



FACULTY OF LAW  
Lund University

Frida Vall

# Children's right to live with their families and corresponding state obligations under the Convention on the Rights of Persons with Disabilities

JAMM07 Master Thesis

International Human Rights Law  
30 higher education credits

Supervisor: Anna Bruce

Term: Spring 2020

# Table of contents

<b>SUMMARY</b> .....	<b>1</b>
<b>ACKNOWLEDGEMENTS</b> .....	<b>2</b>
<b>ABBREVIATIONS</b> .....	<b>3</b>
<b>1 INTRODUCTION</b> .....	<b>4</b>
1.1 PURPOSE AND RESEARCH QUESTIONS.....	5
1.2 DELIMITATIONS .....	6
1.3 METHOD AND MATERIAL .....	8
1.4 CURRENT STATE OF RESEARCH .....	9
1.5 DISPOSITION .....	10
<b>2 A GLOBAL PROBLEM: SEPARATION, SEGREGATION AND PLACEMENT OF CHILDREN WITH DISABILITIES IN PARTICULAR LIVING ARRANGEMENTS</b> .....	<b>12</b>
<b>3 THEORETICAL BACKGROUND</b> .....	<b>15</b>
3.1 MODELS OF DISABILITY .....	15
3.2 THE HUMAN RIGHTS MODEL OF DISABILITY .....	17
3.3 UNDERSTANDING OF DISABILITY AND AGE IN THE CONTEXT OF THE CRPD.....	18
<b>4 THE OBLIGATION NOT TO SEPARATE CHILDREN WITHOUT THE AGREEMENT OF THE PARENTS</b> .....	<b>23</b>
4.1 BEST INTEREST OF THE CHILD.....	25
4.2 CIRCUMSTANCES UNDER WHICH A SEPARATION IS “IN THE BEST INTEREST OF THE CHILD”.....	27
4.3 PROCEDURAL REQUIREMENTS AND LAWFULNESS OF A DECISION TO SEPARATE CHILDREN FROM THEIR PARENTS .....	30
4.4 SEPARATION BASED ON THE CHILD’S IMPAIRMENT AS VIOLATING THE RIGHT TO NON-DISCRIMINATION .....	37
<b>5 THE OBLIGATION TO PROVIDE ADEQUATE ASSISTANCE AS A PREREQUISITE FOR THE ENJOYMENT OF THE RIGHT TO LIVE WITHIN A FAMILY</b> .....	<b>40</b>
5.1 THE OBLIGATION TO PROVIDE ASSISTANCE .....	41
5.2 THE OBLIGATION TO PREVENT NEGLECT AND / OR ABUSE THROUGH THE PROVISION OF ADEQUATE ASSISTANCE .....	43
5.3 THE OBLIGATION TO FACILITATE FAMILY REUNIFICATION THROUGH THE PROVISION OF ADEQUATE ASSISTANCE .....	45
<b>6 THE OBLIGATION NOT TO SEGREGATE CHILDREN FROM THEIR FAMILY IRRESPECTIVE OF THE PARENTS’ AGREEMENT</b> .....	<b>47</b>
6.1 THE OBLIGATION TO ENSURE THE <i>EQUAL</i> RIGHT TO LIVE WITHIN A FAMILY .....	48
6.2 THE OBLIGATION TO PROVIDE ADEQUATE ASSISTANCE AS A PREREQUISITE FOR THE <i>EQUAL</i> ENJOYMENT OF THE RIGHT TO LIVE WITHIN A FAMILY.....	49
6.3 THE BEST INTEREST OF THE CHILD .....	51

