swedish disability policy and all legitimised by an idea of normal living that is narrower and much more carefully guarded for this group than it is for the general population (see Yates et al, 2008:249).

Thus, the perception of people with intellectual disabilities as being unable to see the consequences of their actions not only incites motivational work, but can also provide support workers with a justification for deciding over the people they work with. In these situations, the ethos of citizenship is supplemented by technologies that breach the law. This way of justifying restrictions and coercion is brought up in a clear majority of the interviews and in all municipalities that I have visited<sup>21</sup>. This overarching view is also mirrored in the conversations with the members of Grunden, who indicate that experiencing restrictions and having their rights to self-determination and autonomy curtailed are commonplace, not only for them personally, but also for the members of their organization in general. Their stories can be seen as depicting the LSS as in a continuous state of exception, where support workers can decide when the rights of independence and self-determination should be excepted. In their view, this has severe and devastating consequences for people with intellectual disabilities, as the paternalism of present disability services crushes self-confidence, hurts people's independence, and produces a lot of suffering.

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<sup>21</sup> For a similar example from the Netherlands, see Schipper et al (2011:529-30).

Although infringements on decision-making can occur in almost any conceivable situation in the supported living setting, there are some kinds of situations that reoccur in the material and that I want to mention here. The first one concerns what people with intellectual disabilities are allowed to eat. Interestingly, when asked open ended questions about whether the interviewees know of situations where restrictions are employed or can be justified, they often spontaneously give eating habits as an example. The efforts that go into achieving good eating habits are also stressed by Grunden, which asked why healthy food should be such an overt concern for people with intellectual disabilities whilst the staffers are allowed to eat whatever they want. In several group homes that I have visited, dinner is eaten collectively and food is ordered from a supplier that the municipality has an agreement with. At these places, staff decides what is served and do the cooking, although possibly allowing tenants to put in a request for their favourite dish once a week. A more drastic measure to this end, which has been described to me as occurring in several different municipalities, is to put padlocks on the refrigerators of tenants: people with intellectual disabilities are allowed to buy whatever they like as long as they agree that the food will be locked up. Although my material does not allow me to draw any conclusion about the frequency of such measures, the fact that it exists and is more than an isolated mishap, certainly says something about the concurrent adherence to and neglect of self-determination.

A second area in which restrictions seem to be frequent revolves around sexuality. A first-line manager (AM4) told me that she found out that the tenants of a group-home that she managed were given birth control pills without consent. Outside of the formal interviews, several bureaucrats have told me that this occurs in other municipalities as well. Although the scope of such practices also requires a more systematic examination, their very existence is both worrying and analytically important as they point to how the lives of individuals are restricted. When speaking with the activists of Grunden, they share similar experiences. One of them describes how she was told by staff that she would only be allowed to live in a satellite apartment if she agreed to insert a birth control hormone stick. Another member recounts how she was not allowed to have guests of the opposite sex stay overnight and a third that she was frequently visited by staff when she had her boyfriend over, which she perceived as a poorly masked attempt to monitor what they were doing.

Lastly, a third restriction of the formal goals of the politics of inclusion concerns the freedom of movement. This is sometimes manifest just by

looking at how supported living is built. For example, I know of several group homes surrounded by locked gates. The activists in Grunden state that locked doors are commonplace in order to ensure that tenants do not leave without the permission of staff. They also tell me how staffers often demand to know where they are going when leaving and require that they be home at certain times. Similar stories are shared by first-line managers. This presents itself as a form of *de facto* confinement, in direct conflict with the Swedish constitution (8 § RF, 2 kap.). These restrictions of when and how people with intellectual disabilities are allowed to leave their homes blatantly contradict any common conception of citizenship<sup>22</sup>.

To summarise: the productive power of ‘governmentality’ targets individuals presumed to be capable of acting rationally and intentionally. Since people with intellectual disabilities are understood as, at least partly, lacking these capabilities, there is a need to complement this technology of subject-formation with discipline and coercion. In this way, supported living is characterised by actively producing citizens that are included, whilst also targeting them with technologies of exclusion (see Gilbert, 2003:40). Thereby, people with intellectual disabilities remain others, even within the services that should be advocating for their inclusion.

### *Controlled subjects*

The historical, classificatory, and philosophical inclinations to construct this condition as the otherness of reason and rationality means that the LSS, along with similar legislations and international agreements of similar ideological origins, produces a situation where the *outside* of citizenship is figured *within*. The politics of simultaneous inclusion/exclusion – that is, the politics of post-institutionalisation – responds to this by both relying on governing through citizenship and by excluding from citizenship.

Together, the technologies of *making* and *restricting* intellectually disabled citizen-subjects create an organization of disability services that works by control. I argue that this system can be characterised by specifying four prominent features:

- (1) The logic of *control* stems from the concurrent monitoring and, when deemed appropriate, intervening in the decision-making of the individual. This is a result of the latent need to make decisions concerning if and how to motivate or steer choice making in order for the targeted individuals to

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<sup>22</sup> See Yates et al (2008:254) for similar descriptions of restrictions of the freedom of movement.

comply with the ideals of citizenship. As has been argued by Gilbert (2003), consequential reasoning is a vital characteristic of how individuals monitor their own behaviour. When people with intellectual disabilities are seen as deficient with respect to this capacity, as the interviewees suggest, support workers overtake this monitoring role. Consequently, when people with intellectual disabilities are doing whatever they want, they are *allowed* to do so by someone in a position of authority; if tenants for example are leaving their homes to have a beer, this will generally be preceded by support workers consulting work-place routines, deciding on whether the individual in question can manage to leave the house, deliberating on whether they should be allowed to drink alcohol, pondering the potential consequences, weighing the results of these deliberations against the ethos of the LSS, and thereafter making a decision on how to respond – by standing back, motivating, or using coercive force.

(2) This means that the logic of control rests on a *hierarchy* between support workers and tenants: prior to any decision on whether a person with intellectual disability is allowed to have a beer or not is the positioning of support workers as capable of interfering. The practices of motivation and nurturing citizenship as well as technologies more blatantly departing from the ideals of citizenship, are premised on staff having the authority to know what citizenship requires and how a citizen-subject can be accomplished.

(3) The regime of control must be *constant* since decisions on technologies of motivation or steering are context and person specific. There is no way of knowing beforehand when a situation that calls for motivation or coercion will arise. This marks an important difference as compared to institutional care. Strict rules, locked gates, pre-decided menus, and so on, were the exemplary technologies of government of the institution. In supported living, these have transformed into practices of micro-management of individuals. Decisions on courses of action in supported living often regard mundane situations that occur more or less everyday: every time a tenant decides on what to eat, to have a cup of coffee, or whether to leave the home, group home staffers are potentially faced with situations that they may believe require steering or motivation. In contrast, when food was cooked and eaten collectively, coffee served at specific times, and leaving the institution forbidden, there was no need for constant monitoring as appropriate behaviour was largely enforced by collective regulations and restrictions of behaviour.

(4) This implies that control is *individualised*. Since the capacities of citizenship and the likelihood to make what is seen as ‘harmful choices’ are not evenly distributed within the population of individuals with intellectual disability, control must be adjusted for each person. Thus, we do not see general rules in the group home prohibiting buying one’s own clothes. Instead, we see how every employee at each group home is ‘responsible’ for a

tenant, helping them with practical matters provided their understanding of the needs of that particular individual. This requires the creation of personal bonds and detailed knowledge. Sometimes the tenant will be prevented from buying certain clothes, sometimes personnel seek to convince tenants that certain clothes should be bought, and sometimes it means not interfering with which clothes people with intellectual disabilities buy. Therefore, the views and character of the individual support worker will impact how situations are handled. Some might be very likely to intervene, some less.

These are the general features of the decentralised government of post-institutionalisation. In institutional care, the life of the individual was *enclosed* by power and government; it was restricted by rules; constrained by the walls of the institution building; and temporally divided by collectively enforced schedules. In the new regime of simultaneous inclusion and exclusion, the life of the individual is instead *penetrated* by government. The cultivation of citizenship capacities, the enforcement of occasional restrictions, and the application of technologies of motivation require that public officials enter the heads of the individuals that they work with: support workers must be trusted, yet seen as authorities; they need to apply individualised technologies to convince, win over, and detract; and they need to be able to estimate when the individuals that they work with can be trusted with self-determination and independence (see Gilbert, 2003). Again, I want to stress that my ambition here is not to make support workers scapegoats of this regime of power. Their actions are conditioned by the dual construction of people with intellectual disabilities as others and as worthy of inclusion.

It is worth noting that only the particular blend of rationales that simultaneously view people with intellectual disabilities as both 'citizens in the making' and as 'failed citizens' can produce the microcosm of power described here. During institutionalisation, when individuals with intellectual disability were categorically seen as non-citizens, there was no need for monitoring or deciding on interventions on an individual and constant basis. On the other hand, in a system where the ideals of citizenship are compatible with the targeted group, this kind of control would not be necessary since there would be no otherness calling for control in the first place. Instead, such a regime would rely on conformity to social norms (see Foucault, 1990:144). It is only when people with intellectual disabilities are regarded both as potential citizens and as failing to be citizens that the regime of control is activated.

## Government of Citizenship

A common assumption of much disability research is that citizenship and power are opposites, which means that politics of inclusion serves the purpose of freeing individuals with intellectual disability from power. I believe to have countered this view by showing two things: first, in support work power flows through relations between staff and individuals with intellectual disability in the form of 'motivation' and nurturing of capacities, along the lines of the support worker's ideas of what citizenship entails. Thus, although seeing their support work as within the boundaries of the legislation, this clearly cannot be seen as the absence of power. Secondly, coercion and restrictions, when occurring, are not remnants of the past, but correspond to the idea that people with this diagnosis lack capacities necessary for self-determination and independence. We saw this same idea of otherness throughout the history of philosophy and we witnessed how it operated in the global disability discourse. Indeed, in the first two chapters, we saw how it is ingrained in the very definition and common understanding of what intellectual disability is. In supported living, making decisions for people of this group reoccurs and is integrated into the service provision of most group homes that I have visited. It is hence a vital aspect which is entrenched in how supported living functions. This testifies to the disruptive effects of intellectual disability on citizenship ideals, also in the settings where policy transforms into actual services. Thus, directly countering the ambition of the politics of inclusion of a government withdrawal from the lives of people with intellectual disabilities, post-institutionalisation meant an intensification of government, constant, individualised, and penetrative in how public officials attempt to enter the mind of the individual.

Deleuze (1992:3-5) has argued that towards the end of the 20<sup>th</sup> century, 'control' was on the verge of becoming a new paradigmatic mode of government, succeeding disciplinary institutions and replacing them with calculus and surveillance of flows of individuals. Not considering the wider implications and merits of the argument, he stresses that a disciplinary regime means that the individual ceaselessly starts again, 'from school to the barracks, from the barracks, to the factory' (Deleuze, 1992:3), and so on. In contrast, in a society of control 'one is never finished' (5). This certainly seem to say something of importance concerning the control of people with intellectual disabilities, who are always monitored, being worked on, nurtured, in order to become what they are not. The processes of never-ending nurturing and restricting are instigated by the predicament of post-institutionalisation:

whilst institutionalisation was designed to separate and discipline the otherness of human reason, politics of inclusion works by moulding such others into citizens and to simultaneously retract their rights in situations where they are seen as incapable.

A basic theoretical proposition of this book is that citizenship requires a certain kind of subject: the subject of humanism that went into the constitution of intellectual disability when this group first emerged. But as intellectual disability remains outside this notion of what characterises human beings, efforts of inclusion will be ridden with conflicts and tension, disruptions and supplements that end up in a politics of simultaneous inclusion/exclusion. In this way, present biopolitics is both founded on, and haunted by, the instability of the structure of inclusion/exclusion; it needs designations of otherness in order to direct interventions, but it also needs government by inclusion to craft a self-ruling citizenry. Hence, if the first part of the book examined how intellectual disability consolidated the otherness of humanist reason as a diagnosis, attached with certain pre-political characteristics, the chapters of this part have examined how a regime of citizenship-making seeks and fails to incorporate such naturalised otherness. In a sense, the construction of 'intellectual disability' establishes a residual difference that politics – no matter how inclusive its ambitions are – will never be able to remedy; politics of citizenship cannot alter the constitutive outside of itself. Hence, when citizenship politics targets this particular group, the stakes and inner workings of the politics of inclusion are exposed. It follows that the politics of post-institutionalisation cannot be made sense of in the terminologies that presently dominate disability politics; of 'emancipation' as 'citizenship'; of 'power' as opposite to 'freedom'; and of 'inclusion'/'exclusion' understood as a dichotomous and mutually excluding pair. The way that people with this condition are being governed does not fit the dichotomies used to make sense of disability politics, as 'inclusion', or 'exclusion', or as 'citizenship' or 'power'.

To summarise the movement that I have described throughout the book and up to this point, the emergence of 'intellectual disability' was a response to how some people did not fit into the separation of the humanist subject from non-human living things. Before classification and modern medicine, these people were part of an unnamed melange of various groups that were seen as occupying the space between humans and animals. Consider, for example, how Clifford Simplican discusses the insecure positioning of 'idiots' and 'changelings' in Locke's philosophy, neither fully human nor beasts. Biopolitics attempted to govern this constitutive outside: classification

would name them 'mentally deficient', and similar, and designate them as 'others' of human reason. They were incorporated into binary schemes of inclusion/exclusion, normal/pathological, and reason/lack of reason. Thus, the unruly constitutive outside was tamed and managed, confined and removed from the rest of society, as targets of the politics of exclusion. When government set out to once again include this group, however, without reconsidering its constitution as the defining outside of the ideals of citizenship, it gives rise to a politics where this group is simultaneously being both inside and outside of the sphere of citizenship. Hence, people with intellectual disabilities again appear as an extreme that eludes the prevailing conception of politics, this time neither 'excluded' nor 'included', but both. As we shall turn to next, the rifts and contradictions of post-institutionalisation, and the threat posed by intellectual disability to the humanist subject, may serve as a starting point of critique and resistance.

# *Part III: Resistance*

An electron traveling through the wires and loads of the external circuit encounters resistance. Resistance is the hindrance to the flow of charge. For an electron, the journey from terminal to terminal is not a direct route. Rather, it is a zigzag path that results from countless collisions with fixed atoms within the conducting material. The electron encounter resistance – a hindrance to their movement.

THE PHYSICS CLASSROOM

*Resistance*

The critical ontology of ourselves has to be considered as an attitude, an ethos, a philosophical life in which the critique of what we are is at one and the same time the historical analysis of the limits that are imposed on us and an experiment with the possibility of going beyond them.

MICHEL FOUCAULT

What is Enlightenment?

## 7. Care

To kick off this third part, I will devote a few pages to set the stage for what comes next. The main focus of this and the coming chapters is the possibility of resisting the biopolitics of intellectual disability. I will tackle this question in a rather straightforward way by engaging three instances of resistance. However, it is important to note that these chapters are precisely ‘instances’ rather than the complete story: there are numerous struggles and contestations which have been left out because of lack of space and time (and most certainly still more that I am not aware of). It is not possible to tell a story about resistance as coherently as I have in the first and second parts about the biopolitics of intellectual disability. To some extent, this is because resistance, as I will elaborate upon later, has its eyes set on the future, which has yet to unfold, and which lacks a scripted ending. Furthermore, the instances to be focused on only rarely deal with common examples of resistance, such as social movements, demonstrations, strikes, and parliamentary struggle. This is based on the conception of resistance that has guided me (which will be discussed under the next heading) and on the way that I formulated the focus of these three chapters; concerning the *possibilities* of resistance rather than how resistance is *actually carried out*. The cases that this and the subsequent chapters focus on are chosen because I think they may help us examine the ways we can move beyond the contemporary biopolitics of intellectual disability. In order of their appearance, I will examine how support workers resist citizenship inclusion by mobilising an identity as ‘carers’, how political activists diagnosed with intellectual disability engage in representational politics, and how a discourse of ‘ethics’ frames attempts to contest present policies of prenatal diagnosis. Strictly speaking, the ninth and last chapter deals with discursive constraints on efforts to contest, which means that the subject of resistance, to some extent, is me seeking to show how this discourse can be moved beyond by an analysis of government.

There is also an overarching argument in this section. First, the instances of resistance that are focused on emerge when inclusion and

exclusion come into friction. Thus, the mobilisation of ‘caring work’ arises as support workers recognise a gap between promises of citizenship and a perceived lack in the people that they work with; the representational politics of intellectual disability transpires as activists demand that their ascription of citizenship status should also entitle them to political self-organization; and contestations of prenatal diagnosis must be understood against the background of the rift between common ascriptions of equal human value and screening practices which effectuate the prevention of intellectual disability. The reason why spaces of resistance open up at precisely these points is that the prevailing discourse does not seem to add up; it presents itself as sanctimonious (although including *and* excluding is how the system of government actually works) which means that processes of questioning, challenging, and reassessing, can take off. This is the first part of the argument; that the simultaneity of inclusion/exclusion described in Part II creates spaces for contestation. The second part is that resistance against the biopolitical regime comes with both promises of progress and threats of consolidation of the biopolitical regime. Hence, in this chapter we shall see how the discourse of ‘care’ becomes integrated into the present governmental system by justifying paternalism. At the same time, the notion of ‘care’ may also lead us to consider vulnerability as a constitutive feature of human being, thereby destabilising the dichotomous division between ‘able’ and ‘disabled’. Similarly, politics of representation carries both the promise of self-representation and the threat of essentialism, and the ‘ethical’ framing of debates about prenatal diagnosis works both to de-politicise this practice and can point towards the opportunity to re-politicise ethics itself in the context of intellectual disability politics.

Before turning to the topic of this specific chapter, I shall start by saying a few things about resistance in light of the arguments and theoretical commitments of the previous parts of this book.

## **Power and Resistance**

Throughout, ‘biopolitics’ has been my primary theoretical term when discussing the government of intellectual disability. It therefore seems apt to begin my discussion of resistance with Foucault. I will first point out a few general points in his theorisations of resistance, before turning to how his thinking on resistance evolved during the last decade of his life.

It follows from the general theoretical starting points of this book that 'resistance', just as power, is complex. This can be illustrated by Foucault's (1980:142) interpretation on the relationship between the two:

there are no relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised; resistance to power does not have to come from elsewhere to be real, nor is it inexorably frustrated through being the compatriot of power.

As indicated here, power and resistance cannot be understood as dichotomous forces, clashing in struggles over the future. Rather, the reason why resistance appears everywhere we find power is that power itself is never completely free-floating and devoid of friction with the societies it shapes. The electro physics quote that preceded this third part is apposite here: power is a flow through a circuit whose material will always deter the freedom of its movement, sometimes to the point where it comes to a halt. Resistance to electricity is located at the precise points and moments where and when electricity passes, which by analogy is to suggest that resistance and power are coexistent: power will always encounter resistance and resistance requires a force to resist.