<b>7 THE OBLIGATION TO PROVIDE ALTERNATIVE CARE AND ACCEPTABLE LIVING ARRANGEMENTS .....</b>	<b>53</b>
7.1 ALTERNATIVE CARE WITHIN THE WIDER FAMILY OR IN A FAMILY SETTING .....	53
7.2 ACCEPTABLE LIVING ARRANGEMENTS AND THE LEGALITY OF THE PLACEMENT OF CHILDREN WITH DISABILITIES IN ANYTHING ELSE BUT A FAMILY .....	54
<b>8 THE SCOPE AND STRENGTH OF THE RIGHT FOR CHILDREN WITH DISABILITES TO LIVE WITH THEIR FAMILIES UNDER THE CRPD .....</b>	<b>58</b>
8.1 THE SIGNIFICANCE OF PARENTS' AGREEMENT TO SEPARATION AND / OR SEGREGATION FOR STATE OBLIGATIONS .....	58
8.2 THE CONNECTION BETWEEN THE STATE OBLIGATION TO PROVIDE ASSISTANCE AND THE RIGHT TO FAMILY LIFE.....	60
8.3 THE OPTIONS FOR STATES IN PROVIDING ALTERNATIVE CARE AND ACCEPTABLE LIVING ARRANGEMENTS FOR CHILDREN .....	62
8.4 SUMMARY OF CONCLUSIONS.....	64
<b>BIBLIOGRAPHY .....</b>	<b>66</b>

# Summary

The thesis analyse children's right to live and grow up in a family under the United Nations Convention on the Rights of Persons with Disabilities. It aims at interpreting the scope and strength of children's right to live with their family and corresponding state obligations established under the Convention. The thesis is carried out by employing a legal dogmatic method. At its core, the thesis attempts to create a new problem-based legal analysis of children's right to live within a family. The legal analysis proves that the right to family life under the Convention has the potential to protect a wide scope of situations where children with disabilities risk segregation, separation or placement in particular living arrangements. Parents' agreement to a separation or segregation is of particular significance for state obligations. However, irrespective of parents' agreement, the best interest of the child is – as a rule – to live within a family. Children's equal right to family life is dependent and intrinsically linked to the state obligation to provide adequate assistance. Any denial of assistance to families to care for their child constitutes a violation children's right to live within a family, given that assistance serves as a prerequisite for the enjoyment of that right. Further, the only acceptable living arrangement for children with disabilities is within a family setting. A placement of a child with disabilities in any other living arrangement undermines children's right to live within a family and constitutes a violation of the Convention. Conclusively, children's equal right to family life under the Convention creates far-reaching obligations on states to promote, protect and ensure the enjoyment of this right in practise.

# Acknowledgements

The completion of this thesis would not have been possible without the impressive expertise, constant guidance and endless encouragement from my supervisor Anna Bruce, Senior Researcher at the Raoul Wallenberg Institute of Human Rights. I hereby wish to express my sincerest gratitude for her support, and for the knowledge and inspiration she brings.

A special thanks is also warranted to the Raoul Wallenberg Institute for providing the opportunity to become part of the "Raoul Wallenberg Institute Human Rights Clinic 2019-2020". A truly valuable initiative providing practical experience by working with contemporary legal issues with the aim of combatting human rights abuses through strategic litigation.

Last but not least, I want to express my gratitude to my partner, Peter Lönqvist. Having someone who always believes in you, encourages you, and put things into the wider perspective is invaluable during a journey like this. For that I am more than grateful.

May 2020  
*Frida Vall*

# Abbreviations

<b>CoE</b>	Council of Europe
<b>CRC</b>	International Convention on the Rights of the Child
<b>CRC Committee</b>	Committee on the Rights of the Child
<b>CRPD</b>	International Convention on the Rights of Persons with Disabilities
<b>CRPD Committee</b>	Committee on the Rights of Persons with Disabilities
<b>ECHR</b>	European Convention on Human Rights
<b>ECtHR</b>	European Court of Human Rights
<b>HRC</b>	Human Rights Committee
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>ICIDH</b>	International Classification of Impairments, Disabilities and Handicaps
<b>UDHR</b>	Universal Declaration of Human Rights
<b>UN</b>	United Nations
<b>VCLT</b>	Vienna Convention on the Law of Treaties

# 1 Introduction

To live and grow up within a family is an essential aspect of children's health, well-being and development. It is also a crucial aspect for children with disabilities to be included in the community on an equal basis with others. According to international human rights law, the right to live and grow up in a family belongs to *all* children, including children with disabilities. This right is outlined in the Convention on the Rights of Persons with Disabilities (hereinafter the "Convention" or the "CRPD")<sup>1</sup> which purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities".<sup>2</sup> In particular, the Convention establish obligations on states to "ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children",<sup>3</sup> including all children's right to live in a family.<sup>4</sup>

Regrettably, to live and grow up within a family is not the reality for all children. Children's right to family life is challenged by the global problem often referred to as "institutionalisation" of children with disabilities.<sup>5</sup> History reveals that children with disabilities run a higher risk than other children of being separated from their parents and placed in "particular living arrangements",<sup>6</sup> commonly described as "orphanages" or "institutions".<sup>7</sup> The phenomena of separating children with disabilities from their family and the subsequent placement in particular living arrangements outside a family setting is visible throughout many countries and cultures around the world.<sup>8</sup>

<sup>1</sup>United Nations General Assembly, Convention on the Rights of Persons with Disabilities [hereinafter CRPD], A/RES/61/106, 24 January 2007.