This metaphor ends here, however, as resistance is not of a fundamentally different quality than power (the way the material of the circuit is fundamentally different from the flow of electricity). In Foucault's thinking, power and resistance are ontologically similar, which means that resistance can be seen as 'power challenging power'. Consequently, some of the things that characterise power also characterise resistance, most importantly, that it is productive and that it is not necessarily intentional, coordinated, or exercised from the top-down. Like power, resistance emerges from everywhere, which means that dominating social movements, radical political parties, and the like, are not the only places, perhaps not even the most important ones, where we shall look for contestations. In the context of intellectual disability politics, Goodley (2000:200-1) has warned of the danger of assuming that self-advocacy is only possible within and through formalised organizations and groups<sup>23</sup>. However, resistance is also exercised in the everyday to deter how mechanisms of power shape subjects. This means that what we call 'resistance' and what we call 'power' is an analytical

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<sup>23</sup> In this context, Goodley speaks of 'resilience' rather than 'resistance', however, his understanding of resilience is compatible with the Foucauldian idea of resistance that I discuss here.

choice and depends on our vantage points. The productive and omnipotent nature of power in Foucault's analysis also means that no pre-set moral division between power and resistance can be assumed; power in itself is not 'bad' and resistance in itself is not 'good'. It is a normative proposition of mine that makes me view intellectually disabled self-advocates as exercising resistance rather than power. At the same time, as we shall return to, there is also a certain risk here, namely that we overlook the dangers of resistance due to our normative investiture. It is important to note that for Foucault, and me, resistance is never external to the powers that be. As we shall see, resistance against the biopolitical regime emerge in tandem with systems of government and within its discursive and structural confines, again, right at the points where power is exercised. Therefore, resistance may end up reproducing what it aims to overthrow.

In an enlightening paper, Hartmann (2003) argues that Foucault's thinking on resistance underwent important changes during his work with the three volumes of the *History of sexuality*. In the first volume, we find a version of the famous statement 'where there is power there is resistance' (Foucault, 1990:95). At this time, Foucault seems to see resistance as tied to specific power relations concerning particular groups that challenge how they are being subjected to rule. We can call this an 'agonistic' conception of resistance. Foucault gives two primary reasons for why resistance is possible provided this view. First, there is a latent potential for resistance since technologies of power are reversible (Foucault, 1990:100-2). Thus, groups subjected to specific technologies of power can themselves make use of these technologies. We shall, for example, see this in Chapter 8 when the activists with intellectual disability describe cognitive normalcy as a 'disorder'. Secondly, Foucault seems to think that agonistic contestations are a possible, perhaps even likely, result when the workings of power are exposed (Pickett, 1996:452). Throughout his work, it is presumed that technologies of rule rely on being hidden or masked as something else. For example, the reason why the classification of intellectual disability is an efficient tool of government is precisely that it is not recognised as power, but as a neutral description of a natural category. However, when we acknowledge that this is a technology of determining subjects which should be targeted by government interventions, and start to see institutionalised care and systematised sterilisation as its materialisation, classification becomes contestable and resistance will follow. Thus, to describe how power operates is itself a way of making space for agonistic contestation (see Pickett, 1996:454).

When developing these ideas, Foucault had already moved away from structuralism and a depiction of power as a unified, totalising, and coherent system. The fact that power never fully achieves full control, that it never fully determines the fate of subjects, is what makes resistance possible. At the same time, it must be noted that resistance at this stage of Foucault's writings is depicted as reactive and following from specific governmental techniques (see Hartmann, 2003). Thus, here, to resist means to answer to government, it is contextual in the sense that it opposes a specific configuration of power, and it targets dominating, established, or even hegemonic orders. Taken in this way, resistance is what deters a *specific* flow of electricity at a *specific* time, and in a *specific* circuit, rather than an ever-present and self-evolving capability of whatever material power flows through. Thus, at this point Foucault had not fully taken on the consequences of his depiction of power as decentralised and emerging from everywhere.

During the latter years of his life, while working with the second and third volumes of his history of sexuality, Foucault came to see resistance as a way of governing oneself. Since resistance is productive, it may emerge precisely at the points where subjects strive to reshape themselves; caring for oneself appears to be an important site of resistance. We can call this *positive resistance*. These ideas were developed in tandem with the analysis of power as 'the conduct of conduct'. Whereas Foucault previously, and quite straightforwardly, had denoted subjects as effects of discourse and power, here he came to refine his analysis to state that subjects come into being in relation to discourses, norms, and institutions. In turn, this means that the making of subjectivity can also be a site of critique (see Butler, 2005:17). Thus, Foucault's interest in 'the care for oneself' is essentially an interest in the possibility of navigating fields of action in order to come into being beyond the confines of the rationalities of government (see Hartmann, 2003). This is not merely a question of how to choose provided certain available options, but about how to mould oneself in opposition to dominating norms. Thus, ultimately, Foucault turned his interest towards resistance as a way of being an agent, not freed from constraining forces, but, to some extent, free to act in relation to such forces. His engagement with Kantian critique (Foucault, 1997:23-82, 101-45; 2008:1-41), with ancient modes of self-fashioning (Foucault, 1988; 2008), and his particular interest in 'parrhesia' as a specific mode of truth-speaking (Foucault, 2010:41-74; 2011:23-32), all engage the opportunity to act and think provided an omnipresent and productive form of power. Foucault's (1997:101-34) follow-up on Kant's (1991[1784]) 'An Answer to the Question: 'What is Enlightenment?' is

especially interesting in this context. In his identically entitled paper, Foucault identifies in Kant's analysis of human limitations of knowledge the seeds for a critical attitude which can simultaneously examine and transgress the boundaries of what is possible to think. In Foucault's analysis, Kant's notion of 'critique' transforms into a call to examine the history of the forces that have shaped the limits of our thinking, an exercise that may open up the possibility of transcending these limits. This means that the idea of 'critique' and the notion of 'resistance' here appear as intertwined.

These developments certainly do not erase Foucault's prior commitments to agonistic resistance, but rather expand and shift its emphasis (see Hartmann, 2003). What we see here is a notion of resistance more attuned to the view of government as diverse and productive, where the question of subjectivity and agency has replaced Foucault's prior focus on subjugated groups and mobilisation. Since power operates not only through coordinated and totalising systems ordered from the top-down, but emerges from everywhere and grows from the bottom-up, there will always be spaces where thinking and doing differently is possible; cracks in systems of rule that can be activated and used as springboards for alternative ways of existing, thinking, and doing (see Simons, 1995:90). Hence, as Simons (1995:81) notes, subjects are always enmeshed by relations of power, but never completely subsumed; always limited, but never trapped. The structures of opportunity inherent to this conception of power-resistance correspond to how other post-structural philosophers, often following Derrida and deconstruction, have analysed language and discourse as open ended and ever-changing systems. This will be exemplified by how the disabled activists interviewed in Chapter 8 overturn the presupposed hierarchy in our conversation by addressing me as the 'normal researcher', hence, making visible, and implicitly mocking, the supposed expertise of non-disabled individuals such as myself. To understand what happens during such instances, we must see language both as the limit of our thinking and limitless since its meaning is never fully determined (Simons, 1995:89). Thus, at its most productive, critique as a form of resistance transforms the limiting nature of power/knowledge/discourse to become a starting point for examining and reshaping who we are (see Simons, 1995:17).

As I have already indicated, and provided the context of the politics of post-institutionalisation, contestation and critique seem to emerge from the recurring frictions between inclusive and exclusive technologies of government. Precisely the recognition that the promise of inclusion is both made and broken, that the dichotomy of inclusion and exclusion is collapsed,

constitutes the sense that things do not add up, that the pre-established categories need to be reconsidered, and that the question of power and rule must hence be asked again. At such instances, thinking beyond the pre-established categories becomes possible, but so does the risk that criticism ends up reifying these categorisations. This duality, of possibility and re-inscription, characterises instances of resistance against the politics of intellectual disability.

## **Caring Resistance**

As previously shown in this book, contemporary intellectual disability politics simultaneously constitutes and restricts citizen-subjects in the supported living setting through technologies of nurturing and restraining the ideals of self-determination and independence. In the remainder of this chapter I will concentrate more specifically on when these ideals are departed from and I will do so by analysing such departures as a form of decentralised resistance against the formal goals of politics of inclusion. When support workers suspend the law they are also contesting it, delineating its reach, and countering its explicit purposes. As I will argue, the recurring circumventions of Swedish disability legislation are motivated by a uniform set of values and beliefs, expressed by care workers who see themselves as involved in emotional, almost family-like, relationships with tenants. Hence, in contrast to the formally sanctioned relationship between a citizen and a public servant, support workers activate another discourse that enables another set of actions in order to sidestep formal regulations. It is a form of resistance that arises as a reaction against the nurturing of intellectually disabled individuals to become self-regulating citizens, it is decentralised in how it is not tied to any specific movement, organization, or coordinated plan, and it is best analysed as a set of interrelated discursive and enacted constructions.

Examining this, I will go on to argue two things. *First*, legitimising coercion and challenging liberal citizenship by reference to one's informal and emotionally entangled relationship to tenants reinforces the belief that people with intellectual disabilities are distinctively 'other' in relation to an all-embracing imagined 'normality' bound up with rights of self-determination and autonomy. This is not a form of resistance that, in its present form, has the potential to transform the politics of intellectual disability, but it is nevertheless resistance as it deters the flow of power generated by the discourses of politics of inclusion. Resisting citizenship

politics in this way serves to reinforce the overarching biopolitical logic of simultaneous inclusion and exclusion. *Secondly*, however, the interviews also highlight a boundary of liberal thinking that is important by merit of what may lie beyond it. Remember here Foucault's (1997) reading of Kant as posing questions concerning the limits of knowledge. In a similar way, the narratives of emotional engagement and affective involvement direct attention to a dimension of caring, as practice and attitude, which needs to be explored for its potential to unsettle presumed assumptions concerning the humanist subject and disability politics. 'Care' directs us towards the limits of liberal citizenship.

Lastly, a note of clarification: the material analysed below consists of the same interviews that were dealt with in the previous chapter on technologies of power in Swedish supported living. They are quoted from much more sparingly, as the practice of departing from the LSS was thoroughly discussed there. Hence, this chapter builds on the previous by isolating those instances in which the law is contested, and by analysing how these instances are based on certain patterns of justification and self-understandings of the support workers.

### *Justifying coercion*

Let us follow a classic liberal-democratic template for a moment, which provides that support for individuals with intellectual disability is very often carried out within the confines of what is considered within this tradition as the 'the private sphere'. Thus, it is *public* work carried out in the *home*; in the kitchen or toilet; helping individuals to sort out their hygiene, make food, and take their medications. This means that the border between private and public, so central to traditional understandings of state responsibility in liberal democracies, is considerably blurred from the outset. This border is not only traversed as concerns *what* staffers do and *where* they do it, but also concerning *how* they see their own role and principle task.

In this job, it is much like a home. They are people, you know. We are with them in their everyday lives so of course I take with me my personal beliefs and views upon life. (AP10)

I think that people [with intellectual disability] are developing [from close relations with personnel]. We are their arms – we are their family. Unfortunately, that's how it is. We work intensively with them all the time. They probably know more about us than our own parents. Some of them have

followed staff home to celebrate Christmas – we don't get paid for it, but we want to do it. (AP8)

These quotes showcase a way of looking at work that seems alien to traditional notions of the civil servant and to the task of guarding the rights and autonomy of individuals with intellectual disability. The traversed border between a professional role and an informal role is of special importance when actions that break with the formal regulations are legitimised. For example, one of the interviewees (AP1) explains that it feels wrong to order people around. The example she provides is to take a walk when a person does not want to, if she and the person do not have a so-called 'tight relationship'. Thus, what makes it possible to 'order people' – a choice of words far removed from the self-determined citizen-subject described in the legal text – is the nature of the relationship between tenants and staff. If there is no 'tight' relationship, then actions breaking with the ethos of citizenship 'feel wrong'. This exemplifies how the discursive border between referring to tenants in supported living as subjects of formal rights and as subjects of emotional bonds is traversed in explanations of the necessity to impose constraints or use coercion. Whilst, for the most part, formal disability politics constructs individuals with intellectual disability as subjects who are to live independently and whose rights are protected and facilitated by state representatives, what we see here is a challenging role stemming from emotional ties, leaned on in order to construct individuals with intellectual disability as objects of care and protection. Since the actions justified by this role violate the intentions of the LSS, this switch of identity can be seen as something that allows for resistance against the implementation of citizenship politics.

As I will discuss at some length in this chapter, the interviewees often appeal to an ethics which echoes of feminist notions of care, as developed by Carol Gilligan (1982), Joan Tronto (1993), Selma Sevenhuijsen (1998; 2003) and others. This literature contests the instrumental reasoning of liberal philosophy by emphasising 'caring' as a specific class of actions and attitudes transmitting a specific ethos. As such, the target of criticism of the ethics of care is the narrowness of view in mainstream moral and political philosophy (Pettersen, 2011:61). This narrowness is understood as tied to norms and ideals of masculinity, thus, rather than emphasising 'instrumental reason', 'detachment', and 'impartiality', proponents of the ethics of care value 'emotional commitment', 'contextualisation', and a moral anchored in

‘interdependent relationships’<sup>24</sup>. Since there are important similarities between the ethics of care and how interviewees narrate their departure from a formal civil servant role, care ethics can function as a reference point for understanding the normative underpinnings of this form of resistance against citizenship politics.

In the interviews, it often appears that switching from a formal role as a public servant to an emotionally invested informal role as a carer is motivated by a deeply felt cognitive dissonance on behalf of the support workers:

There is a responsibility to follow the law, but also a responsibility to cater to their well being. It becomes so frustrating... But I feel that if they live here, they are not fully capable. In that case, they also have a right to be cared for, to get the best care there is. (BP2)

In this way, watching the people one works with make ‘bad’ decisions causes distress and bad conscience on behalf of the interviewees. Thus, these are moments when the ideals of inclusion and the constitutive otherness of intellectual disability come into conflict. In such situations, support workers tend to empathise with the ascribed suffering of the people they work with and they do so from a position of seeing themselves as better judges concerning what is good for them. However, acting on this paternalistic impulse is not possible as long as their formal role of implementing the law is understood as the primary source of legitimation. As seen in the quote, ‘caring’ here is juxtaposed with the self-determination and independence associated with the law; it offers a different grounds for legitimation.

The shift to a caring role is marked by a number of recurring characteristics. When acting against the self-determination of people with intellectual disabilities, the interviewees see themselves as (1) *emotionally* tied to the people they work with, (2) *responsible* for their safety, and as acting based on an (3) *informal*, rather than a formal relationship. In addition, (4) they come to focus on the *individual* and their suffering, rather than on overarching principles of justice. They do so based on the presumption that they have (5) *superior knowledge* as to which choices are wise and which are not. In sum, this means that meetings between staffers and people who have been granted the right to supported living are no longer seen as involving

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<sup>24</sup> Early proponents of the ethics of care leaned on an unsophisticated gendered essentialism that is alien to the post-structural feminism I align myself with. Since the literature on caring ethics has departed from this perspective, most notably seen in the work of Selma Sevenhuijsen and Joan Tronto, I see no need to address this tendency here.

‘public servants’ and ‘citizens’, but rather as following the structure of parental relationships<sup>25</sup>.

In this way feelings of attachment and responsibility are hard to fit into a conceptual framework founded on individualism and procedural justice. In this sense, the depictions of an emotionally ridden relationship with tenants point towards what is perceived as a limit of citizenship. Whilst citizenship implies rule of law and formal rights, in extension leading to an impartial and rule-bound rationality where there is a firm line of demarcation separating individual freedom and state power, here, the justifications of constraint rather expose a logic of action organized around commitment, empathy, and protection. In the interviews, this is repeatedly described by the metaphor of a ‘family’:

How do you handle such situations with your kids, what they are allowed to eat and what are they allowed to do and not do? I am not allowing my kids to go out in shorts in the middle of the winter. I cannot allow the people I work with here do that either, just because they are supposed to be “self-determined” and “independent”. (AP8)

Well, self-determination... surely, we do that as long as it works. But we eat together here, for example, so they do not get to choose what to eat every day. No one here can have food in his or her own refrigerator, because it will be gone the next morning. And the people living here enjoy eating together, although there might be some bickering around the table, it is more like a family. The staff are sitting together and eating with them, although we have brought our own food, so we all eat together. Sometimes they ask us what we are eating and if they can have a bite, and of course they can. We have worked with them for such a long time that we really know them well. (AP4)

The ‘family’ metaphor operates by incorporating the norm system of the family, for example in disallowing one’s kids to eat whatever they like, into the context of publicly regulated disability services. In the first quote, the interviewee seemingly understands that the LSS do not authorise her deciding whether to allow tenants to wear shorts or not. However, as a mother, such a use of coercion with her children is perfectly appropriate. In order for this particular support worker to be able to legitimately make decisions for this

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<sup>25</sup> Similar informal and emotional relationships have been noted by disability researchers before. See the description of Kelly (2013:788) for a particularly interesting example.

disabled individual, she transforms her self-identity into that of a 'parent', which legitimises her paternalistic decision-making.<sup>26</sup>

Thus, the circumventions of citizenship rights that restrict people with intellectual disabilities are very rarely expressions of malice or indifference, but are, to the contrary, framed as expressions of commitment and concern stemming from emotional engagement. Implicitly, this kind of emotionally driven self-valorisation is understood as diverging from the formal role as a support worker. It implies that there is something more which allows for something other than the LSS and its focus on citizenship and professionalism. Repeatedly, the LSS is depicted as removed from practical day-to-day matters, as stale and overly rigorous in relation to work in supported living, and therefore as inadequate and sometimes even inept. This means that we are dealing with something other than a remnant of institutional care. Although paternalism and coercion were frequent, the institutional era did not require that these were justified; there was no need to invoke a discourse of 'family', for example, to justify why people with intellectual disabilities were not allowed access to their own food. Such restrictions were simply a part of the rule-bound rationality of institutionalisation. This particular method of justification is only needed in a context in which people with intellectual disabilities are seen as both worthy of citizenship and incapable of citizenship.

Despite the problematic way that the support workers use emotional commitment to legitimise their use of power, there is also something worthwhile in their stories. As the interviews reveal, the language of rights and professionalism are seen as unable to account for the multitude of feelings, anxieties, and conflicting intuitions that emerge in work within disability services. The same way that the ethics of care challenges a moral ontology of self-sufficient individuals striving to be independent, the interviewees draw on a similar set of values to contest these ideas as expressed in disability legislation. However, whilst care ethicists have increasingly come to see dependence and care as universal to human interaction, the interviewees firmly place such dependency on the tenants and therefore their emotional engagement works to legitimate unequal relationships.

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<sup>26</sup> This is similar to how Clement and Bigby (2010:124) describes 'parent-child interactions' in UK group homes.