<sup>2</sup> Article 1, CRPD.

<sup>3</sup> Article 7(1), CRPD.

<sup>4</sup> Article 23(3-5), CRPD.

<sup>5</sup> The definition of the term "institutions" is a controversial and highly debated issue. The word is not mentioned in the text of the CRPD and there is no universally accepted definition. An analysis of the word "institution" and its meaning is conducted under chapter seven "The obligation to provide alternative care and the definition of acceptable living arrangements" below.

<sup>6</sup> The expression "particular living arrangements" is found in article 19(a) of the CRPD and will be used for the purpose of this thesis as a compilation of all kinds of living arrangements.

<sup>7</sup> For instance, around 45% of children in Russian institutions have a disability, see Human Rights Watch Publication, *Abandoned by the State: Violence, Neglect, and Isolation for Children with Disabilities in Russian Orphanages*, ISBN: 978-1-62313-1579, 15 September 2014, p. 5; see also Mulheir G and Gyllensten L *'Institutionalization and the commodification of children' in Dolan P and Frost N (Eds.) The Routledge Handbook of Global Child Welfare* (Routledge 1st Edition 2017) [hereinafter Mulheir and Gyllensten, 2017] p. 295.

<sup>8</sup> In Sweden for instance, there is a development today where children with disabilities are placed in particular living arrangements – so called "group homes" - and consequently separated from their families; see for instance United Nations Committee on the Rights of Persons with Disabilities [hereinafter CRPD Committee], List of issues prior to submission of the combined 2nd and 3rd periodic report of Sweden, UN doc. CRPD/C/SWE/QPR/2-3, 12 October 2018, para 4(g).

In some parts of the world the problem have been present for a long time, while other parts have been more progressive in terms of prohibiting and abolishing particular living arrangements such as orphanages or institutions.

Currently however, organisations and experts describe a worrying development in many countries with placement of children with disabilities in a “new generation of smaller institutions” which may be called everything from “family-like residences” to “group homes”.<sup>9</sup> Essentially, the separation of children with disabilities from their families is often due to the lack of access to community based services and support to the families to care for their child.<sup>10</sup> This development can also be seen in previously progressive disability rights countries, such as Sweden.<sup>11</sup> The problem could therefore be described as continued in some parts of the world and indicate a retrogression in others.

The separation, segregation and placement of children with disabilities in such living arrangements - outside a family setting - raise the question of CRPD state parties’<sup>12</sup> compliance with their human rights obligations.<sup>13</sup> Children’s right to live with their family is protected under article 23 on “Respect for home and the family” of the CRPD. The core question covered in article 23 is the right for families, parents and children, to be able to stay together. Consequently, article 23 entails state obligations, both positive and negative, to ensure that children can live with their parents and not be separated or segregated. In order to reach a better protection for children’s right to family life – and highlight an ongoing global problem – it is imperative to understand and ascertain the scope and strength of article 23 on children’s right to live with their family under the CRPD.

## 1.1 Purpose and research questions

The main purpose of the thesis is to interpret and ascertain the scope and strength of children’s right to live with their family and the corresponding

<sup>9</sup> Rosenthal, Eric, Position paper on “The right to live and grow up in a family for all children”, [hereinafter, Rosenthal, 2018] on behalf of Disability Right International, European Network for Independent Living, Validity, TASH, 14 December 2018 and; Disability Rights International publication, Recommendations to the UN General Assembly on Behalf of Children Without Parental Care, [hereinafter Disability Rights International, 2019] September 12, 2019.

<sup>10</sup> Rosenthal 2018 and; Disability Rights International, 2018.

<sup>11</sup> See for instance: <https://www.svd.se/omfattande-utokning-av-barnboenden-pagar> <https://www.svt.se/nyheter/inrikes/svt-avslojar-funktionshindrade-barn-tvingas-flytta-till-barnboenden>, latest accessed 26 May 2020.