In summary: parallel to how the ethics of care contests liberalism, the descriptions made by the interviewees can be read as contesting the liberal humanism of citizenship inclusion. The ideology of citizenship in present disability politics depicts the state apparatus as a constant threat of individual freedom. This is why rights are needed as safeguards against state infringements, why the state must be restrained in order to be legitimate, and hence also why this tradition is not very well-prepared to handle the kind of relationships described by the support workers. It is against this ideological background that the stories of the support workers must be understood. Their resistance is located at the limits of liberal conceptions of citizenship, depicting a kind of relationship that has no evident place in the dominating story of how citizens and the state are related.

### *Reinforcing biopolitics*

Although the support workers are exercising resistance against Swedish disability legislation, this is not resistance against the broader scheme of government. Rather, what we see here is a form of resistance that ultimately works to effectuate the overarching logic of the biopolitics of intellectual disability. To understand this, it is important to heed Foucault's (1990) contention that government is not a straightforward, top-down, or unilateral activity. Rather, government is made up of numerous different actors, with different agendas, that are generating different kinds of power/resistance (see Rose, 1999:19). This is why the resistance of the support workers can both deter the flows of power of the politics of citizenship *and* reinforce the more general biopolitical logic of concurrent inclusion and exclusion.

Consider here the working conditions of street-level support workers. The fact that they can shortcut the legislation without authorisations testifies to a substantial amount of room for discretionary decision-making (see Lipsky, 1980). This can be interpreted as a result of lack of detailed regulations, control, and sanctions when the law is superseded. It can be interpreted as *absence*. There are no institutionalised and systematic controlling mechanisms, for example, and very few evaluation tools to measure the extent to which the goals of the law are met in everyday support work. The absence of direct steering and control, however, does not testify to the *absence* of government. To the contrary, the lack of steering has its own governmental logic of allowing discretion; the *absence* of regulation and the allowance of discretion constitutes a form of government which operates by *neglecting* to intervene in the instances where the promise of citizenship is withdrawn. The fact that there seems to be a general awareness that the law is

not being followed and that the legislation is circumvented exposes this logic: it is a mode of government which allows the promise of citizenship to be broken, effectuating all of the small interventions into the individual autonomy of people with intellectual disabilities. These are neither mistakes nor examples of deliberate evil, but a structural feature of the government of disability. It is a form of steering which relies on the absence of formal steering, and thus allows for the disruption of intellectual disability to be handled at the lowest level of policy implementation.

Accordingly, the ambiguous positioning of people with intellectual disabilities as being both entitled to citizenship and the defining others of citizenship, is ultimately handled where a leeway to cope with the contradictory status of the group exists; the dual rationalities for action transform the impossibility of simultaneous inclusion and exclusion into actual work in supported living. If giving and retracting ‘citizenship’ characterise post-institutionalisation, the emotional engagement expressed by the interviewees serves to justify the retraction. The space for support workers to resist, emerging in the rift between the rights and defining lack of people with intellectual disabilities, is thus ultimately used in ways that revert to a notion of this condition as marked by inferiority. In the stories of the interviews, recognising the dependency of others never amounts to recognising dependency and vulnerability in oneself. Now, this begs the question: if ‘caring resistance’ works to uphold the biopolitics of intellectual disability, might there still be something of value to it that can point beyond this regime of government?

## **Vulnerable Subjects**

If the first argument of this chapter concerned paternalism as resistance against citizenship, the second argument – that I will elaborate on below – engages the presumed dichotomy between ‘independence’ and ‘dependence’ and the notion of ‘vulnerability’, in order to explore the opportunities of mobilising critique and resistance beyond the confines of the present biopolitical regime. In other words, how can we theorise at the limit of liberal citizenship – the very limit that the interviews directed us to – without reverting to re-inscribe a constitutive and pre-political lack of people with intellectual disabilities?

### *'Independence' as mythology*

As was made clear above, the ethics of care attempts to highlight an ignored dimension of mainstream political discourse concerning human relationships, namely that 'care' is never a one-directional activity, involving a caregiver and someone dependent on the care, but an activity binding people together through our interdependencies. As Hettema (2014) points out, the ethics of care seeks to set up a framework for thinking about justice that opposes and highlights the limitations of the individualism which permeates present Western societies – the same limits, I argue, that the interviewees seek to push by mobilising an identity as informal caregivers. Central to this philosophical project is a relational ontology that sees humans as dependent on care in order to be caring toward others (Fine, 2004:218; Pettersen, 2011:55, 58). This insight has led care ethicists to reflect on human relationships in terms that come close to the emotional commitment exposed in the interviews, highlighting context, dependency, and engagement. However, opposed to how the interviewees justify their paternalism, the theoretical work on care seeks to depart from a binary division between 'carers' and 'care-receivers', instead arguing that everyone, in principle, is capable of providing care and that everyone at some point will receive care (Sevenhuijsen, 2003:184).

A central point of the ethics of care is its critique of the presumed oppositional relationship between 'independence' and 'dependence'. Instead of seeing these as strict opposites, dependency on caring relations is analysed as a precondition of independence. In taking this view, acting on the vulnerability of others means that we are simultaneously providing their basis to function as autonomous and purposeful individuals. Thereby, the firm separation between those in need of help and those who are living 'independently' is undone. This conflicts with how independence/dependence is understood within the politics of post-institutionalisation, where 'dependency' is often presumed to represent powerlessness, exposure, and a lack of control (see Verstraete, 2007; WHO, 2011:37, 263). This suggests that developing a language of 'care' that can account for the coexistence of 'independence' and 'dependency' may provide us with ways of thinking that reach beyond the stalemate of either seeing people with disability as independent *or* cared for.

I believe that this may have important implications for how we understand certain critiques of ethics of care directed from within disability studies and, more importantly, as concerns the place of 'independence'/'dependence' in debates about disability politics more

generally. The accusation that caring ethics ascribes ‘dependency’ relies on the presumption that ‘independence’ is superior and the norm. When a prominent disability scholar such as Oliver (1996:65) declares that ‘dependency’ is an effect of discriminating social, economic, and political forces, he takes the liberal yardstick of ‘independence’ for granted, failing to acknowledge a more fundamental kind of dependency which is integral to the human condition, perhaps sometimes more manifestly so for people labelled as ‘disabled’, but nevertheless ever-present. This is a mode of critique that fails to address the ontological underpinnings of what it criticises. The proposal that humans are intrinsically dependent as interdependent beings not only challenges the liberal ideals inherent to disability legislations, but also much of the ideological underpinnings of disability studies research that attempts to critically assess these legislations. To be able to develop this into a positive notion of human relationships, however, we also need to account for how some disability scholars have theorised human vulnerability.

### *Constitutive vulnerabilities*

Within disability studies, and from theoretical positions similar to my own, some scholars have sought to draw on ‘vulnerability’ to destabilise the firm separation between ‘able’ and ‘disabled’, stressing that we all go through phases of dependence in our lives, whether we are labelled ‘disabled’ or not (see Davis, 2002:3; Garland Thomson, 2012). For individuals understood as ‘normal’, our universal dependency most often goes unacknowledged. After all, most people in Western societies are dependent on things such as the availability of food in our local stores, on our phones operating as expected, on public transportation running smoothly, on public information targeting us in times of crisis, and on dental care to take care of our teeth when they hurt. Every one of these examples presupposes a functioning supply chain, where numerous others are necessary in order for us to uphold a ‘normal’ way of life. Yet, none of these examples are acknowledged as ‘dependence’ in a politically relevant sense. As a political term, ‘dependence’ has come to denote a state of being associated with individuals who are separated from what is considered ‘normal’ (see Fraser & Gordon, 1997). This is why ‘dependence’ on functioning public transportation is only acknowledged as such when it concerns disabled peoples’ access of riding the bus using wheelchairs, whilst it goes unacknowledged for ‘normal’ people commuting to work. The line of division here is made up of the prior judgement that people with disability are a special category of human being, a certain class

requiring special attention, whose needs and views are repeatedly ignored when things such as public transportation is in the planning stages.

When we start to see our own lives, or any life, in light of the fluctuating needs we all have, we are provided with the opportunity to question the distribution of independence/dependence; how certain dependencies are understood as 'bad' and how these serve as the constitutive outside of the valued position of 'independence'. Thus, Kittay's argument that 'dependency' is 'grounded in the inevitable circumstances of the human animal' (Kittay, 2003:260) directs attention towards how we all fall short of ideals of full ability and complete independence. Provided this insight, 'disability' can be understood as a consequence of our biology being fragile and open to injury when encountering the world (see Siebers, 2008:7), in turn suggesting that 'disability gathers us into the everyday community of embodied humankind' (Garland Thomson, 2012). Basically, disability is a reminder of what it means to have a body that exists in a world of things that appear to be external to it, which is to suggest that the vulnerabilities and dependencies associated with disability cannot be separated from 'normal living' (see Siebers, 2008:5). Garland Thomson (2012) has pointed out that the script of fully normal development is a path very few of us can follow for an extended period of time. Most of us are, in some stage of life, temporarily disabled. The construction of 'disability' as a designation of a specific group thus obscures how disability is a shared experience, constantly making in-roads into 'normality', and a lurking possibility and potentiality in all of us. Not unpoetically, Garland Thomson (2012:342) formulates this latent potentiality as bearing 'witness to our inherent receptiveness, to being shaped by the particular journey through the world that we call our life'.

In this way, 'disability' is not alien to normality, but an integral part of what it means to be human. It is separated in order to protect the ideals of full functionality and independence. In this context, Garland Thomson (2006:262) writes of a societal 'will to normalize'; to rid life of all unpredictability and non-conformity by means of regulation and control of deviancy. For Susan Wendell (2006:247-9) this stems from our unwillingness and our incapacity to confront our own bodies, which we cannot accept as fragile and open to injury (see Davis, 2002:3-4). Hence, our cultural insistence to control the body shifts blame onto people with disability for failing at this task, and so this particular form of otherness comes to embody our universal failure to meet the ideals of 'independence' and ability. By these processes, our universal vulnerabilities are hidden by being projected onto groups that stand as examples of what 'dependency' is and looks like. In

this masquerade, the intellectually disabled subject appears as the removed expressions of our lack of reason, faltering cognition, emerging dementia, and so on, creating the impression that such common traits are outside of normalcy. Kristeva (2010:251) calls this ‘a *narcissistic identity wound* in the person who is not disabled’ and goes on to state of the non-disabled person that ‘he inflicts a threat of *physical or physical death*, fear of collapse, and, beyond that, the anxiety of seeing the very *borders of the human species* explode’. In a less theoretically dense formulation, Goodley (2014:38) states that ‘disability reminds ability of its own vulnerability’, appearing as a threat, indeed, a psychological one at that, I would add, to our ontological foundations. Hence, when the norm of the reasonable brain, the self-sufficient master of one’s own life, is constructed and contrasted to the otherness of intellectual disability, the threat is simultaneously handled and created, producing both the assurance the dependency associated with a lack of reason is somewhere else and the possibility that the difference between ‘us’ and ‘them’ is not as firm as it seems. This is akin to what Butler (1993:26-7) calls ‘the spectre of a terrifying return’, in which disability haunts normality by threatening its coherence and reasonableness. The sustained efforts to remove intellectual disability and to distinguish it as a qualitatively different class of human existence is a way of defending the border of normalcy.

#### *Doubly vulnerable*

Now, I believe that this line of reasoning can ultimately provoke us to reconsider the phenomenon of intellectual disability as such. First, the vulnerability stressed by Garland Thomson, Goodley, Davis, and Wendell, emerges in the interface between body and world. I believe that this only tells half of the story: although these disability theorists successfully highlight the potential of ‘vulnerability’ to deconstruct the division between ‘able’ and ‘disabled’, their accounts downplay an equally important aspect of what the notion of vulnerability can lead us to suggest, namely that it also concerns how our bodily constitutions are always made sense of in discourse and that we emerge as subjects through social categorisations. The cultural nexus of ideas about disability, denoting it as a special category and difference of sorts, and the assemblage of governmental technologies developed to handle these differences, all represent aspects of the social and political appropriation of biology that I analysed in the first part of this book. And it is precisely by means of such social frames of interpretation, constructed in language, that we are able to understand the bodily fragilities that constitute us as vulnerable beings.

As I believe that this is somewhat new theoretical grounds, expanding on already rather complex arguments, I shall try to tread carefully. In *Excitable Speech*, Butler (1997:1-2) examines the implications of understanding subjectivity as constructed in language, stating that such constitution exposes a fundamental vulnerability stemming from the fact that discourse conditions our being. In Althusser's (1971 in Butler, 1997:24) wording: the speech act inaugurating the subject precedes the subject (see Butler, 1997:24). This means that the terminologies through which we know ourselves and our relations to others are never of our own making. Indeed, as Butler (1997:26) develops, there can be no protection against a call into existence that appears in language and which is necessary in order to consolidate our identities. Therefore, we may cling to the terminology that constructs who we are and designates our social existence (Butler, 1997:26). In essence, this suggests that subjects are always constituted in a terminology beyond their own control (see Butler, 2005). In the context of this chapter, this means that the categories of 'able' and 'disabled' necessarily precondition how we make sense of human vulnerabilities, how we neglect and hide them by projecting them onto certain people categorised along the lines of 'normal' and 'deviant'.

In other words, the fundamental human vulnerability which stems from our bodily encounters with the world will be meddled through an equally fundamental vulnerability that stems from these encounters always being made sense of in a discourses that precedes our emergence as subjects (see Butler, 1997:4; 2004:43). Butler (2005:35-6) talks of this as 'exposure' in order to highlight how other people, equally exposed, are always implied in these processes of subject-formation. As the category that people with intellectual disabilities come to inhabit becomes naturalised, there is little chance of escaping the associated terminology of 'disorder', 'cognitive deficit', and 'risk'. At the same time, this very language, and its underlying normativity, provide the justification of seeking to erase intellectual disability, by prenatal diagnosis, new drugs, or genetic counselling, showing how this is ultimately a question of existence and extinction (see, Butler, 2005; Taylor, 2013). To exemplify this argument: consider here how the authority of norms, institutions, sciences, laws, and regulations are all brought to bear on subjectivities being shaped. In turn, consider how these apparatuses construct intellectual disability: how people with this condition are medically defined and diagnosed through the language of 'intelligence' and adaptive behaviour tests; how routines and local regulations pin down which behaviours are considered to be acceptable in a group home; and how

are related set of associations, ideas, and propositions of ‘intellectual disability’. As Hettema (2014:495) points out, such frameworks precede our actions, are of a higher order than our preferences, and therefore appear to be external to us. This is a network of discourses through which being becomes possible, at times impossible, and even when we pass as ‘normal’, the very division will condition our being.

Thus, we are dealing with two aspects of vulnerability: on the one hand, stemming from the fragility of when body meets world and, on the other, from our fundamental openness towards discursive preconditions of subjectivity. I want to expand on the interlinking between these two aspects a bit more by suggesting that ‘intellectual disability’ emerges at the point where bodily and discursive vulnerability become inseparable. This interlinking can be elucidated by again utilising the proposition that every statement of a body functions as a further formation of that body (Butler, 1993: xix): the very act of describing a bodily vulnerability as a ‘disability’ contributes to constituting that body as ‘disabled’, which represents the discursive vulnerability. Thus, people with disabilities are vulnerable, as we all are, not only by their bodies coming into conflict with the world, but also because this conflict is made comprehensible through a set of ideas that constitute disabled people as ‘deviant’, ‘other’, and fundamentally different from the norm. And in this way, people with intellectual disabilities can be understood as ‘doubly vulnerable’, not because they are especially vulnerable, but because they expose how subjects come into being provided the intertwinement of our exposure towards the world and towards how we make sense of this exposure by discourse.

To conclude this argument, I argued above that disability could be seen as a projection of the universal failure to meet ideals of independence and full functionality onto a specific group. This, of course, also holds for people with intellectual disabilities, whose brains meet the world and its social organization in ways that have resulted in their removal from the sphere of ‘normalcy’. However, I also think that intellectual disability can be made sense of as a result of a parallel removal of our discursive vulnerability. Thus, the same way that our bodily exposure is handled by removal, there is a similar removal with respect to our vulnerability as constituted through language. The implication of Butler’s analysis of how subjects come into being in relation to discourse is that human beings are fundamentally incapable of reaching narrative closure, since they are unable to explain how they became an ‘I’ capable of telling their own story (see Butler, 2005:37). This rendering of subjectivity clearly contradicts the ideal of the humanist

subject, which is transcendental to himself (for the humanist subject is gendered) and able to tell his own story, coherently and effortlessly. This means that Butler essentially suggests that we are all fundamentally incomplete with respect to the ideals of humanist reason. In turn, just like our universal incompleteness with respect to ideals of full functionality, discursive vulnerability is handled by removal and projection onto a specific group that come to stand in for our universal failure to meet this ideal. This is 'the intellectually disabled subject', which appears to mask how we are all displaced by language and thus lacking full control of our own identity.

To summarise this discussion: the medico-political categories of 'disability', 'intellectual disability', etc., rest on an untenable separation between independence and dependence. Rather, as several disability theorists have argued, vulnerability is a common trait to humanity, not only specific to those we understand as being 'disabled'. As a consequence, disability is not alien to 'normal' life, but represents a latent possibility that will sooner or later become manifest, but which simultaneously poses a threat to the ideal that human beings are independent. Lastly, the very act of dealing with this threat, by removing vulnerability from common humanity and projecting it onto certain subjects constituted as 'disabled' is achieved by discourse and hence represents our vulnerability towards the social conditions and discursive frames within which subjects emerge. Intellectual disability can therefore be understood as an outcome of the overlap of discursive and bodily vulnerabilities.

However, this is not to suggest that we should ignore that this group differs, to say that 'intellectual disability' does not exist, or that I seek to collapse their specificity into common humanity. Rather I have argued that we should approach difference differently: instead of understanding some differences that we label 'disabilities', as tied to a pre-set division between 'independence' and 'dependence', I suggest that we see ourselves in the differences represented by the labels of 'disability' and 'intellectual disability', acknowledging the latent possibility of disability in ourselves. Neither is this to call for an appropriation of disabled identity or an attempt to bridge the difference between 'us' and 'them'. Rather, I want to draw attention to the contingent nature of the separation between 'disability' and 'norm'. Hence, instead of only searching for the proper needs of 'dependants' and the political measures through which these needs can be met, I want to ask that careful attention be directed at the instances, appearing in all of us, when the division between 'independence' and 'dependence' breaks down. Following such a route, I believe, represents a mode of critique and resistance

that may be able to do what the ‘caring resistance’ of support workers fails to: to shake the division between ‘them’ and ‘us’.

## 8. Representation

The material of this chapter consists of a three-hour conversation with activists representing the board and national secretariat of the Swedish self-advocacy organization Grunden. Although I had never met the activists participating in this particular conversation before, I had followed their work since I got involved with disability politics and I was familiar with activists from Grunden's local branch of my hometown before I started to write this book. For reasons that will be discussed throughout this chapter, the text that follows is written and structured differently than the rest of this book.

The discussion with the activists revolved around the relationship between notions of 'representation' and resistance against the prevailing politics of intellectual disability<sup>27</sup>. Partly, this was a result of me assuming that issues of self-representation were important to members of the first Swedish self-advocacy group of people with intellectual disabilities. As stated at the opening of the previous chapter, their activism seems to exist in the gap between ideals of equal political participation and the fact that people with intellectual disabilities have often been excluded from organizations speaking for their group. However, the discussion also revolved around representation because they brought up and returned to this theme throughout. Rereading the transcript, three related aspects of 'representation' are central. First, that 'representation' stands for self-advocacy; that Grunden, as an organization, is led by intellectually disabled individuals who represent themselves. This actualises the thorny issue of who can speak for people of disenfranchised groups. Secondly, representation is brought up as an issue of how 'intellectual disability' is depicted and, thus, how activists labelled as such both relate to and resist these representations. In the activists' stories, acts of re-presenting what a diagnosis of intellectual disability implies are central to how they understand themselves as political agents. Lastly, a repeated occurrence during our three-hour long conversation was that the

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<sup>27</sup> Apart from this main theme, I also raised a set of questions that specifically focused on experiences of LSS-services, which was referred to in Chapter 6. These questions will not be presented here.

activists played with, questioned, and unsettled, the supposed dividing line and hierarchy between me, the non-disabled researcher, and themselves. This prompted me to consider my own representation of them in this book and, more generally, the relationship between scholarly work and political struggle. As we shall see, politics of representation – of being seen, heard, and able to voice one's opinions – offers both the opportunity to transgress and the threat of reifying what intellectual disability is presumed to be.

*Monica:* Is it ok if we take some pictures and put on our Facebook?

*Niklas:* Absolutely.

*Monica:* We document everything when someone is visiting us.

*Niklas:* Perhaps you are getting quite used to being visited?

*Monica:* Oh yes, we are.

*Andrea:* There are really lots of people interested...

*Niklas:* I can see that. I wanted to quickly present myself again. As you probably remember from my e-mail, I started to take interest in the politics of intellectual disability when working in group homes over ten years ago. I didn't think that things functioned very well where I worked, I thought that the people living where I worked deserved better. I also did find, when starting to study political science, that many of the things happening in the group home had to do with power and politics. So I just started, and then continued, to study the politics of disability, first as a student, then as a doctoral candidate. That's pretty much the story. Now, would you care to present yourselves?

*Monica:* Yes we can, you start Andrea!

*Andrea:* I am Andrea. I work with public relations at Grunden. I also work with a project on domestic violence. That's very hush-hush... Not everybody have relatives that can help, so it's important. Tomorrow, I am going to Mariestad to lecture for our local organization about it.

*Anders:* I am responsible for the web and our Facebook and our webpage. My name is Anders.

*Monica:* My name is Monica. I am staff manager and ombudsman. I work with spreading Grunden to the wider public.

*Olof:* My name is Olof and I am the chair of the national organization of Grunden.

[One more participant, Emma, will join us later]

In other parts of this book, interview material is presented and directly commented on, thematically sorted, and inserted into a linear argument. This is the regular way of drawing on interviews in social scientific research, a way of writing that ascribes the role of distilling meaning to the researcher. Such narration rests on an epistemological hierarchy that produces texts where the flow of words of interviewees is continuously interrupted by the authoritative voice of the scholar. I do not think that this is inherently problematic. Indeed, producing meaning by means of interpretation pretty much sums up the expertise of social scientific researchers. However, as the flow of words commented on in this specific chapter deals with representation, it seems necessary to allow the topic of the conversation to influence the way the text is structured. This means that the activists provide material that is treated differently than the interviews with support workers of Chapter 6 and 7. This is not because activists with intellectual disability are particularly vulnerable or because I want to tear down the hierarchy between us (and I do not think that the hierarchy between those that writes books and those who are the subjects of the books can be torn down by means of style or good intentions, in any case). Rather, the reason why I do not critically assess the interviewees in the same way as the I did with the support workers is that these two groups are located in different places within the biopolitical regime, inside and other to the norm of reason, and that this calls for differing analytical standpoints, especially in the context of the politics of representation.

*Monica:* I've been working the longest time in Grunden, for 23 years. I have been part of this whole journey. When we started, it was only in Gothenburg, but today we have 19 local organizations.

*Niklas:* Ok.

*Monica:* Grunden is unique today. We are working so that people are allowed to be a part. We don't want to exclude people, everybody should be welcome. What we do is that we hire people with disabilities in different ways. We have a boss who has a disability. That's what's so special about us. If we go back to 1999, we decided that, ok, we did not want to be part of FUB [Parents of Children with Intellectual Disabilities, a major Swedish disability organization]. So, through a long procedure, we decided to be independent. "How in the world will you be able to handle this...?", they were wondering, "can you do this on your own?" For one year, we dealt with the organization's economy, hiring people so we didn't have to think about that. Today we do

everything else by ourselves. We decide what kind of organization we want to be. And we have said that to all of our new local organizations: “you decide!” This has been shocking for many. People like us have never been allowed to decide, but today, we have grown so strong in our organization that we can make decisions about everything.

*Niklas:* That’s the difference compared to FUB?

*Monica:* FUB is for the parents, while we represent ourselves.

*Andrea:* We are really tired of that. Anna Strand started our organization. She works one floor above us now, at the local organization of Grunden. She is an honorary member. She realised that when they had board meetings at the time, with a mix of disabled and other people, the non-disabled had coffee and buns, whilst the disabled had cookies and soda and balloons. So a lot of stuff like that, those involved at the time were really tired of it. Today, we have a lot of philosophies, like ‘participation’, we always try to be that. When we are out giving lectures, which I really love doing, it’s always those of us with disabilities who give the talks. Not our coaches, because they don’t know what it’s like to live with an intellectual disability. Nor do those with power over disability politics.

*Niklas:* I see... Do you cooperate with FUB?

*Andrea:* Not that much. It’s not that we dislike each other, it just hasn’t happened that much.

*Monica:* We have different opinions than they do. But, here in Gothenburg, they’ve seen that we can handle our organisation, what a success we are. We have some contact with FUB Gothenburg now.

*Andrea:* I’ve been working here for fifteen years. I couldn’t do anything at the start.

*Niklas:* So, it was challenging?

*Andrea:* Yes, very much in the beginning. But we learned a lot. If we want to live our lives as everybody else does, then we have to handle it. I have never felt disabled, not ever. My parents told me when I was twelve, but I have never felt it. I have an older brother and they treat me the same as him. So, I didn’t feel different. When people say “you’re disabled” I’m like “uuh, am I?”

On various occasions when I have presented parts of this book, I have been told by fellow scholars that it is crucial that I talk to ‘the actual people’. Although, I have done so from the start and surely have gained from meeting and knowing people diagnosed with intellectual disability, the suggested

reasons for why this is important troubles me. According to these proposals, the legitimacy of my findings hinges on the support of ‘the voice of the intellectually disabled’: that ‘they’ need to be represented and that I have a responsibility to make the ‘competent disabled person’ visible in my work. In this chapter I speak to people labelled so, but what does engaging the ‘voice’ of people belonging to this group actually entail? What are the requirements of an ‘adequate representation’ and why is it precisely ‘competency’ that should be represented? Is there not a risk that I diminish the right to be bad at things if I only highlight the overachieving disabled subject (see Mitchell & Snyder 2010)?

Hence, there are immediate reasons for caution here. First, I do not believe that there is a unified ‘voice’ of people with intellectual disabilities. Assuming that implies that there is an essence to intellectual disability, denying that people labelled as such can emerge as subjects beyond this categorization. Furthermore, these ‘voices’ in particular, of the people involved in this particular conversation, all belong to ideologically motivated organized political activists, which most people with intellectual disabilities are not. Hence, there are critical questions to be asked as concerns the underpinnings of my colleagues’ calls for representation. The suggestion that I have a responsibility to represent, and that the legitimacy of my findings depends on it, seems to rely on an unspoken essentialism of people belonging to this group. Expecting that there is a unified voice speaking the ‘truth’ of the politics of intellectual disability, a ‘truth’ which I shall uncover, suggests that we are dealing with a class of people that first and foremost appear as examples of their diagnosis, thus subsuming all of the differences that we surely would have expected within any group of ‘normal’ people. The urge to hear ‘the voice’ of this group also assumes that these individuals experience the world, and the structures of power that they are entangled in, only from the viewpoint of their diagnosis, but not as inhabiting a certain sex, a certain class, a certain sexual orientation, or a certain race. These problematic aspects of calls for representation mirror the post-colonial insight that research on disenfranchised groups often tends to attribute to these groups a single and ahistorical consciousness. In Spivak’s (1988) analysis of post-colonial patterns of representation, attempts to provide oppressed groups with a ‘voice’ are bound up with a notion of the subject as coherent, autonomous, and carrying experiences that can be accounted for as ‘true’ representations of what such people are like (see Varga-Dobai, 2012:2). The role of individuals of oppressed groups represented in research thus becomes to

validate and exemplify ‘otherness’, whilst leaving the very status of being ‘other’ intact. As a mode of critique, it is a dangerous path, I believe.

*Monica:* Eight years ago I was at FUB-Klippan’s<sup>28</sup> annual meeting. And we discovered that they had board members without disabilities, who took over proceedings. Like, at one point someone was going to talk, “no, you are not allowed to talk”, this person without disability said. Me and my colleague, sitting at the back, we were only visitors... I almost had to put my hand over my colleague’s mouth. He was about to boil over.

*Niklas:* Ok.

*Monica:* Seeing how people are treated can be horrible. At that board meeting with FuB-Klippan, we had only been there for ten minutes, everybody was supposed to be ‘participating equally’, and then we see this. I see how people are treated, at seminars and banquettes and things like that. On these occasions, you often see that personnel, so-called ‘normal’ staffers, are making fools of themselves. At a conference I attended, I overheard a disabled person wanting to have a beer. All of the seminars for the day were over. And this staffer says “just so you know, you can only get one”. I just looked, thinking “Jesus Christ, here I am, sharing a bottle of wine with a colleague”, had she heard that I also had a disability, it would have been one hell of a headline...

*Andrea:* Exactly, we can’t drink.

*Monica:* We are not allowed alcohol.

*Andrea:* They don’t know how to handle us.

*Monica:* Now, how is it for other people? If out on the town, and people are sitting and drinking themselves pissed drunk and become unbearable? That’s fine.

*Andrea:* That’s even worse.

*Monica:* But if we were to be drunk...

*Andrea:* It was like when I was in Jönköping [Swedish town] with Anna. And in the evening, there was supposed to be a party. Only non-alcoholic beer, because they didn’t know how to handle us. And I was thinking “shit... what is this?” Later, I was talking to FUB-Klippan, the chair and a non-disabled supporter. And I was talking for an hour about how we are working in Grunden. And suddenly he, the chair of Klippan, said “but I want to say

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<sup>28</sup> A branch of FUB specifically for people with intellectual disabilities.

‘developmentally disturbed’”, rather than ‘intellectual disability’. “Uhu... well say it then”. I don’t like the word, but you can say it. If you say it, then I know. “But you don’t want me to say it”, he went on. But I never said that. You can say whatever you like. They even applauded because they wanted to use the term ‘developmental disturbance’. I was like, shit, shit, just let them... Anna was boiling over. “Calm down, Anna, calm down”.

Spivak argues (1988) that the impulse to represent, to give voice to, paradoxically mutes: inserting ‘the subaltern’, or whatever group we seek to represent, into frames of discourse produced from the perspective of the coloniser comprises a form of epistemic violence, where the benevolent researcher, rather than hearing and providing space for the oppressed, represents themselves as transparent and as able to give a true account of the authentic needs of the group in question. In her critique of the representation of the oppressed in the work of Foucault and Deleuze, Spivak (1988) argues that their accounts are ridden with a troublesome inconsistency as concerns ‘the oppressed subject’. While these thinkers generally understand subjectivity as an effect of power, as I do as well, their respective analysis of oppressed groups both presumes the ability of such people to authentically speak for themselves, as ‘oppressed’, and the capacity of the Western theorist to hear and transparently represent such voices (Spivak, 1988; see Morton, 2003:55). By treating the oppressed subject as singular, Spivak concludes, Foucault’s and Deleuze’s depictions are in fact constituting this subject whilst obscuring their own complicity in the practice.

Parallel to this, it seems inherently problematic to account for what people with intellectual disabilities are like, rendered so by the general discourse within which I am supposed to make their voices heard. Within disability studies, there has been an on-going discussion about non-disabled researchers who write about disability and about the need to include people with disabilities in research (see Barnes 1996; Chappel, 2000; Barnes, 2003; Walmsley, 2004; McClimens, 2007). ‘Nothing about us without us’, the slogan of the disability movement goes. There is a hidden presumption underpinning this slogan, namely that there is equivalence between the two ‘us’; that nothing *about* people with disability, the general group, ought to be said without some specific involvement of people from this group<sup>29</sup>. As not *all* people with disability, for practical reasons, can participate in research, the notion of representation is implicit. But to what extent can *some* people of

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<sup>29</sup> Here, I am indebted to the stimulating feedback of Katarina Jacobsson on a previous paper.

this group represent the collective of people with intellectual disabilities? Again, assuming this also seems to assume an intellectually disabled essence. Indeed, such representation means that a few people participating in research become embodiments of ‘intellectual disability’, thereby transforming this social and political category into the flesh and bones of certain bodies that partake in research. Consider here how Butler (1990:3) shows that the designation of “women” as the subject of feminism itself is a discursive formation of representational politics which can be assumed to re-inscribe domination on the subject position which is supposed to be emancipated by feminism. Are there not similar risks associated with designating ‘the intellectually disabled subject’ to be the agent of emancipatory research or of emancipation more generally? Although I strongly advocate the inclusion of people with intellectual disabilities in research, caution is needed as concerns using specific individuals to represent ‘intellectual disability’, to legitimise the research in question as normatively admirable, or to represent people with intellectual disabilities as a unified political agent.

*Monica:* We have all of these things to deal with. That is what makes us unique. It is Emma, Olof, Andrea, and me and we are a group of people living in danger. Our disabilities are invisible. We speak for ourselves, we have a politician among us<sup>30</sup>, and we have developed during these years. If we go back to 2009 when the national organization of Grunden was established, then we didn’t know what the platform would look like. Today, we have an employed boss with disability, who also takes care of all the tough things coming along, the things that all other bosses take care of, with contracts and all of that, and who takes charge when difficult situations come up. You have done that [nods to Olof]

*Olof:* Yes...

*Monica:* If this were ten or fifteen years ago, people would have been like “Olof, you will not manage this...”, but now you are at all of these meetings and you handle it.

*Olof:* Yes I do.

*Niklas:* Would you like to say a little bit about this?

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<sup>30</sup> Emma, yet to arrive, is a publicly elected official of a district committee in the municipality of Gothenburg.

*Olof*: Sometimes I sit with the National Board of Health and Welfare [Swe: Socialstyrelsen]. I have even been to meetings with IVO [The Swedish Supervisory Authority of Health and Welfare].

*Niklas*: Ok.

*Olof*: I mean, something like that... I had the hunch that they would be shocked. They don't notice that I am disabled, because it's not something you can see. I bet they would scratch their heads and think "something is not right here..." if they knew. In that way, we have really crushed the myth that "people with disabilities, what can they do?"

*Monica*: As staff manager, I take courses in order to become better. A few years ago, they would have sent a coach with me who would function as an interpreter... "is everything ok... are you managing...?" But it was as easy as anything.

*Andrea*: Before we got our own organization, it was always the staff working with us that went. They attended these courses, it was 'them' and 'us'. We don't want that.

The voice of people with intellectual disabilities, like the voice of 'the worker' or of the 'subaltern', often appear to be represented by a political proxy standing in as the 'voice' of the group in question. When people suggest to me that I must include interviews with people with intellectual disabilities, it seems to be underpinned by precisely such a mythology of 'the voice'; a 'voice' that can validate, not by providing important information or strengthening my argument, but by standing in as the very category itself. By *being* intellectual disability. Ellis (2014:494) notes that the energies mobilised to describe 'otherness' in the most authentic way possible seem to be a search for lost origins. The idea that the 'voice' of people with intellectual disabilities provides legitimacy to my arguments can therefore be understood against the backdrop of a modernist drive to access the centre, the core, the essence, of whatever we seek to understand (see Ellis, 2014:502). Indeed, modernist traces of representation permeate projects of emancipation, privileging 'presence' codified as what is spoken and made explicit. The inquiries of colleagues who wonder whether I aim to speak to 'the actual people', connect to this trope of representational thinking.

Again drawing upon Spivak, I believe that the appropriate response to these problems is to search for a mode of conversation that can disrupt the hierarchy between researcher and research subject. Spivak calls this 'learning to learn from the subaltern'. This also entails figuring out a way to present

the conversation that resists my own tendencies to explain what their words 'really mean'. My representation of our discussion must mirror how the activists have unsettled my position as the authoritative voice and how their perspective interrupts mine. Rather than slating over such instances of disruption in our conversation, by means of theory or through neglect, I have sought to make them visible.

*Emma:* Hi! I am very interested in these things, can I say something?

*Niklas:* Yes, of...

*Emma:* [interrupts] You, who are a researcher and all, why does it still say 'developmental disturbance' in the LSS? Why do you 'compli-velopmentally disturbed' [sve: "invecklingsstörda"] not have your own law, when it is you that complicates matters with all your laws and paragraphs?

*Niklas:* Well...

*Emma:* ...Whilst we try to develop society.

*Niklas:* We can talk about that. We talked about that [on the phone, with Monica, when arranging the meeting], about the terminology of 'developmental disturbance', can you tell me why you think it is a bad term?

*Andrea:* I can tell you that. It started with Anna [Strand, founder of Grunden], you can see that she has [a disability], because she's got Down's syndrome. In Grunden, we don't judge based on diagnoses, we see each other as people instead. We don't care about that, we want to live as others, in society. We want to be people. We don't want to be filed under labels. They called me from Eskilstuna [Swedish city], "I am going now, to meet staff and 'users'", they said, "I am sorry, but you mean 'people', not 'users'!" They never called back.

*Niklas:* Ok.

*Andrea:* It says 'developmentally disturbed' in the law... When I moved to a new apartment within Gothenburg, they had to write down that I was 'developmentally disturbed'. So I said "can you write at the margins that I am not developmentally disturbed, that I am Andrea?". "No, I can't", they responded. "Well, you have to or I leave here and now. It's your choice", I said.

*Niklas:* What did they do?

*Andrea:* She had to write it. Because I am not only helping myself, I am also helping those who cannot speak for themselves.

Grunden is the first organization in Sweden ‘of’ rather than ‘for’ people with intellectual disabilities. Its function is described as being a platform for people with intellectual disabilities to represent themselves. Hence, there is a considerable degree of transgression of pre-established expectations here, relating to what Simons (1995:103) calls ‘[a] politics of those who refuse to be what they are and strive to become other’. Historically, self-advocacy of people with this diagnosis has been rare, as the political movement of intellectual disability rights has been dominated by a number of organizations ruled by parents and relatives, at least in Sweden. Consequently, representing oneself goes beyond the activists speaking for themselves. It also means that they are portraying themselves as subjects that are capable of acting politically. In this sense, two aspects of ‘representation’ are operating in tandem: representation as ‘speaking for’, as in political representation, and as ‘depicting’ oneself as a political agent.