<sup>12</sup> State parties to the CRPD are bound by the provisions enshrined in the Convention and state parties to the United Nations General Assembly, Optional Protocol to the Convention on the Rights of Persons with Disabilities [hereinafter CRPD Optional Protocol], A/RES/61/106, Annex II, 13 December 2006 have also recognised the competence of the CRPD Committee to receive complaints from individuals who claim to be victims of a violation of the provisions in the Convention, article 1(1) CRPD Optional Protocol.

<sup>13</sup> In particular under article 23 “Respect for home and the family”, article 19 “Living independently and being included in the community” and article 7 “Children with disabilities”, CRPD.



state obligations established under the CRPD. The second purpose of the thesis is to highlight a global problem which is continued - and in some parts of the world growing - where children with disabilities are separated and placed in particular living arrangements, apart from their families.

At its core, the thesis aims at creating a new problem-based legal analysis of children's right to live and grow up within a family and corresponding state obligations under the most recently adopted United Nations (hereinafter "UN") human rights instrument.<sup>14</sup> By conducting such an analysis, the aim is to further deepen the understanding of the right and obligations and thereby contribute to a better protection of this right.

The core of the thesis will be concerned with a legal analysis of article 23(3-5) of the CRPD. The overarching research question guiding the analysis is:

1. What is the scope and strength of the right for children with disabilities to live with their families under the CRPD?

In order to answer this research question, three sub-questions will be answered which are:

- a) What is the significance of parents' agreement to separation and / or segregation for state obligations according to the CRPD?
- b) What is the connection between the right to family life and the obligation to provide assistance according to the CRPD?
- c) What are the options for states in providing alternative care and what is considered as an acceptable living arrangement for children according to the CRPD?

## 1.2 Delimitations

For the purpose of the thesis, a number of delimitations are made which set the boundaries for the legal analysis. Children's right to family life is protected under several international human rights conventions adopted long before the CRPD, for instance under the Convention on the Rights of the Child (hereinafter the "CRC")<sup>15</sup> and the European Convention on Human Rights (hereinafter the "ECHR").<sup>16</sup> While recognising this, the thesis focus solely on children's right to family life under article 23 of the CRPD. This is due to the fact that the CRPD is one of the most recently adopted human rights instruments and is specifically targeting children's equal right to live with

<sup>14</sup> A more detailed examination of the thesis contribution to existing literature on children's right to family life is found under chapter 1.4. "Current state of research" below.

<sup>15</sup> United Nations General Assembly, Convention on the Rights of the Child [hereinafter CRC], Treaty Series, Vol. 1577, p. 3, United Nations, 20 November 1989.

<sup>16</sup> Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms [hereinafter ECHR] Rome, 4.XI., 1950.

their family and corresponding state obligations. The provisions on children's right to family life under the CRC and ECHR are therefore not included or analysed to any greater extent than for the purpose of using them as an interpretative source where the CRPD is silent and / or unclear. Given the exclusive focus on the CRPD, the thesis does not take into consideration national contexts or legislation, but instead have an entirely international focus.

While article 23 includes both the equal right to family life for children with disabilities (understood as a civil and political right) as well as the obligation provide adequate assistance to realise this right (understood as a social and economic right), the latter is not analysed alone. Analysing the state obligation to provide assistance by itself would require a thorough analysis of the concept of "progressive realisation" which would render the scope of the thesis too extensive.<sup>17</sup> Instead, the obligation to provide adequate assistance is conceptualised throughout the thesis solely in relation to the enablement of the right to family life in article 23.

It is further recognised that article 23 is comprehensive and includes five paragraphs which are all connected and sometimes overlap. The two first paragraphs – 23(1-2) – are not covered because they do not concern children's right to live within a family. Consequently, the provisions in article 23(3-5) are the provisions analysed.<sup>18</sup> Article 23(3-5) does not only cover children's right to family life, but also parents' right to family life. Despite the importance of parents' right to family life, it will not be part of the present analysis. In this regard, the thesis does not examine the concept of "will" in the context of article 23(4).<sup>19</sup> However, parts of the connection (and possible clash) between parents' right and children's right to family life will be part of the analysis, but is not covered in its entirety.

<sup>17</sup> Article 4(2), CRPD reads as follow:

*With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.*

<sup>18</sup> Article 23(3-5), CRPD reads as follow:

*3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*

*4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.*

*5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.*

<sup>19</sup> According to article 23(4) of the CRPD, a child shall not be separated from his or her parents "against their will".

## 1.3 Method and material

As established above, the thesis seeks to analyse the scope and strength of the provisions concerning the right of children with disabilities to live within a family under the CRPD. This includes a thorough legal analysis of the provisions in article 23(3-5) on “Respect for home and the family”. Accordingly, the primary source of law analysed is the CRPD, including the articles and provisions outlined below. To some extent relevant provisions in the CRC and ECHR are invoked to aid the interpretation of the provisions in the CRPD. Secondary sources of law are used to guide the legal interpretation of the provisions and include General Comments of the Committee on the Rights of Persons with Disabilities (hereinafter the “CRPD Committee”) as well as the Committee on the Rights of the Child (hereinafter the “CRC Committee”), CRPD jurisprudence, European Court of Human Rights (hereinafter the “ECtHR”) case law, commentaries on the CRPD and scholarly articles.

The thesis is carried out by employing a legal dogmatic method. The Vienna Convention on the Law of Treaties (hereinafter the “VCLT”) serve as the legal basis for the analysis.<sup>20</sup> In this way, the provisions under article 31 of the VCLT function as the primary tool for the interpretation of the right to family life under the CRPD. According to article 31(1), a treaty shall first of all “be interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose”. This provision indicates three aspects of treaty interpretation as the “ordinary meaning” of the text, the “object and purpose” and, the “context”.

The object and purpose of the CRPD is interpreted through relevant parts of the CRPD Preamble<sup>21</sup> as to achieve a practical and an effective right for children with disabilities to live within their family. The “context” refers to the rest of the treaty and is further elaborated in article 31(2) which states that the “context for the purpose of the interpretation of a treaty shall comprise [...] the text, including its preamble and annexes”.<sup>22</sup> The contextual analysis of article 23 is interpreted through, in particular, article 7 on “Children with disabilities” and article 19 on “Living independently and being included in the community”. A contextual analysis of articles 23, 7 and 19 also leads to other relevant provisions such as article 2 on “Definitions”, article 4 on “General obligations” and article 3 on “General principles”. Here, the main focus is on 4(1d) obliging states to refrain from engaging in any act or practice

<sup>20</sup> United Nations, Vienna Convention on the Law of Treaties [hereinafter VCLT], Treaty Series, Vol. 1155, p. 331, United Nations, 23 May 1969.

<sup>21</sup> Preamble (e) (p) (r) and (x), CRPD.

<sup>22</sup> In addition, it shall comprise “(a) any agreement relating to the treaty which was made between all the parties in connection with the conclusion of the treaty; (b) any instrument which was made by one or more parties in connection with the conclusion of the treaty and accepted by the other parties as an instrument related to the treaty.” Article 31(2), VCLT.

that is inconsistent with the present Convention,<sup>23</sup> 2(3) in the definition of “discrimination on the basis of disability”, 3(b) on non-discrimination, 3(c) on participation and inclusion, and 3(e) on equality of opportunity. Article 5(2) on “Equality and non-discrimination” is relevant since it prohibits all discrimination on the basis of disability. Article 16(1-2) on “Freedom from exploitation, violence and abuse” is relevant because it regulates when the state has an obligation to act in cases of abuse or neglect of a child. It also specifically outlines the state obligation to take measures to prevent violence and abuse by ensuring assistance and support for persons with disabilities and their families.<sup>24</sup>

Further, article 31(3)(c) of the VCLT outlines that the interpretation of a treaty shall take into account – together with the context – “any relevant rules of international law applicable in the relation between parties”. Since article 23 on the right to family life of the CRPD is complemented and modelled upon some of the provisions in the CRC, relevant provisions of the CRC will be used where the CRPD or the CRPD Committee lacks content to aid interpretation.<sup>25</sup> The ECHR and the case law of the ECtHR will be used for the same purpose to guide interpretation of general requirements relevant to the rights in most human rights conventions. In line with article 32 of the VCLT, preparatory works of the CRPD will be used when article 31 means is not enough; when the meaning remains ambiguous and unreasonable after application of article 31.