*Niklas:* You were about to say something Emma...?

*Emma:* I was going to say that all people develop, but what does ‘disturbance’ mean?

*Andrea:* Yes!

*Monica:* That’s right.

*Emma:* The word ‘disturbance’ is not in our dictionary. And as regards people that need supported living, if someone on the staff says that they are going to Pelle [a generic Swedish name], then they usually say “I’m going to the ‘user’...”. Why can’t they say “I’m going to the tenant”? We have the same right to our apartments as you, who are ‘compli-velomentally’ disturbed. I have gotten The City of Gothenburg to investigate whether people attending day-care services can get salary rather than ‘activity benefits’<sup>31</sup>. For many of us, like Andrea or me, where you can’t see the disability – we often fall between the cracks. Social insurance says that we are too healthy to receive sick insurance, whilst the job centre say that we can’t work because we are disabled. And because of the law on day-care services, we can’t go to the job centre activities, so we can’t get social insurance. What would you do?

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<sup>31</sup> ‘Activity benefits’ are paid to individuals granted day-care service, a service that can entail everything from extensive care for people with severe disabilities, to actual work in cafés or church activity halls.

*Niklas:* I don't know. I mean... I guess I think that if you work, you should get paid properly for it. Activity benefits, I mean... I know people that work just like anybody else, just as good as anybody else does, but since you do it as disabled, getting it as a service rather than as a job, you don't get paid properly. To me, that is injustice.

*Emma:* I have gotten the municipality, here in Gothenburg, the board of adult schooling and the board of labour market issues, they want to have a discussion with us at Grunden to change the system. Here, in Gothenburg, they have taken away Fas 3 [phase 3]<sup>32</sup>, this is the next step, maybe.

There are so many ideas about intellectual disability, coming into conflict with the activists' own conceptions of who they are. In our conversation, they often refer to the stupidity of such ideas. The fact that it is possible to provide these stories as examples of narrow-mindedness and prejudice, to mock them and laugh at them, indicates both an awareness of the norms that dictate how their diagnosis is seen and a position from where it is possible to scrutinise these norms. But, in parallel to Butler's (2005) contention, it is nevertheless in relation to these that subject-formation becomes possible, even when resisted. The organizational context of Grunden seems to be a space in which these stories can be told and in which subjectivities can be articulated in contention with dominating ideas on intellectual disability. However, it is not a space where popular discourse about intellectual disability is absent. To the contrary, it seems to be continuously talked about, referred to, and questioned. The biopolitical constitution of intellectual disability, limiting and damaging as it is described in the conversation, is both that which is contested and the necessary precondition of the activist's resistance.

*Andrea:* It's like, when you are disabled... I got LSS when I was 7, because I was too young to decide. I can accept that. But, I did not get to decide that, so I got a label on my forehead that I am good for nothing. I want to work out there, on the market...

*Niklas:* The labour market?

*Andrea:* Yes. But I have other problems, like a hearing impairment. But I have had got to prove it. I have been an intern in child care, because I love

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<sup>32</sup> Fas3 is a Swedish unemployment program which forces individuals who have been unemployed for a certain amount of time to work unpaid in order to get social insurance. The program has been widely criticized as a prime example of neoliberal 'workfare' politics.

kids. So, I went out and I had to prove it. It's like a label on my forehead that I am developmentally disturbed, and it's there because of the LSS.

*Niklas:* How do you do that? You know, because it seems like one of the things your organization wants to do is to discard that label on the forehead...

*Monica:* What we do, and that's why we are unique, and I had been at day care centres for 17 years, and five years ago, I became employed instead. At the start, I was kind of proud that I had reached that point, to get paid. But it's a whole lot of work before that. I have no guarantees, if I lose my job, I am outside the LSS-system, and then I have to apply again. As things look today, things can go very badly for me.

*Niklas:* One thing I am thinking is that there is one set of rules for, well, people like me, who are not...

*Emma:* Compli-velopmentally disturbed!

*Niklas:* Yeah, if you are "compli-velopmentally disturbed". Then you can do lots of stupid stuff. You know, I've been to group homes where you're not allowed to have more than three cups of coffee a day. Some support workers that I've interviewed tell me this while having three cups just over the duration of my interview. So there are different standards.

*Monica:* I have been living in group homes. At one point, I was having shrimp and wine with my boyfriend on a Wednesday. All of a sudden, a staffer just enters the apartment, for some stupid reason, they wanted to borrow a whiteboard pencil, she said. And I don't have one. It was only that they wanted to check... you know, how things work. I had windows in my apartment.

*Andrea:* If you were drunk or something?

*Monica:* Or if I was doing something naughty with my boyfriend.

During a few instances in the conversation, Emma addresses me by referring to my status of not being intellectually disabled; 'you, the researcher'; 'the compli-velopmentally disturbed'; and so on. Interestingly, she invokes this as a rhetorical gesture when drawing attention to something she finds strange and unjust. During these instances, such strangeness becomes associated with me and there is a clear sense of the dividing line between 'norm' and 'deviance' being re-inscribed, as well as an awareness of the distribution of power which comes out of it. By pointing towards this line, however, something happens to the distribution of power. I represent the categorisation, the distinction between us that she seeks to challenge, and she

does so by naming my 'normalcy'. This works to undermine my pre-established authority, it contests the culturally held presumption that researchers know something while people with intellectual disabilities know nothing.

*Andrea:* Excuse me...

*Niklas:* Go ahead!

*Andrea:* Always when I lecture, I say "I am not disabled, I am societally disabled". It is society that made me so. I have never felt disabled, not in my whole life. It's society. So, I have never had that problem. I am going to Mariestad tomorrow and I will say that again.

*Niklas:* If you see yourself as disabled, then you go to the doctor or to rehab. But if you see yourself as 'socially disabled', then you become a member of Grunden...?

*Andrea:* That's why we are doing this, to change things.

*Niklas:* So, somehow attitudes...

*Andrea:* Yes, the attitudes in society aren't good. Let's say I go by the tram or something, if you walk strange or something, as some friends of mine do, then people stare. "Is something wrong", I say to those looking. I am not afraid to do that, to speak my mind. One time, in the grocery store, someone was really staring at me. I was thinking "ok, what's wrong now...?" She really glared at me. When I left, do you know what I said? "Go buy a TV if you want something to stare at!" She really panicked. I know that it was not nice, but I could not help it.

*Niklas:* I can see that one becomes fed up.

*Andrea:* Yes, you really do get fed up. I am only human, there's a limit to how much I can take.

The displacement of taken-for-granted role ascriptions is also evident in the terminological invention of 'compli-velopmental disturbance'. The term is an intricate word play, alluding to the fact that the antonym of 'develop' in Swedish is the same word as 'complicate'. Thus, the inversion of 'developmental disturbance' that Emma uses as a label for 'normal' people literally means having a disturbance of complicating matters. At the same time, it also attaches to normalcy, to the 'compli-velopmentally disturbed', a kind of deficit that mirrors 'developmental disturbance'. When first introducing the specific term, Emma explicitly stated that it was 'us', the

‘compli-velopmentally disturbed’, who complicated matters infinitely, with special laws and regulations, that do not make sense. As such, this way of addressing normalcy interrupts how otherness is articulated within the hegemonic discourse. Through the use of ‘compli-velopmental disturbance’, Emma destabilises presumptions concerning whose standpoint should be the voice of ‘reason’ and whose mode of address should be privileged.

*Emma:* It was a few years ago, about Glada Huddik [a theatre group famous for having intellectually disabled actors], Per Johansson, their boss, was there in the TV-studio. Do you know what I said?

*Niklas:* No.

*Emma:* I said “you put us with disabilities in a cage like monkeys and feed us bananas. But we are humans that need just as much love as anybody, we are not small monkeys in a cage!”

*Niklas:* Yeah, I’ve also been thinking about this show *En annan del av Köping* [Swedish documentary series about life in a group home, eng: *Another Part of Köping*]...

*Andrea:* Oh my god.

*Olof:* I was watching half a show or something like that, and I turned it off thinking what kind of degrading kind of thing is this...

*Andrea:* They do not tell stories about real lives. It’s only cuteness and all nice... It’s like everybody with intellectual disabilities likes dance band music [a genre which has been subjected to much mockery due to its low-brow status in Sweden] and hugging. What’s that all about?

On a related note, there is a curious link between otherness and cuteness as concerns cultural representations of intellectual disability and how ‘the monkeys in the cage’ are allowed to be seen. Depictions associating intellectual disability with ‘cuteness’ can be interpreted as premising the visibility of people with this diagnose. Hence, TV-shows and other cultural representations tend to portray people with intellectual disabilities as overflowing with love and thankfulness, easy-going, and over-achieving *despite the odds*. The show *En annan del av Köping*, referred to above, is a good example. It is focused on the rosy moments of everyday life in the group home, showcasing that people with intellectual disabilities are able to fall in love, to form relations, to have friends, and so on. The fact that a TV-series can be formed around such mundane moments suggests that the

audience is supposed to be surprised. At the same time, the main message is that these are people just like any of us. But, if the individuals focused on were really seen as ‘normal’ it would be a really boring show, since it would be completely devoid of dramaturgy or conflict. It is plainly about how wonderful it is that these people are doing what most ‘normal’ people also do. Rather, the dramaturgical motor of the show is the otherness of the group as such: it is a series about *unusual* people doing *usual* things, seeking to represent the normalcy of the exception, where deviancy operates as the very premise for why we are supposed to be interested in watching these people cooking, talking, and having coffee, in the first place. As is stated by Andrea in the conversation, this does not represent ‘life’.

*Monica:* I was on SVT Debatt [Swedish weekly television show hosting debates on topical issues] one and a half months ago. With Olof. I was so pissed off, because there were professors there, doctors, who are supposed to be so smart and good. I couldn’t keep quiet, so I raised my hand and said “We live in the 21th century, I am a mother, I have an intellectual disability, if we were not here, how would the world be?” The debate was about prenatal diagnosis.

*Niklas:* That’s also something I’d like to talk about...

*Monica:* You can watch the show.

*Niklas:* Yes, I watched it.

*Emma:* What was your name again?

*Niklas:* Niklas Altermark

*Emma:* I have no idea when it comes to names.

*Niklas:* As a matter of fact I have a friend who said that I would probably meet you, he is also a member of the same political party as you here in Gothenburg.

*Emma:* It is funny that you say that, it highlights that we can do things like that.

*Niklas:* Perhaps it’s like with SVT Debatt. It isn’t always the professors and medical professionals who have the smartest views.

*Andrea:* Ann, who was here earlier [a women entered to ask something earlier during the conversation], she wanted to say something in the studio, but didn’t get a chance. Later, we learned that she was only there to show what Down’s syndrome looks like.

*All:* What!?

*Andrea:* Yes, Erik and I were told that. They wanted to show Down's syndrome... what about that?

*Monica:* Now, I am even more pissed off.

Throughout our talk, tensions arose in relation to the construction of the 'intellectually disabled citizen' of Swedish disability politics. It appears that most of the activists do not view themselves as supporters of the LSS or Swedish disability politics. On the other hand, the language of politics of inclusion frames their political agency and therefore provides them with a terminology to pose political demands in. This exemplifies the intertwined nature of flows of power and practices of resistance. Their contestation of the present order of things is parsed in the dominant humanist and liberal terminology. Yet, its meaning is often shifted: they demand 'citizenship', albeit a lack of belief in the legislation granting them precisely that; although 'participation', 'rights', and 'living as others' play a large part in the conversation, here this vocabulary is used to name an ideal which lies ahead in the future. Hence, the activists are making up their own script by shifts and disruptions internal to the existing one, creating their own conditions of possibility, but *within* the established language of politics of inclusion and post-institutionalisation. In our conversation, it seems that we are searching for a political alternative that lies beyond the language at our disposal. And, in a sense, this alternative presents itself as performed rather than fully articulated.

*Niklas:* I believe many think that, no matter what it is with you, it must be the disability... the ears, the foot, depressed... As soon as something arises, then it is explained by disability. It reduces you to a diagnosis. What do you think about this? What can you do about it?

*Emma:* Lecture... as we are doing with you! Then you can write a book about it that may lead to something. Throw away all the old books. Burn them like the Nazis did. Throw away the old books, write new ones. I became disabled when I was six. I was out walking in the woods with my little brother and daddy, who walked in front of us. My brother shouted "dad, I can't wake Emma up". In the ambulance, they said that they should be prepared that I would not make it. When they realised that I would, they said that I would be a vegetable for the rest of my life, I would not be able to learn how to sit, to

walk, to talk... But what am I doing today? I am speaking and I am a politician.

*Andrea:* Thank God for that, say your parents...

*Emma:* In 2012, I became a politician, just like that. Even though I am disabled, I can talk. When you meet rehab personnel or group home staff... some think that we can't talk for ourselves. So, you have to have someone speaking for you who follows you around all the time.

*Andrea:* Yes, I was also supposed to have this kind of woman with me. Then she quit. And my case worker became fixated on this. She was rude to me. When we had a meeting, I said "I think you weren't very nice to me". And I like to look people in the eyes when I speak. And then she became really uneasy. That was her way of saying that people with disabilities, we should always obey...

*Emma:* ...follow orders.

Again, there is a reversal of roles as Emma declares that they are lecturing me. I am not there to hear and represent them, nor for the benefit of my research. Rather, Emma suggests that they see my visit in instrumental terms, where they are using me to amplify and promote their viewpoints. Since I have been educated in social science, still influenced by the ideal of the objective researcher, this instils some uneasiness: what does it mean for the validity of my material if the interviewees are motivated by political strategy? Pillow (2003 in Varga-Dobai, 2012:9) has argued for a 'reflexivity of discomfort' as concerns the relationship between researcher and research subjects. Such a reflexivity renders the relationships between the knowing Self and those being researched tenuous and troubling. This corresponds to how I experience our talk, in which I am surprised, questioned, and made accountable for the hierarchical relationship between people with intellectual disabilities and 'normal' people. Importantly, the stimulus for this comes from them, rather than from my meta-theoretical presuppositions, especially at those instances when they make explicit that there is a divide separating us. They address me as distinct from what they are, no matter our mutual awareness of my personal sympathy and alliance with their cause. Paradoxically, this has the effect of making me question the meaning of the lines of demarcations as such. It urges me to start to ask questions about whether it is possible to establish a mode of conversation of speaking *with*, rather than *about*, people made 'other', and if sometimes this could rather be an issue of *them* forcing *me* to hear what they have to say.

*Emma:* Niklas, I have made a lot of proposals for our party congress. And I am disabled. I am not supposed to be able to do that, but I have – about tobacco, special schooling, and lots of other things. And I am ‘developmentally disturbed’. But I can write all of these things anyway. I have written lots of debate articles, if you Google me and search for my name you will find lots of articles I have written. And I am supposed to know nothing, I can’t even make my own tea. [...] I am better at dragging politicians here. The first year we had the Social Policy Committee from the national parliament visiting us. The second year, I invited politicians from the Committee of Education. The third year I invited the Committee of the Labour Market. This year we had guests from the Committee of Social Insurance. If you look at Mickel or Johnny [two, provided the context of the talk, supposedly non-disabled persons occupying the room next door], they would never manage that.

*Niklas:* That’s how I think, too. We are good at different things. I am good at cooking, my fiancé can’t....

*Monica:* ...That’s how it’s like for us too, I am the chef at our place because I have problems with my eyes, so I can’t do other stuff needed to be done at home.

*Niklas:* But some of these things, that you can be less good at... they are bundled together and labelled ‘intellectual disability’. I think that everybody should get support if they need, but within the group of people called ‘disabled’ there are too many needs to name them all.

*Monica:* Ok, I am sorry, but I got to leave now. Here is a t-shirt for you, since you’ve been so nice and come here. And here is our magazine that you can read on the train. Promote us in Lund now [the city of my university]!

*Niklas:* Yes, it has been great to talk to you.

*Monica:* Normally, we charge people for this, but today you get it for free...

*Niklas:* Thanks.

*Monica:* It’s part of our job. It’s how we make a living.

*Andrea:* I would not survive without it.

[Monica leaves]

*Emma:* I have a question for you. You are a researcher, or whatever you are.

*Niklas:* Yeah.

*Emma:* In the first paragraph of the UN declaration, it says that all people, also according to the convention of the rights of children, that all have the same rights. But since the law of special schooling is older than the law of discrimination, the law of discrimination cannot interfere when kids in special schooling don't get equal grades. But kids in special schools should have a right to equal grades. UN says that all have equal rights, but if a complementally disturbed kid is wrongly placed in a special school, then they get compensation. If a person with a disability is placed in special schools, they don't, never mind that they are just transferred to day-care rather, rather than the labour market, after finishing. Since we get day-care, and aren't prepared for working, we cannot earn money to get good pensions. We have many people working as cleaners, but they are not allowed to enter the unions.

*Niklas:* Yes, I agree about this difference, also Swedish disability policy is...

*Emma:* That's what I am trying to change.

*Niklas:* Yes...

*Emma:* That's why I do all of these things.

In the words of Wisweswaran (1994 in Varga-Dobai, 2012:12), one way to formulate the purpose of this chapter is as formulating a self-reflexive research practice of 'betrayal', deliberately questioning its own authority to represent. When repressing the impulse to unify, clarify, and explain the meaning of their voices into an overriding and homogenous argument, there may be a mode of analysis that allows the researcher to be surprised; a way of relating where it is possible for the activists to upset and astonish and to create a sense of disbelief, hence, forcing me to reflect on my own presumptions. In Spivak's work, the subaltern is speechless due to the colonial impairment of hearing. In this conversation, the activists are forcing me to listen. Theoretically, I have not assumed their inability to exercise this kind of agency. Biographically, since I know many people with intellectual disabilities, the experience is not new. Yet, in the context of analysing this conversation, it is striking how discursive features of their address change the framing of the talk and how that makes me lose my train of thought occasionally. If the inability of the dispossessed to speak stems from their inability to be heard, I would suggest that no discourse is so firm that it renders impossible resistance by means of discursive shifts that force the dominant party to learn how to listen, indeed, that no temporary configuration of power is so stable that it is impossible to imagine its

collapse. In this context, resistance seems to be the practice of forcing non-disabled individuals to unlearn their deafness.

*Niklas:* As I see it, the law is really clear that in group homes, locked doors are not allowed, tenants have the right to come and go as they wish. It's not a prison.

*Emma:* They say "risk of fire"

*Niklas:* Risk of fire?

*Emma:* Yes, they use that. But we have the same right to risk burning down our homes as anybody. As any compli-velopmentallally disturbed. I have invented that word.

*Niklas:* Yes, I figured.

*Emma:* Since I am also a politician, I feel that... why don't you have your own law? We are all under the general social care law, why isn't it so that LSS helps those in need? When it really matters, the case workers break the law. The LSS says that day care services, as far as possible the individual should decide where she wants to work, but they don't care about that. They just go "you should be there and you should be there and you should be there!" But if I want to be over there instead...? "No, you should go there!" You are not allowed to have a bottle of red any day because you can't take care of yourself. But your mother doesn't call you [directed at me] to ask "are you drunk?"

*Niklas:* No.

In conclusion: It follows from Spivak's argument that the oppressed has no place other than as 'spoken for' within the dominating discourse. The possibility to understand 'the other' is circumscribed by the discourses that we have at our disposal, precisely since there can be no knowledge of otherness outside a language that renders certain subjects 'other' (Kapoor, 2004:636). To represent oneself also means to re-present oneself as a political agent, against the designation of otherness and speechlessness. In light of this, the accounts provided by the activists of their refusal of derogatory terms such as 'developmental disturbance' also seem to be a refusal to accept the linguistic and epistemological conditions of their emergence. As Goodley (2014: xi) has noted, (intellectual) disability is all too often immediately linked to pathology, marked by a set of medical terms that are assumed to be neutral. The activists displace this linkage by forming new conceptual

constellations, for example linking together 'disability' with 'contestation', 'intellectual disability' with 'self-representation', and by questioning the division between 'disability' and 'normalcy'. One way to read Spivak on 'post-colonialism' is as a reminder that our representation can never escape the bias of our positioning (see Kapoor, 2004). My way of seeing this conversation is that resistance may present itself in instances when the speech of groups rendered 'other' unsettle such bias, making it visible, and exposing its limits.

## 9. Ethics

To finish of the examination of the opportunities of resistance, as well as of the biopolitics of intellectual disability more generally, I will turn to the highly contested and often debated issue of prenatal screening. There are two special reasons for ending this book with a chapter on this topic. First, as the practices of scanning for certain conditions are underpinned by judgements of pathology and hence can be seen as an expression of biopolitics, the subsequent examination summarises and ties together many of the themes that have been discussed throughout the book. Secondly, as resistance of prenatal diagnosis is often embedded in discourses of 'ethics', examining how present scanning practices are understood and fought against can serve as a bridge into a concluding discussion on the overarching ethos of my own research project and on the opportunity to mobilise an ethics of resistance.

In the two previous chapters, I have argued that resistance is pertinent in situations where the inclusive and exclusive aspects of the government of intellectual disability comes into friction. Yet, the emergence of resistance is necessarily preconditioned by the prevailing mode of government. Therefore, contestations may end up strengthening the particular order that is contested, as when 'care' is mobilised to legitimate paternalism or when self-representation turns into essentialism. This general argument also holds for attempts to resist the present organization of prenatal screening. According to official narratives, individuals with disability are of equal value, different, but still human beings worthy of the same respect as anyone else. At the same time, some conditions associated with intellectual disability are systematically discarded by means of more and more sophisticated prenatal scanning techniques. Hence, the inclusive ambitions seem to clash with the realities of which kinds of children are desired. Accordingly, there are numerous attempts, by disability organizations and disability scholars, to critically assess and sometimes question, prenatal diagnosis. I will argue that these are hampered by how the practice of screening is depicted and understood as an 'ethical', rather than a 'political', question. This has the troubling consequence that the political rationales of prenatal diagnosis are

obscured in favour of moralisation and individualisation. In this way, prenatal diagnosis is deceitfully de-politicised because moral arguments take precedence over analyses of power. Against the 'ethical' framing, and in order to re-politicise the issue, I will argue that we need to acknowledge how practices of prenatal screening can be understood as a technology of government. Thus, in a sense, my analysis of power will be the instance of resistance focused on here. To end the chapter, I will explore the opportunity to re-politicise ethics, as such, urging us to rethink the fundamentals of the government of intellectual disability in light of critique as an ethical stance towards oneself and others.

### **Ethics as 'Resistance without Politics'**

Some five years ago I stumbled upon a person diagnosed with Down's syndrome, wearing a t-shirt that said 'Jag är utrotningshotad' (*eng*: 'I am under threat of extinction'). The message, of course, referred to the increased use of prenatal testing, which has resulted in growing numbers of pregnancies being terminated due to conditions associated with intellectual disability. The message struck me as peculiar; it operates by inserting 'Down's syndrome', the phenomenon, into a discourse associated with endangered animals, however, underhandedly proposing precisely that people with Down's syndrome are *not* animals, even though they are perhaps treated as such, as if the subtext read 'you are endangering my kind as if I were an animal, but you won't notice or admit it'. Hence, the t-shirt text highlighted the conflict that exists between policy promises of equal value and the actual practices of erasure. In my gut, that t-shirt made me realise that the issue at stake here is that sometimes, only certain lives are considered worth living. In this sense, prenatal diagnosis actualises Butler's (1993: xiii) fundamental question concerning which human beings are allowed to become subjects in the first place, worthy of grievance and worthy of protection (see Samuels, 2002:60).

As prenatal screening has become obstetrical practice in many countries, questions have been raised concerning how this will affect views on people living with disabilities and what the world will lose when certain syndromes risk disappearing. These discussions are now taking place in light of new non-invasive tests being introduced into the growing market of pregnancy management, tests which only require small samples of maternal blood to provide allegedly conclusive results. These are cheap, safe, and easy to use, which means that it is likely that they will further reduce the number of births

of people with Down's syndrome and other conditions associated with intellectual disability (Kaposy, 2013:299)<sup>33</sup>. As with the introduction of other screening techniques, the new tests have caused debate and worries within the disability movement, but, as I will argue, it appears that screening practices are hard to fight. Disability organizations have primarily sought to point out the fact that people born with Down's syndrome today can live rich and meaningful lives, without really calling for such tests to be abandoned or for the state to prevent their use. As I will argue, this is typical and a consequence of how prenatal screening is discursively framed as an issue of 'ethics'.

Essentially, the argument I will present is the result of a theoretical engagement with debates over prenatal diagnosis, specifically focusing on how the issue is framed. In addition, I have also conducted interviews with individuals that are, or have been, engaged as representatives of disability organizations in the public debates about prenatal screening, for Svenska Downföreningen and FUB. In the context of this chapter, however, they are not speaking for these organizations, but are expressing their individual views on prenatal diagnosis.

### *Practices of screening*

Modern scanning technologies equip us with the ability to, more or less, eliminate a number of syndromes associated with intellectual disability. While working on this book, I have met quite a few people who are seriously concerned that this will happen in many countries within the foreseeable future<sup>34</sup>. The procedures surrounding prenatal diagnosis differ considerably between and within states (see Buckley & Buckley, 2008:79; EUROCAT, 2010): some recommend screening all pregnant women, combining it with more or less explicit incentives and recommendations that affected pregnancies should be terminated, whilst other countries set an age for when testing is offered, most often at a maternal age of 35. What more or less all programs of prenatal testing have in common, which will be key to my analysis, is that the coercive force of the state is absent: health care and maternal care provide information, sometimes strong recommendations, but parents decide (see EUROCAT, 2010).

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<sup>33</sup> In Swedish media, the new test was quickly labelled 'the Downs test', reflecting the fact that Down's syndrome is the diagnosis which dominates discussions on prenatal testing, although other syndromes are screened for, as well.

<sup>34</sup> For a glimpse at how the general sentiment goes and is reflected in the public debate, see the New York Post article 'The End of Down Syndrome' (<http://nypost.com/2011/11/13/>)

Prenatal diagnosis starts with an initial screening that provides a probability calculation measuring the likelihood of a set of medically defined conditions (Vanstone & Kinsella, 2010:453). The purpose of the initial screening is to estimate whether it is necessary to go through with invasive and conclusive testing, which presents further risks for the foetus. This means that there is a cut-off point (usually at the point where the probability of having an affected baby exceeds the risk of hurting the foetus by testing) for when it is recommended that one follows through with amniocentesis (Buckley & Buckley, 2008:79). In turn, programs of prenatal testing must balance the detection rate with the risks associated with invasive testing. The significance of the new non-invasive blood tests is that they take this balancing of 'risks' and 'benefits' out of the equation; there will be no need to refrain from testing out of concerns for the safety of the foetus.

There are different reports on the effects of prenatal diagnosis on the overall number of people with syndromes screened for. On the one hand, increasing maternity age of parents in many countries means that the effect of prenatal diagnosis is hampered since the likelihood of having children with Down's syndrome increases with maternal age (see Buckley & Buckley, 2008:79). What can be said with certainty is that prenatal diagnosis significantly diminishes the relative number of births of children with syndromes associated with intellectual disability; in most contexts, termination rates of affected pregnancies range from 65-90% (see Mansfield et al, 1999; Buckley & Buckley, 2008; Kaposy, 2013). Hence, this appears to be a highly efficient means of decreasing the number of certain kinds of human beings from entering the world.

#### *'Ethicisation'*

A very striking feature of how testing practices are publicly discussed and academically analysed is the focus on moral imperatives. Hence, there are on-going debates concerning whether prenatal testing and the termination of some pregnancies can be justified, on what grounds, and given what premises. It is also within this discourse that we find many of the objections to contemporary testing, in which disability scholars, along with representatives of the disability movement, question the justifications of today's practices (Amundson & Tresky, 2007; Kaposy, 2013). This debate has gained some popular recognition, as utilitarian philosophers such as Peter Singer (1993) and Jeff McMahan (1996) (in)famously argue for the termination of pregnancies that will result in disabled lives, and where Singer even argues that killing disabled infants can be justified. Naturally, this has

caused a moral philosophical trench-war with representatives and advocates of the disability movement. The arguments proposed by disability advocates are often geared to appeal to our moral sentiments, where principles of rights to exist, to equal human dignity, and the like, are proposed as presenting a case for the preservation of human diversity (see Parens & Asch, 2003; Kaposy, 2013). This can be read as a neat illustration of how resistance is discursively pre-structured: with the ‘ethicisation’ of prenatal testing follows an ‘ethicised’ resistance and thereby a framework of ethics comes to compose the main battlefield over prenatal diagnosis. An exemplary case can be seen in Shakespeare (2006:85-102): whereas this is essentially a book about disability and social theory, the issue of prenatal diagnosis is solely discussed in terms of moral justification and moral philosophy, without ever coming close to an analysis of power. As I will argue, the possibility that there are other issues, outside the scope of ‘what can be justified’ which may be of equal or even greater importance than moral justifications of terminating certain pregnancies, has been lost along the way. Admittedly, issues of power are occasionally pointed out by disability scholars and advocates (see Parens & Asch, 2012 for an overview), but they are rarely developed in a proper analysis of government. Later on in this chapter, that is what I will set out to do.

There are two sides to the ethical framing. On the one hand, as discussed above, it leads to philosophical arguments concerning which decisions are possible to justify (see Singer, 1993; Heyd, 1995; Shakespeare, 2006; Amundson & Tresky, 2007; Kaposy, 2013). On the other hand, it also seems to suggest that prenatal diagnosis pertains to individual decisions that politics has no business interfering in (see García et al, 2008). At least in Europe, critical voices of disability organizations have most often refused to side with the anti-abortion movement, to their credit, staunchly refraining from moralising on individual choices. But as the ethical questions regarding prenatal diagnosis are interpreted as primarily concerning expecting individuals, there is no obvious arena to be politicised. By extension, many disability organizations mobilise to provide pregnant people with better and more nuanced information to base their judgement on – a mode of resistance that, at the same time, reifies the individualised framing of the issue. As such, issues pertaining to power, to discursive constructions of the diagnoses targeted, and to societal and cultural attitudes, rarely enter public discussion on prenatal diagnosis. The frequent returns to the personal and individual nature of these choices in the literature on prenatal testing reinforces the impression that the aggregate effects of screening are regarded as beside the

point (Acharya, 2001:30; García et al, 2008; Addington & Rapoport, 2011:513; Skirton et al, 2014).

The ethical framework has been further strengthened by the rise of bioethics as an academic field of research. The underlying narrative of this discipline is that technological and scientific advances provide us with new moral problems (Vailly, 2008:2541). Intuitively, this perspective may seem appealing: first, it is a call for caution against the un-reflected use of scientific innovations and, secondly, it urges us to consider these innovations in light of moral questions which had previously been rarely considered in debates about policy and science. However, as Amundson and Tresky (2007:541-542) note, what becomes an issue of bioethics in the first place is far from evident. The bioethical debates about ‘disability’ are primarily preoccupied with questions about the conditions that make it morally permissible to end or prevent disabled lives (see Wolbring, 2003). This should make us suspicious. Why ask these questions? What circumstances must be in place for such questions to be asked? What questions are concurrently suspended? Not surprisingly, people with disabilities are notably absent from these discussions (see Wolbring, 2003:175). To understand what this way of discussing prenatal diagnosis entails, it is necessary to examine what it excludes.

#### *‘Ethics’ as an effect of politics*

So, the question of practical ethics in the context of prenatal diagnosis is ‘what can be justified?’ The question of politics, to the contrary, is ‘how does power operate?’ It follows that when an issue is framed as ‘ethical’, our focus is detracted from asking questions concerning how our views are shaped, by what actors, and to what means, in favour of questions regarding what views can be justified, by what arguments, and to what, assumingly universal, moral end (see Brown, 2008:109-10). This means that many of the theoretical tools we associate with political action and activism are rendered out of bounds; the ethical framing of prenatal diagnosis means that we rarely see objections on the grounds of analyses of distribution of power. In order to productively engage with and resist the present order of things, it is necessary to instead consider what is happening when biopolitics is made into a question of ethics in the first place, that is, to study ‘the ethical question’ as a political effect rather than as an ethical problem to be solved.

First, as hinted at already, the discourse of ethics has the effect of *individualising* prenatal diagnosis. How should parents act? How should the state provide parents with information to act on? Do individuals who have

suffered from a 'wrongful birth' have a legitimate claim to compensation? Do their parents? (see Pritchard, 2005) Provided this way of asking questions, bioethicists are made authorities on dilemmas facing individual parents, providing them with grounds for justification, but never shedding light on the underlying power relations between disabled and non-disabled people. Underpinning the ethicisation of prenatal testing is the view that it presents parents with a 'moral or existential dilemma', as Kelly (2009:82) formulates it, or that it constitutes a 'very personal decision', as Addington and Rapoport (2011:513) have it. These formulations are indicative of how the macro-politics of technological and scientific advances are transformed into individual quandaries. When we ask 'the ethical question' in this way, we mask the political stakes of knowledge and technology, instead pushing individuals to solve conflicts of power through personal ethical investiture.

A second limitation coming out of this discourse concerns how the ethical framework obscures our understanding of government by depicting the relationship between the state and morals as a matter of choosing sound principles. Thus, as long as the state acts by justifiable doctrines, and as long as prenatal diagnosis is coupled with balanced information and the informed consent of parents, as many bioethicists would have it, we can be assured that everything is working out fine (see Acharya, 2011:30; Skirton et al, 2014). The idea of moral universalism is that certain principles transcend the messy world of politics, although this messy world should ideally be guided by universal principles. This presumption means that the complexity of government is not sufficiently handled and that power, culture, and discourse are implicitly seen as hindrances to detecting such universal principles. In the context of bioethics, power relations, discourses, and subject-formation are all discarded when ethical guidance for testing procedures are being derived. As a result, the ways that parents are understood to make choices ends up being a complete fiction, since the depiction of the decision-making process ignores the ways that subjects are *always* entangled in relationships of power and acting in context.

Thus, resistance that takes this framing for granted will consequently continue to obscure the way that power is exercised. What we get can be characterised as 'resistance without politics'; a kind of oscillation between seeking to convince would-be parents that they should not terminate pregnancies by providing them with more positive images of intellectual disability on the one hand, and moral arguments about the ethics of selective abortion (for an overview, see Parens & Asch, 2012) on the other. There is a

need to approach this issue differently<sup>35</sup>. Much more important than asking what parents ought to do, or insisting that state regulations should provide parents with accurate information, is to ask *how* prenatal testing governs. Analysis which begins with this question may not be able to help us answer how we, as individuals, should approach testing or how we should act if tests are positive, but it may provide us with an understanding of prenatal testing as a system of power. Before returning to how such an analysis might look, I will turn to discussing how people involved in the disability movement see the issue and how their efforts to resist are both restricted by and point beyond the ethicisation of prenatal testing.

## Stories of Resistance

The stories of resistance I will focus on here are derived from interviews with two individuals: the spokesperson on prenatal testing at FUB, which is the leading Swedish advocacy organization for people with intellectual disabilities, and the former spokesperson on prenatal diagnosis for Svenska Downföreningen, which is the primary Swedish organization that focuses specifically on Down's syndrome. As stated earlier, the views that they express here should not be seen as representing their respective organizations.

To start with, both interviewees feel that there is a need to specify what it is they oppose:

At the heart of the matter, this is about what kind of society we want to live in. And within this society, the individual. We have legislations about these matters and there are parents that need a more nuanced picture in order to reach a decision. With all due respect for whatever decision they come up with. We have been very clear that this is not about anti-abortion. We have been approached by Respekt för livet [the primary Swedish anti-abortion organization] who wanted to cooperate. But we are not a religious organization. We defend free abortion, it is the legislation we have in Sweden and there is no contestation on our part, although there may be individual members who think differently. (Marita Wengelin)

Although, the wordings differ between the interviews, the sentiment is the same: this is definitely not an issue about restricting the right to abortion, nor

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<sup>35</sup> A clarification: as Taylor (2013) has pointed out, moral philosophy dealing with disability may be important in some contexts, for example in defending welfare entitlements under threat or to argue the case for equal access to society. My arguments here are criticising this way of arguing as concerns prenatal diagnosis, specifically, not in general.

is it about removing all opportunities for prenatal diagnosis. Rather, the interviewees want to focus on how the prenatal testing is carried out and what the outcome says about how we, as a society, value certain kinds of differences. In fact, I have never come across any publication or statement by a Swedish disability organization that blames parents if they abort pregnancies. The target of criticism is instead continually described in abstract and vague terms, for example as an issue of societal values and information provided to parents. It seems clear that the abstract and diffuse nature of what is opposed presents these organizations with difficulties as concerns what to do and what prospects there are for changing things:

Of course it's good that the technologies of prenatal testing are developed. But the ethical dimension also becomes more and more difficult. [...] So we raise the ethical questions, we debate and have discussions, but I think that it all comes out rather lame. I mean, sure, it is really good on the macro-level, that there are discussions and, therefore, maybe more people start to think for themselves "ok, who am I and where are my core values in all of this? Would I be ok with giving birth to a kid with Down's syndrome?" But there is nobody, whether in politics or health care, who says "stop, what we are doing is not ok". I don't know what is actually ok and not, what can be justified, what deviances we should try to pinpoint. But if it is Down's syndrome and intellectual disability, then we have to say "these are the people we wish to detect because they cost an awful lot of money". (Marita Wengelin)

Since blaming pregnant people or moralising over their choices are not described as viable ways to resist, the only choice left is to continue to bring up the ethical perspectives, to nurture debate, inform the public, and hence try to affect what parents do with their freedom of choice. As was pointed out above, it is quite common for disability organizations to produce material that aims to give a more nuanced idea of what Down's syndrome means, attempting to convince parents to see the condition in less 'ableist' terms (see Global Down Syndrome Foundation, 2012; National Down Syndrome Society, 2015). However, I have failed to find any material that challenges the basic architecture of the system, its underlying rationales, or that seeks to formulate a strategy that addresses this as an issue of government. In the quote above, Marita discusses and exemplifies how pregnant people may reason, thus presuming their agency as the relevant arena where prenatal testing operates. At the same time, it is significant that she, at the end of the quote, asks for a rationale to be spelled out – for someone to say that 'these people cost too much money' – although she clearly disagrees with that.