Finally, the legal analysis of the right to family life for children with disabilities under article 23 is framed from the disability- and age perspective enshrined in the CRPD, which thereby provides the theoretical framework of the thesis.<sup>26</sup>

## 1.4 Current state of research

Among international human rights instruments, the CRPD is a “young” accomplishment. It is the most recently adopted UN human rights convention and in comparison to its predecessors it has not been subject to the same amount of scrutiny. While children’s right to family life has been subject to scrutiny under human rights law in general, in particular in relation to CRC, the scope and strength of children’s right under article 23 of the CRPD has gained less attention. In addition, there exists extensive research on particular living arrangements for children (such as orphanages, residential care and

<sup>23</sup> And to ensure that public authorities and institutions act in conformity with the present Convention.

<sup>24</sup> Article 16 of the CRPD also specifically outlines the state obligation to take measures to prevent violence and abuse by ensuring assistance and support for persons with disabilities and their families.

<sup>25</sup> The connection between relevant provisions in CRPD and CRC will be elaborated upon in section 1.4. “Current state of research” below.

<sup>26</sup> The perspective of disability and age under the CRPD will be explored under chapter three “Theoretical background” below.

group homes), the reasons behind this phenomena, the danger and harm it causes and the need for de-institutionalisation.<sup>27</sup> With this said, few authors have analysed all children's rights (including children with disabilities) to live and grow up in a family under international law, including the CRPD.<sup>28</sup>

The current thesis aims at complementing existing human rights law literature by creating a new problem-based legal analysis of children's right to live within a family and corresponding state obligations. It is specifically directed towards countries having a history of "institutionalisation" of children with disabilities. The legal analysis is based upon potential situations where children with disabilities risk segregation or separation and subsequently placement in particular living arrangements. Taking into consideration existing different interests – with the CRPD-lens of understanding disability and age – the thesis provides an answer to what the scope and strength of children's right to live within a family and corresponding state obligations under article 23 entails in practise. In this way, the thesis seek to provide literature – consisting of newly created problem-based analysis – that could be used by, in particular, civil society and policy makers as a practical reference in the debate concerning state parties' (non)compliance with the CRPD.

## 1.5 Disposition

Chapter two introduces the global problem of separation, segregation and placement of children with disabilities in particular living arrangements. A short background of this global problem is key in order to understand the centrality and importance of children's right to live within a family and states' obligations to protect, promote and ensure this right. Chapter three situates the concepts of disability and age under the CRPD which serve as the lens through which children's right to live with their family is analysed. In order to understand these concepts, the chapter introduce the main models of understanding disability in the context of the CRPD with a special focus on the "human rights model of disability".

Chapters four to seven are divided on a basis of different problem-based situations upon which the legal analysis of children's right to live within a family and corresponding state obligations is conducted. Chapter four concerns situations where separations of children with disabilities from their

<sup>27</sup> See for instance, Mulheir and Gyllensten, 2017; Mulheir G, 'Deinstitutionalisation: A Human Rights Priority for Children with Disabilities' (2012) 9 *The Equal Rights Review* [Mulheir, 2012] and; Mollidor C and Berridge D '*Residential care for children and young people: Policy and practice challenges*' in Dolan P and Frost N (Eds.) *The Routledge Handbook of Global Child Welfare* (Routledge 1st Edition 2017) [hereinafter Mollidor and Berridge, 2017].

<sup>28</sup> See for instance Rosenthal E, 'The right of all children to grow up in a family under international law: implications for placement in orphanages, residential care and group homes' (2018-2019) 25 *Buffalo Human Rights Law Review*.

families are enforced by the authorities without the agreement of the parents. Chapter five address one of the main underlying reason for segregations and separations – the failure to fulfil the state obligation to provide adequate assistance. Chapter six concern situations where segregation of children with disabilities from their families have been conducted with the agreement of the parents (the opposite situation to chapter four). Chapter seven examines the state obligation to provide for alternative care and seeks to establish which alternative living arrangements to the family that are in conformity with the CRPD.

Chapter eight summarises the analysis in chapters four to seven by relating back to the research questions. The chapter also problematises the conclusions of the legal analysis by applying the human rights model of disability. Finally, the section provides a short summary of the main findings of each sub-question including the protection article 23 gives, the situations it covers and the strength it possesses.