Similar calls for power to be revealed are expressed by Judith (as will be seen in an upcoming quote).

Both Judith and Marita believe that the development is heading the wrong direction. Judith formulates it this way:

I feel very pessimistic in regards to the increasing use of prenatal testing. Thank God my daughter is 18 so there is still a sizeable group of people of all ages living with Down's syndrome. This is of course an aspect that enters into the picture when parents consider testing. Even if you personally would prefer not to pursue prenatal testing, what if your child could theoretically be the only one born with Down's syndrome during a particular year? That would be very tough. This line of reasoning definitely plays in I would think. Also, the easier testing gets, there is a risk that less time is given for reflection. So yes, I am very pessimistic. I think there is a risk that we will see dramatic changes in the number of babies born with Down's syndrome.

When asked what could be done about this development, it is striking that the interviewees grapple with how a strategy on prenatal diagnosis can be formed. This is also reflected in statements and written material on the issue of the disability movement, where suggestions rarely move beyond 'providing better material' for would-be parents and 'informing the public' (see Jansson & Hård af Segerstad-Lindhoff, 2014; National Down Syndrome Society, 2015:7). In both interviews, a very tangible threat of extermination is explicitly referred to, however, the forces constituting this threat are not easily pinned down. Thus, resistance is described as both difficult and necessary. Hence, it appears as though these organizations are fighting for the issue to be considered 'political' in the first place. This is why they want responsible actors to state the purposes of screening, as I interpret their answers. In order to resist, we need an analysis that is able to politicise prenatal testing, a language in which demands for change can be parsed, and a framework for understanding the forces that threaten the existence of certain ways of being.

In the interviews, some instances which offer ways out of the present predicament are indicated. For example, Judith argues:

I would have wanted a discussion about why regional municipalities choose to prioritize financing of testing with the intention of detecting Down's syndrome. These tests costs millions [Swedish crowns] per year simply to find a few hundred fetuses. Is this the best use of so much public funding? We see that widespread prenatal testing for specific diagnoses can produce stigma. One doesn't test for 'positive' things, one test for things that are considered 'negative' – something that you want to avoid. So, when you think

about it, regional municipalities are taking a forceful stance in terms of how public funds should be used.

In this quote, we leave the narrow confines of individual choice making, however, without resorting to abstract notions concerning ‘what society we want to live in’, or similar. Instead, Judith directs our attention towards how prenatal testing is upheld by social structures and is underpinned by certain ideas and rationalities. It is also notable that Judith addresses a political agent that can be held responsible. Throughout the interviews, a multitude of related actors are brought up as relevant. For example, Judith talks about regional government, Marita mentions media discourse as well as the medical profession, whilst the activists of Grunden stress the importance of more general culturally held views about intellectual disability. My impression is that we are facing a situation in which it is really hard to tell who we should be fighting against as to the extent we do not want to target pregnant people who elect to have abortions. On the other hand, this may also point towards a mode of resistance which focuses not on specific actors, but on how the underlying ideology of prenatal diagnosis can be countered.

There are some important clues in the interviews which concern how such an ideology can be seen. For example, Marita oftentimes brings up the relationship between ‘health’ and ‘pathology’:

I have met a lot of geneticists and such people and my impression is that there are some medical professionals that want to get our viewpoint, but that it quickly becomes very clinical, a medical perspective, on everything. In health care, they want to cure what is sick, deviating or impaired, and to promote health. We see this all the time concerning disability. But I would say that what we really need to discuss is what we consider ‘healthy’ and ‘sick’ in the first place. What do we consider to be required for a good life? Since amniocentesis began, very mature pregnancies have been aborted, sometimes it could have been a child born one week later and it would have survived.

What is identified here is the basic biopolitical rationale which separates ‘sick’ from ‘healthy’, that I discussed in the first part of the book. Although recognising this division does not answer the question of exactly how resistance should be carried out, it directs attention to how an often unacknowledged presumption affects the substance of debates on prenatal screening. Indeed, it shows that the ‘ethical question’ is loaded with normative considerations at the outset, since it takes for granted the distinction between ‘normal’ and ‘pathological’. Here, Marita’s observation is akin to how Newell (2006:277 in Goodley, 2014) argues that prenatal

testing can never be value neutral, but is instead always framed by a society that favours non-disabled lives over disabled. In a similar way, Judith oftentimes analyses the explicit justifications of prenatal testing as unrelated to what actually drives the system. For example, she notes that the explicit goals of prenatal testing – of identifying chromosomal aberrations and providing information to prospective parents – are evaluated by counting the number of aborted pregnancies. Clearly, these do not add up; either the evaluative quality criteria takes for granted that unbiased information will lead to termination or the quality criteria and the explicit goal are totally unrelated, indicating that the actual rationality is the prevention of intellectual disability. What Judith points to here is that prevention, for economic or other reasons, constitutes a much more reasonable way of understanding the rationality of screening than the explicit goal of providing pregnant individuals with good information. During these instances in the interviews, we see the contours of an analysis of power rather than the struggles over ethical principles; an emerging politicisation of prenatal diagnosis that refocuses our attention away from the prevailing discourse.

### **Politicising Prenatal Diagnosis**

Elaborating on how Marita and Judith seek to politicise prenatal diagnosis, I will now try to develop an understanding of screening as a system of government. It is my contention that this is necessary in order to open up new spaces of resistance.

In her discussion of ‘the moralization of politics’, Brown (2008:199-200) discusses how the force of history is seen at once as heading in the wrong direction and as unstoppable. The effect is that history will be moralised *over*, rather than seen as a process that can be influenced. Certain actors will be singled out and blamed, as manifestations of all that is wrong but unalterable. The situation that Brown depicts on a theoretical level bears important similarities with some aspects of narratives on prenatal diagnosis – as concerns the force of history which appears to be unstoppable, devoid of visible driving forces, and heading in a direction that hence becomes all too easy to moralise over rather than change. As seen above, however, the interviews indicate a politicisation beyond this predicament: by asking questions concerning the governmental rationalities of screening for certain syndromes, history can instead be seen as the continual unfolding of politics.

To start with, and as Marita pointed out, prenatal screening is organised around the fundamental division between norm and pathology. As Vailly (2008:2532) notes, even from their outset, the labels of 'normal' and 'abnormal' have consisted of more than factual circumstances, as they were bound up in attributions of value. This is what Canguilhem (1991:239) alluded to when declaring that the 'norm' is used to 'square and straighten'. As such, the idea of 'normality' establishes a bridge between description and evaluation: 'normalcy' is ostensibly used to describe, but also to judge and formulate principles (Hacking, 2007). When viewed in this light, the phrase 'everything looks normal', uttered by the midwife nurse, carries important meaning beyond its immediate effect of reassurance. Not only does this describe the foetus, but it evaluates it against the prior normativity that justified the testing procedure in the first place.

The division between 'normalcy' and 'pathology' also underpinned eugenics. Etymologically, 'eugenics' comes from the Greek for 'good birth' (Gupta, 2007:217), showcasing the idea that 'good births' can be distinguished from 'bad' ones. 20<sup>th</sup> century policies of eugenics served the purpose of calibrating the population by preventing some people – often poor individuals labelled as 'idiots' or 'imbecilles' – from breeding, whilst encouraging others to reproduce (Gupta, 2007:217). Underpinning these practices were considerations on the quality of the population and the presumption that undesirable groups tended to produce more children (see Pritchard, 2005:82). This was a centralised system of biopolitics which consisted of the active management of human reproduction in order to rid the population of 'defects'. While we easily uncover the operations of power in measures such as forced sterilisation, the governmental dimension of prenatal screening often goes undetected. I believe that this is because of the liberal-humanist presumption that individual freedom and power are opposites. Thus, we are not very well prepared to analyse a system which emphasises and enhances individual decision-making, in this case of pregnant people, as a system of power. But precisely that, I argue, is what is needed if we are to re-politicise the present system of detecting and erasing intellectual disability.

The central component of how prenatal screening operates as a mode of government is captured by the notion of 'reproductive autonomy', denoting the right of expecting parents to access the best possible information concerning their pregnancy. According to this logic, autonomy increases when people understand the genetic conditions of their future children because it helps them to make a more informed decision concerning whether to go through with the pregnancy. Thus, what distinguishes contemporary

prenatal screening as a modulation of population management, and what marks its success, is precisely the technology to shape and target the freedom of choice for pregnant individuals. In this way, it is possible to govern without interfering: governmental authorities can manage by shaping fields of action instead of enforcing certain routes of action. This is to say that 'reproductive autonomy' is exercised in contexts that are ideologically and normatively loaded: some choices will appear to be more reasonable and responsible whilst other alternatives will be deemed unfavourable. The efficiency of prenatal diagnosis lies in the fact that it does not intervene in decision-making, but that the context is moulded so that termination will often be seen as the preferred option. Obviously, this is not to say that this is the outcome of design, of a malevolent ruler who plans how individual choices should be made. Rather, this is the result of numerous different forces, discourses, and incentives surrounding the individual; it is an underlying logic of a society that favours a specific understanding of cognitive ability and that views intelligence as a defining characteristic of human beings.

Accordingly, throughout the processes of prenatal testing, the act of individual choice is frequently emphasised: concerning whether one should undergo screening in the first place, whether one should go through invasive testing if the screening shows an increased likelihood of a syndrome; and whether the pregnancy should be terminated if the amniocentesis is positive (see Pritchard, 2005:85; Gupta, 2007:225; Buckley & Buckley, 2008:79; García et al, 2008). All the way through, the freedom of parents to decide is absolutely central, as described by disability scholars, in state policies, and in the material of disability organizations. This focus contributes to obscure the forces behind why fewer people with syndromes associated with intellectual disability are born. The causal chain is displaced as the emphasis on 'choice' make it appear to be the aggregate result of how pregnant individuals decide rather than the outcome of a system that enables and contextualises these choices. In turn, once we recognise this, we must also recognise how parents are encouraged to see themselves in these situations. Here, previous empirical research provides some important clues. Consider, for example, how Kelly (2009:82) argues that screening and testing have become associated with responsible and mature maternal behaviour and how 'responsible parenthood' is linked to ensuring the production of a 'healthy' baby. In this way, reproductive testing technologies appear in a much broader socio-cultural field of 'personal responsibility' for one's pregnancy (Kelly, 2009:93). Along these lines, García et al (2008:757) has shown that parents often believe they

have the ‘right to choose’ whether the characteristics of their would-be child fit their individual life-styles. Parenthood turns into a ‘personal project’ and pregnant people are compelled to see their own life situations and needs as the reasonable starting points for deliberations surrounding prenatal diagnosis (see García et al, 2008). Furthermore, this relates to how screening practices are discursively linked to managing the ‘security’ of reproduction, checking in on whether everything is running its ‘normal’ course, and described as a way of having control over the pregnancy (Kelly, 2009:93; Vanstone & Kinsella, 2010:460). All of these are aspects of the ‘field of action’ in which the freedom to choose is targeted and exercised.

Seeing prenatal diagnosis from the perspective I have illustrated here is a way to re-politicise it by understanding it as a system of government. Implicit in many arguments in favour of prenatal diagnosis is the attempt to drive a wedge between state coerced eugenics and individual choice, arguing that we have moved from a system of power to a system which empowers parents (see Gillon, 1998 in Pritchard, 2005:84). On the contrary, along with Foucault (2007), I argue that the primary difference between then and now is that two distinct technologies of government are made use of, but to similar ends. Power has transformed to target the freedom of pregnant people, rather than use its coercive force to sterilize. As Gupta (2007:225-6) points out, blatant eugenic policies may not be needed as parents act and comply with eugenic rationales voluntarily. Now, an analysis along these lines can help us redirect our attention away from individual choices, away from assumed, universal ethical principles, and towards the distribution of power of systems that make intellectual disability a question of which lives are deemed to be worth living.

### **Ethics, Critique, and Resistance**

‘Ethics’, as it has been presented in this chapter, may seem like a consolidating, even conservative, concept, operating to preserve a certain order by excluding certain kinds of criticism. Of course, the way of understanding ‘ethics’ that I have criticised here is not the only possible one, but rather a specific discourse that is an effect of the particular modulation of government that surrounds prenatal screening. Just like ‘representation’ and ‘care’, ‘ethics’ may lead to forms of resistance that consolidate the biopolitical regime or that upset it. Indeed, I believe that the politicisation that I have attempted to formulate in this chapter – and throughout this book

– itself carries a specific ethos. It is therefore appropriate to end this chapter with an extended discussion on how we can rethink ethics in light of the above.

Brown (2008:109-10) has pointed out that in much political thinking, there is a preconceived opposition between ‘right’/‘truth’ and ‘power’. These are understood as different domains which deal with different things, and their preconceived separation explains why the opposition between the political world of power and the ethical world of righteousness recurs throughout the history of philosophy. Brown (2008:110) argues that the moralisation of politics means that political questions become abstracted from the contexts in which they emerge, seeming to call for answers that are derived from universal principles rather than political mobilisation. Now, one of the great achievements of the post-structural philosophers which I have relied on throughout this book (and which are all, in this sense, successors of Nietzsche) is that they help us approach the relationship between politics and ethics differently, seeing that power guarantees and produces moral truth (see Simons, 1995:44). Precisely such an understanding is what has enabled me to analyse ‘ethicisation’ as integral to the technology of government that is prenatal diagnosis, operating to curb the scope of criticism. However, this way of attending to the relationship between truth and power has its own set of ethical implications and I argue that examining these can help us reconsider the ethical dimension of prenatal diagnosis.

I want to start here from Foucault’s ethos of permanent critique, which stems from his recognition that ‘everything is dangerous’ (Foucault, 1984:341). This statement can be linked to the empirical fact that social forces once activated to emancipate easily slip into becoming tools of repression (see Simons, 1995:86). It also relates to his epistemological commitments: if there is no vantage point from where the universal good can be accessed, if moral ‘truth’ is always contingent on *something*, then there is no transcendental point from which our actions can be judged as right or wrong. When Nietzsche (2001 [1882]:120) declared the death of God, this was what he alluded to: a human being left without a universal moral script to follow. The implication for Foucault is that we must attend to critical analysis of whatever functions as our moral guidance, examining its origins, operations, and underlying rationales. In doing this, ‘moral truth’ can never substitute political struggle, as Brown (2008:106) formulates it, and this is so since moral truth itself is an outcome of power; the reasons why certain choices appear to be justifiable and others do not is that we are always situated in a

certain place, at a certain time, and in a certain position. 'Right' and 'wrong' are socially constituted; the struggle over truth is a struggle over power.

Butler (2005:110) formulates the ambition of theorising subjectivity as inherently political to be an act of seeking to dislodge the "I" from being the *grounds* of ethics and politics to being the *problem* of ethics and politics. In contrast to how the 'ethicisation' of prenatal diagnosis relies on an autonomous subject that freely chooses how to act, Butler (2005) argues for an ethos of critical reflection: acknowledging that our identities are always emerging provided a social context does not imply that ethics is impossible, but that one ought to relate to one's becoming in an active fashion and that we ought to consider how this social context structures how we relate to others. To use the language of Foucault, regimes of truth, of what is possible and not possible to think and do, offers the terms that make attempts for (partial and incomplete) self-recognition possible, they existed before we emerged and will outlive us. Such regimes of truth affect what will be perceived as a recognisable way of inhabiting the world (Butler, 2005:22). We are not determined, but the regimes of truth become the point of reference for any decisions we subsequently make. It is in relationship to such discursive frames that recognition, of others and oneself, takes place. It follows that calling into question a regime of truth means calling into question the truth about oneself (Butler, 2005:23), and indeed also questioning one's ability to tell the truth about oneself; it effectively means questioning one's own ontological status. Hence, viewed in this way, although we cannot author our lives, we can reflect on the social structures on which our becoming is contingent, we can recognise them, and we can resist them. The ethical question of prenatal diagnosis thus transforms from one which pertains to whether the actions of expecting parents are justifiable, to a call to understand *why* one thinks of this issue as one does; *why* one sees the prospect of disabled children in a certain way, and how the very practice of prenatal diagnosis itself reinforces the continual inscription of the division between 'normalcy' and 'deviancy'. It requires us to understand how we are made in relation to the distinction between 'able' and 'disabled'. In this way, recognising the social constitution of subjectivity does not erase the possibility of ethical accountability, but provides us with an ethical imperative to understand and navigate the social and discursive conditions of our emergence. Being ethical, given this perspective, forces us to consider politics by means of critique (see Butler, 2005:124).

Our social constitution not only has implications for how we relate to ourselves, but also for how we relate to each other. Starting from a reading of

Levinas, and expanding on Hegel's notion of recognition, Butler (2005:10) denotes 'the scene of address' the (abstract and fictive) place where subjects come into existence by being recognised as belonging, qualified, and recognisable through how they relate to a set of already established norms. According to Butler (see 1997:25-31; 2004:138-9), 'the scene of address' is a place of judgement as concerns whether other humans conform to such norms, and hence also a place of erasure, as not all will qualify. Thus, Butler here discusses how we recognise each other based on existing categorisations and norms. Accordingly, divisions along the lines of gender, race, and functioning will shape how we are perceived and how we understand ourselves and our fellow human beings. At the same time, any such act of recognition will concurrently cut off alternative ways of being (Butler, 1997:41); as I am recognised as a 'normal man' (which often seems to be the case), my opportunity to come into being in other ways is effectively precluded. Our ethical responsibility for each other – in addition to our responsibility to scrutinise the norms that condition our emergence as subjects – is to suspend judgement at the scene of address in order to maintain the openness of the subjectivity of the other (Butler, 2005:44; see Taylor, 2013). Hence, ethics for Butler (2005:44) requires approaching oneself and the other through cessation of the routine procedure in order to avoid the normative violence of calling the other into being, requiring them to exist in a predetermined way. Such a notion of critical ethics, in the context of this chapter, consists in refusing to take for granted the received wisdom of the separation between 'normalcy' and 'intellectual disability' and to neglect searching for the moral 'truth' about prenatal diagnosis as it is organized along the lines of this division. Indeed, it requires us to stop using 'intellectual disability' as a judgement when confronting the possibility of a life labelled as such entering the world.