## 2 A global problem: separation, segregation and placement of children with disabilities in particular living arrangements

Children's right to live within their families is challenged by the widespread state practice of separating children with disabilities from their families and subsequently place them in particular living arrangements outside a family setting. The problem of placement of children with disabilities in particular living arrangements have been present for a long time and is seen as a human rights concern.<sup>29</sup> A short background of this global problem of "institutionalisation" and its current practise is needed in order to understand the centrality and importance of children's right to live within a family and states' obligations to protect, promote and ensure this right.

The problem of exclusion and segregation of children with disabilities most likely exist everywhere, but may take different forms and be defined differently depending on the context and country. In some countries the problem might be that children with disabilities are hidden away by their own families by fear of discrimination or stigmatisation.<sup>30</sup> Other countries may have a history of "institutionalisation" – placing children with disabilities in particular living arrangements. In Sweden for instance, orphanages and other institution-like living arrangements for children were set up during the first half of the last century when these living arrangements were seen as a good option for children in need of care.<sup>31</sup> Irrespective of how this exclusion is expressed, the underlying problem behind different forms and degrees of segregation and separation is that children with disabilities are "being defined and judged by what one lacks rather than by what one has" and is by this definition seen as inferior.<sup>32</sup> Children with disabilities face an increased vulnerability and risk stigmatisation, discrimination, and exclusion and are disproportionately subjected to violence and abuse.<sup>33</sup> Recognising the multiple ways children with disabilities encounter different forms of

<sup>29</sup> Mulheir, 2012.

<sup>30</sup> United Nations Children's Fund (UNICEF) Publication, The state of the world's children 2013: Children with disabilities, [hereinafter UNICEF, 2013], p. 64.

<sup>31</sup> This view of providing "care" to children with disabilities also corresponded to the Swedish welfare system. See for instance: SOU 2009:99 "Utredningen om vanvård i den sociala barnvården".

<sup>32</sup> UNICEF, 2013, p. 2.

<sup>33</sup> United Nations General Assembly Resolution, Rights of the child, UN doc A/RES/74/133, 20 January 2020, [hereinafter GA Res, Rights of the child, 2020] p. 4.

exclusion, the thesis is directed towards countries having a history of “institutionalisation” of children with disabilities.<sup>34</sup>

Just as the terms, definitions and practices of exclusion and segregation of children with disabilities differ and varies between countries, data collection and reporting on these issues also vary and often lacks consistency.<sup>35</sup> Therefore, comparing global statistics is hard. The exact scope of the problem - the number of particular living arrangements and the number of children living in them - is unknown.<sup>36</sup> However, throughout the European region it is estimated that between 600,000 and 1,000,000 children are separated from their families into particular living arrangements.<sup>37</sup> Globally, estimates range from two to eight million<sup>38</sup> children.<sup>39</sup> The statistical gaps as well as differences in reporting might however indicate that the numbers are even higher.

Given this scarcity of data on the amount of living arrangements and the number of children placed in them, the exact reasons behind the separation and the subsequent placement is also unsettled. However, existing research<sup>40</sup> – together with the historical records of many countries – suggests that children with disabilities are significantly over-represented in particular living arrangements and therefore runs a higher risk than other children of being separated from their parents and placed in such living arrangements.<sup>41</sup> In addition to disability, poverty and “abandoned” or “orphaned” children are two other reasons for separation and segregation commonly referred to. The latter however to a large extent represents a myth since approximately 80 percent of the children living in particular living arrangements have a living parent.<sup>42</sup>

Research suggest, and state reporting to the CRPD Committee confirms,<sup>43</sup> that the separation of children with disabilities from their families is often due to the lack of access to and / or availability of community based services and support to the families to care for their child.<sup>44</sup> This is also reported by a range of disability rights organisations and experts confirming the scarcity of

<sup>34</sup> See section 1.4. “Current state of research”.

<sup>35</sup> Mollidor and Berridge, 2017, pp. 282-283.

<sup>36</sup> Mulheir and Gyllensten, 2017, p. 295.

<sup>37</sup> See for instance; Mulheir, 2012, p. 117; Mulheir and Gyllensten, 2017, p. 295.