Given these arguments, prenatal diagnosis is not an ethical question because it requires us to make sound choices grounded in universal and defensible principles, but rather because it forces us to reflect on the production and positioning of subjectivity. Perhaps it should not be necessary to say this, but I should anyway clearly state that I am not the least interested in condemning whatever choice pregnant people make as concerns prenatal diagnosis. However, I do believe that we all have a responsibility – an ethical one at that – to not shy away from asking ourselves some hard questions concerning why we perceive the prospect of a disabled child as we do and to recognise that our choice will be embedded in a culture and society that devalues disabled lives and privileges abilities of human reason. Re-

politicising the ethics of prenatal diagnosis as a strategy of resistance means precisely that: to turn our critical abilities towards how the situation of choice is pre-structured and try to figure out how it could be structured in other ways.

As a more general conclusion to these final three chapters, the notions of ‘care’, ‘representation’, and ‘ethics’, and the way that they emerge to contest the government of intellectual disability, all surface in spaces of openness emerging due to the fact that the government of intellectual disability at the same time both includes and excludes. Viewed in this way, the questions of resistance that I have discussed herein are bound up with *re*-politicisation of intellectual disability, pointing towards a politics that does not take norm/deviancy or inclusion/exclusion for granted. Brown (2008:37) argues that the tension between the particularity of individuals and a collective ‘we’ – inherent to liberal notions of society, ethics, and citizenship – can only remain as long as the conditions of emergence of subjects remain de-politicised. Thus, we can continue to see the coercive state as the primary vehicle of power only to the extent that we ignore that the ‘free’ subject is also an effect of power. I believe this speaks to why I have found this whole project to be important: in the end, this book can be read as an attempt to politicise the emergence of subjects constituted along the lines of divisions between ‘reason’ and ‘lack of reason’, that is, between ‘intellectual disability’ and ‘normal’ cognitive functioning.

# *Conclusions*

# Critique and the Future

On the first page of the conclusions, it is as if the researcher is left with an unspoken obligation to declare the state of things and how they should be fixed. I will try to refrain from acting on such a sense of duty for reasons discussed already: the researcher always risks transforming themselves into a spokesperson for people thus prevented from speaking for themselves. The ideas that I want to develop a bit further in these final pages concern the opportunities for criticism which serve as a way to create spaces from which people with intellectual disabilities can speak. This means that the discussions taking place in these final few pages will not present the main conclusions or a summary of the book (the compulsory summary will come after this section, however). Instead, I will elaborate on three things: first, how the characteristics of post-institutionalisation require new modes of critique and how the act of demanding that impossible promises are kept can serve as a strategy. Secondly, I will elaborate on the implications of the notion of ‘double vulnerability’. Lastly, I will entertain the idea that joint criticism, across divisions between ‘normal’ and ‘deviant’, can enact a vision of equality beyond this very separation.

But first, a short recap of the three parts and how the research questions have been answered. The overarching argument of the first part is that the condition ‘intellectual disability’ can be seen as the outcome of biopolitics, in which the division between ‘normalcy’ and ‘deviance’ with respect to the humanist subject, is instituted in this condition. Classification and clinical knowledge of intellectual disability is knowledge which makes governing possible, whilst, at the same time naturalising intellectual disability so it is seen as existing prior to politics. Provided this analysis, ‘intellectual disability’ can be understood as a diverse assortment of individuals who are rendered a homogenous group by means of scientific knowledge and governmental technologies. In other words: understandings of intellectual disability as a biophysical phenomenon rests on an untenable separation between biology and society. As such, the constitution of ‘intellectual

disability' as a diagnosis means that people of this group can be pinpointed by government programs which historically have served for their exclusion.

The arguments of the second part focus on how people with intellectual disabilities are targeted by policies that aim to include the group. Contemporary biopolitics has increasingly come to adhere to modes of government which rely on 'citizenship' and 'inclusion'. When these ideals are projected onto the intellectually disabled subject – a subject interpreted as deficient and lacking, by nature – politics is faced with the dual task of including to make similar whilst upholding the otherness of the group in question, in order to protect the humanist subject. 'Otherness' is both what citizenship inclusion seeks to erase but necessarily will re-inscribe. Thus, I argue that post-institutionalisation is characterised by concurrent applications of technologies of inclusion and technologies of exclusion; a way of governing that both seeks to nurture the reason and autonomy of individuals, and that upholds their otherness by surveillance and restraints. The intellectually disabled subject is, thus, at the same time, both included and excluded.

In the last three chapters, I discuss how the very friction between inclusion and exclusion provides spaces for resistance. But for resistance to lead beyond the prevailing mode of government, and to alter the status of people with intellectual disabilities as the 'others' of humanist reason, contestations must depart from the ontological underpinnings that produced the exclusion of the group in the first place. My argument here is that the three instances of resistance examined, on the one hand, bear witness to the risk of re-inscription, where resistance merely turns into a confirmation of humanism by demanding access to it, and, on the other hand, to the possibility of a politics of intellectual disability beyond the divisions 'inclusion'/'exclusion' and 'normal'/'deviant'.

Thus, in the era of post-institutionalisation, intellectual disability is still socially constituted as the outside of humanist reason, now targeted by policies that seek to achieve people worthy of inclusion whilst maintaining their otherness, and this mode of politics is resisted during the instances in which inclusion and exclusion come into friction.

## **Critique Post Institutionalisation**

Throughout, 'post-institutionalisation' has served as a description of the present state of the politics of intellectual disability: an era in which

institutional care is in the process of disappearing and where inclusion by citizenship has become the overarching goal. However, as is indicated by the analogy to 'post-colonialism', individuals with intellectual disability continue to endure the consequences of otherness, at some places still institutionalised and at others entangled in the web of power of the group home; members of this group are restricted from having a say in their own lives and are, thus, far from fully participating and equal citizens. Just as 'post-colonialism' directs attention to what happens after de-colonisation, it has been my ambition to direct attention to what happens after societies have taken it upon themselves to include people with intellectual disabilities.

I should say a few more things about this. As I have made clear already, the simultaneity of inclusion and exclusion indicates that this very binary fails to appropriately capture the politics of intellectual disability. Expanding on Butler's (1993:13) discussion on Irigaray and Derrida, it can be said that the binary of inclusion/exclusion, itself, excludes the politics of post-institutionalisation, which it simultaneously produces; this way of governing intellectual disability is, to a certain extent, the result of the lack of a political language that can make it comprehensible. Its structure and efficiency depend on our inability to name it. In conjunction with this, perhaps the construction of intellectual disability has again shifted, from a definite otherness of human reason during the era of institutionalisation, to an exterior of the binary of reason/otherness in post-institutionalisation. As I have tried to make clear, people with this label are both targeted as citizens and deemed incapable of citizenship, reasonable yet unreasonable. Hence, congruent with the unnamed politics of post-institutionalisation is the unnameable condition of being neither a subject of reason nor its other. The fundamental division between inside and outside the humanist subject appears to be broken, precisely since it fails to clearly locate people with intellectual disabilities. The politics that emanate from liberal humanism and the ideal of a rational subject can no longer place this group on either side of its most fundamental divide.

Now, it is my contention that this new regime of power requires new forms of critique. Rather than calls for liberation, freedom, citizenship, and condemnation of the remnants of institutionalisation, we need to accept the fact that contemporary rule relies both on technologies of exclusion, which are systematised, and on technologies of nurturing citizens, which often go undetected. Thus, critique needs to speak a language that does not take for granted the ideals that the politics of inclusion are founded on; a language of government that allows us to recognise how power operates both by restraining and shaping freedom. This implies that we should stop forming

critical strategies around master concepts – such as ‘citizenship’, ‘independence’, and ‘inclusion’ – but rather study these very concepts as political effects and as discourses that make possible (and impossible) certain ways of thinking, doing, and being. The correspondence of inclusion and exclusion, furthermore, shows that this language, understood as designating two opposite ways of being related to community, is inadequate to capture the government of post-institutionalisation. Instead, there is a need for activism and research that seeks to undo the border between inside and outside societal belonging as such. The elaborations of double vulnerability, the activists’ mode of representing themselves, and the ethos of critique – developed in the third part of the book – are all meant to gesture towards some possible starting points for such politics.

In the introductory chapter, I argued that the government of intellectual disability is a crucial case to examine contemporary biopolitics more generally. This is based on the centrality of the idea of reason as humanity’s defining characteristic, recurring in many of the central conceptual building blocks of liberal democracies; for example in notions of ‘citizenship’, ‘right’, and ‘consent’. If our political history has been ingrained with this ideal, and if our political institutions, to some extent, are founded on it, then ‘intellectual disability’ has the capacity to enlighten our view of our present social organization more generally. After all, making and undoing promises – of equal value, of belonging, and of participation – can be seen as a wider tendency of liberal democracies. For example, perhaps the very tangible signs that people are not valued equally are not suggesting that the near universal subscription to equality of human worth is ‘yet to be fulfilled’ or ‘requires more work’; perhaps the simultaneous making and breaking of this promise is how the politics of human rights works. If that is the case, rather than pointing out hypocrisy, we need to start to ask questions which focus on the congruence of stating the importance of human equality whilst continuously treating human beings unequally. Similarly, perhaps the promise of political equality inherent to ‘democracy’, and the very tangible signs that people are far from political equals in actually existing liberal democracies, should not direct our attention to how liberal democracy can be improved, but rather to how liberal democracy is founded on making and breaking this promise.

In this way, the structure of concurrent inclusion and exclusion, of promises made and broken, may pervade politics more generally, on the one hand setting up norms for how subjects should behave whilst also intervening, restraining, or discarding us when we fail. This is not to dismiss human rights or liberal democracy as normative principles, but rather a way

of advancing a critical approach which does not take such grand concepts as self-evident starting points. It seems to me that much of critical political discourse stops with recognising the gaps that exist between ideals and practice, indicating hypocrisy. This tendency, I believe, hampers our political imagination as concerns looking for ways of living together beyond the ideals in question.

Now, I want to finish this first concluding reflection by pondering one possible strategy of how such a critique can take shape. Simon Critchley (2007) argues that (political) philosophy starts in the disappointment of a grand opportunity being lost. We are all democrats now, despite the eroded version of this grand concept that we continue to put up with. We are all advocates of universal human rights whilst the abuse lies ahead of us in plain sight whenever we read a paper. And we are relied upon to continue to ignore these sad facts. This introduces a certain schizophrenia as concerns our political discourse. In Critchley's view, the nihilism that results from promises being revealed as empty is best countered by demanding the impossible, naively asking, for example, to have equal human rights or full democracy, in the face of the opaqueness of such demands. Now, I do not suggest this primarily as a political strategy, but as a strategy of critical reflection: we should demand that promises be kept in full awareness that they are considered to be impossible, that the promises in question – of democracy, citizenship or equal human value – are founded on silent exclusions and that certain things are simply not meant to be realised. Thus, this is a strategy which targets the naturalised ways in which ideals are retracted from. In the context of intellectual disability politics, promises of citizenship are not formulated to be kept, as they contain within themselves the exclusion of certain others, of exceptions, and hence of their own undoing. By asking ourselves and each other what it would take for the promise of full and equal rights to be kept, by demanding it, we will essentially be forcing ourselves to envision a very different world, not organized around notions of 'independence', 'reason', or on the removal of otherness. It is a critical exercise in setting free political visions constrained by the very ideals that are not met.

## **The Political Body**

If critique of the politics of post-institutionalisation needs to set free our political imaginary by developing new vocabularies of resistance, the

challenge will be that those interested in formulating such a critique are also trapped within discourses and ideologies that are integral to contemporary biopolitics: no critic can be completely external to what they criticise. This, of course, begs the question of how new politics can arise. In this respect, I believe that I have hinted towards two answers. First, criticism should concern itself with the limits of knowledge, which is to say, with the forces that constrain the possible ways to perceive social organization. Although it is impossible for us to locate ourselves outside of our present ways of understanding intellectual disability, it is possible to examine how such understandings have been consolidated and evolved. Secondly, criticism at the limits of knowledge can start from the failure of discourse and ideology to reach closure, for example focusing on how people with intellectual disabilities appear to be both included and excluded. This kind of critical discussion, that examines the very failure of discourse to fully put into words what it is constructing, always seems to leave us with something: the concepts that have been engaged are transformed, denaturalised, and can therefore serve as starting points for further reasoning. Along these lines, I now want to elaborate on how the 'biology of disability' has changed through my engagement, resulting in the notion of 'double vulnerability', and how this, in turn, has implications for how the future of disability politics can be envisioned.

The argument I developed with respect to human vulnerability and intellectual disability is that our shared physical vulnerability is made sense of in language, often in ways that seek to project it onto certain others in order to secure the norm of full ability and cognitive capacity. Our exposure to discursive frames of interpretation and our exposure as embodied beings therefore necessarily overlap. This analysis has some important implications. First, it suggests that we should stop asking whether or not 'intellectual disability' exists. Rather, questions about the productiveness of power and resistance concern how something comes into existence. Debates on various diagnoses often seem to revolve around questions which concern whether certain diagnoses are 'real' or 'socially constructed'. This way of framing the debate severely underestimates the force of social constitution; indeed, that a diagnosis is socially constructed, or rather emerges from a place where biology and social forces are indistinguishable, in no way diminishes its realness. In fact, 'double vulnerability' is a way of recognising the social constitution of kinds of human existence.

Furthermore, recognising individuals as 'doubly vulnerable' challenges the liberal humanist subject of reason: it challenges the norm of full ability,

as our physical vulnerability is seen as a precondition to our lives, and it challenges the subject of reason since our discursive vulnerability points to how we are always displaced by discourses that we cannot control. Thus, brought to bear on the endless debates of ‘nature versus nurture’ and the essence of being human, my argument is distinctively anti-essentialist in the sense that it recognises the constitutive force of the social upon the body (or whatever we project notions of ‘human nature’ on). However, in doing this, ‘double vulnerability’ itself becomes an essential aspect of being human, perhaps even one of its defining properties. In other words, this is a way of developing a positive answer to questions concerning what characterises being human without resorting to essentialism.

Now, although this argument was developed with respect to intellectual disability, it is certainly an argument about the human predicament, in general. In fact, I believe that it may even be an argument about how human beings can live together. The implication of a critique of the separation between politics and human nature is that we can neither take difference for granted, as it is seen as a politically invested, nor seek to collapse it into common humanity, as that would only create a new master narrative of what humans are. Rather, I believe that we should take the recognition of the socially constituted body as an impetus to ‘approach difference differently’. In line with my discussion on the ethics of criticism at the end of Chapter 9, to approach difference differently is to take difference as a starting point for an examination of what constitutes and upholds categorisations of human beings, why certain differences appear to us, and what we, as individuals and as a society, invest in them. Confronting difference in this way means moving on from questions regarding the (often biological) causes of difference, towards questions that revolve around the political rationalities and mechanisms which run beneath their constitution. From this perspective, encounters with ‘intellectual disability’ should urge us to reflect on why it has been so important in modern and late-modern societies to classify this as deviancy. Ultimately, approaching people who are different from ourselves by seeing what separates us as contingent on social and historical forces is to transform our relationships; when we realise the political stakes of dividing humanity into categories that affect how we see and understand our interactions, it may instil the humility necessary to abstain from judgement in order to keep open the subjectivity of the other.

## Critique and Equality

A recurring proposition of this book is that even deeply needed societal changes, including the ones we appropriately label 'emancipation', are tainted with power. The era of post-institutionalisation testifies to precisely this – how something that we in hindsight easily detect as horrendous can give way to something else, a new mode of governing which continues to constrain the lives of people with intellectual disabilities. I started this book by telling the story of a tied-up man in a group home in Malmö, Sweden. Here, the vocabulary that was first invented to set him free, metaphorically and literally, has instead continued to restrain the possibility of releasing numerous others who have been targeted by similar procedures. It continues to tie all of us up, because we are all coming into being in relation to ideals of cognitive capacities that can or cannot be used to justify such violent measures.

In the short section on research ethics in the introductory chapter, I mentioned in passing that the process of writing this book has been one in which I have had to find a vocabulary to put into words my occasional but recurring sense that there is something suspicious going on in the way that I relate to those people I know with intellectual disability. Our interactions are seemingly distorted by structures that lie beyond my grasp but that are still inevitably constitutive of who I am and of the scenes of recognition where we meet. The critical ethos that I described at the end of Chapter 9, and developed above, relates to this, as it calls upon us to examine the border which separates the other from myself. Thus, this state of being unable to give appropriate recognition to others within the present regimes of truth can, as Butler (2005:25) suggests, serve as a starting point for a radical questioning of our present ways of living together. Indeed, this whole project has been a mobilisation of my social scientific training, my readings of philosophy, and the inspiration I have found in various critical perspectives on disability and other social categorisations, for the purpose of putting into words how 'normal' people and 'intellectually disabled' people are divided. The very nature of discourse and power implies that my attempt has failed. It is my hope that, at the very least, I have failed in a productive way.

I say this because I think it is important to ponder what drives critique, how efforts to understand these things in new and better ways are stimulated and motivated by an underlying ethos. Critical approaches to social divisions and power are never mere intellectual exercises. Interpretation, here and everywhere, serves a purpose. My final proposition is that the critical ethos of

approaching difference differently is not only an interpretive tool to understand difference. It is also a response to it; trying to make sense of how human beings are separated is ultimately anchored in an urge to bridge these divides, that is, an urge to meet in equality. I do not see 'equality' here as a philosophical construct, as a specific conception that can be argued for or against by means of logic, but rather, as a longing and sense that something needs to change, that whatever distorts our interactions by attributing different value to us must be removed. In other words: I believe that criticisms of how differences are manufactured ultimately spring from the normative appeal of meeting beyond these boundaries.

Although the difference between intellectual disability and normalcy is important, because of its centrality to our political world views and by how it is materialised in political, social, and scientific institutions, it is my suggestion, or hope, that it may be possible to bridge this divide precisely in the act of criticism, itself. This is to say that a criticism of the divisions separating us – in this context along the lines of 'intelligence' – can be a joint effort undertaken across the divide between 'them' and 'us' where their hierarchical relationship is suspended. In other words: perhaps the act of examining what makes us different from each other is a place where, at least temporarily, we can be equals. Thus, one possible future for intellectual disability politics may start in the mutual and critical endeavour of examining why we are separated by historical and social circumstances, why a hierarchy exists, put before us and between us, and to allow ourselves to do this across the very boundaries dividing us. Of course, this can be read as a statement of support for more joint research and political activism. But it can also be seen as a way of recognising something that persists outside of such formally instituted projects, for example visible in the activists' mode of addressing me, and certainly in numerous other settings where people with and without intellectual disability meet. The everyday enactment of criticism as a longing for equality is thus already here. It seems to me that the question is whether we are prepared to attend to it.

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# Appendix 1

## *Municipality A*

### **2009-10**

Street-level support workers: AP1-AP15

Managers: AM1-AM2

### **2013-14**

Managers: AM3-AM5

## *Municipality B*

### **2014**

Street level support workers: BP1-BP2

Bureaucrats: BB1-BB2

Sheltered Employment: BSP1-BSP3

## *Municipality C*

### **2014**

Street level support workers: CP1-CP5

## *Municipality D*

**2016**

Street level support workers: D1

## *Disability movement*

**2014**

Grunden – Andrea, Olof, Monica, Emma, Anders.

FUB – Judith Timoney

Svenska Downföreningen – Marita Wengelin



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