<sup>38</sup> In 2006, 8 million of the world’s children were reported to be in residential care, United Nations General Assembly on Rights of the Child, Report of the independent expert for the United Nations study on violence against children, Paulo Sérgio Pinheiro, submitted pursuant to General Assembly resolution 60/231, UN doc A/61/299, 29 August 2006, para 55.

<sup>39</sup> Mulheir and Gyllensten, 2017, p. 295, see footnote 13.

<sup>40</sup> Mulheir, 2012, p. 117.

<sup>41</sup> Mulheir and Gyllensten, 2017, p. 295.

<sup>42</sup> Mulheir, 2012, p. 121.

<sup>43</sup> As will be part of the legal analysis below, the CRPD Committee has continuously, through their general comments and state reports, recognised the problem, emphasised the importance of tackling it and raised critique against states who does not live up to their state obligations to ensure children’s right to live within a family.

<sup>44</sup> Mulheir, 2012, p. 121; Rosenthal, 2018 and; Disability Rights International, 2019.



community based support in many countries.<sup>45</sup> Financial resources is often the main arguments brought forward by states to explain the lack of community based assistance and the justification of placements in particular living arrangements.

Crucially, the impact on children's health, well-being and development and the serious harm caused to children placed in particular living arrangements is well documented.<sup>46</sup> As already mentioned, children with disabilities generally run a higher risk of neglect, abuse and violence than most children.<sup>47</sup> Additionally, children placed outside a family setting are facing a considerably higher risk of harm than children living within a family. The placement of children in an environment of particular living arrangements is therefore considered part of the vulnerability and risk children with disabilities are facing.<sup>48</sup> In particular, the High Commissioner for Human Rights Report on Mental Health stresses the fact that "institutional care in early childhood has such harmful effects that it should be considered a form of violence against young children".<sup>49</sup>

Thus, children's right to live and grow up within a family is a human rights priority. It is therefore vital to carefully examine states' obligations to ensure inclusion and participation in the society; to provide family- and community based services and support to families to care for their children;<sup>50</sup> to adopt, enforce and repeal laws that prevent children with disabilities from being separated from their families and subsequently placed in particular living arrangements.<sup>51</sup>

<sup>45</sup> Rosenthal, 2018 and; Disability Rights International, 2019.

<sup>46</sup> Mulheir and Gyllensten, 2017, pp. 296-300; and Mulheir, 2012.

<sup>47</sup> For instance, children placed in particular living arrangements do not have access to daily parental care in the same sense as other children, but staff are instead replacing the parents. Given that the staff is continuously replaced and no substitute for a parents, the child lacks the possibility to develop a strong personal bond with a caregiver. This is particularly serious for children with disabilities which "may require even more sustained adult engagement to help them to develop", see Mulheir and Gyllensten, 2017, pp. 296-7.

<sup>48</sup> *Ibid*, p. 298.

<sup>49</sup> Report of the United Nations High Commissioner for Human Rights on Mental Health and Human rights, [hereinafter OHCHR, 2017] UN doc. A/HRC/34/32, 31 January 2017, para 58.

<sup>50</sup> The recently adopted UN General Assembly Resolution on the rights of the child stress the importance of "[e]nsuring the availability of a comprehensive range of quality accessible and disability-inclusive alternative care options, in the best interests of the child and on a case-by-case basis, in line with the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities", see GA Res, Rights of the child, 2020, para 35 (b).

<sup>51</sup> A process often referred to as "de-institutionalisation", see for instance CRPD Committee, General Comment No. 5: Article 19: on living independently and being included in the community [hereinafter CRPD General Comment No. 5, 2017], UN doc: CRPD/C/GC/5, 27 October 2017.

## 3 Theoretical background

This chapter examines the concepts of disability and age under the CRPD. It is essential to elaborate on these two concepts given the centrality of the concept of disability in the CRPD at large and more specifically the importance of the intersection of disability and age for the analysis of children's right to live within a family. In addition, the perspective of disability and age is at the forefront in both article 7 on "Children with disabilities" and in article 23 on "Respect for home and the family". Two articles which are at the core of the analysis for the purpose of the thesis.

The perspective of disability and age under the CRPD will serve as the lens through which children's right to live within a family and corresponding state obligations are analysed. It thereby frames the legal analysis and enables an examination of the scope and strength of the right. Crucially, references to the perspective and the intersection between disability and age will serve as an illustration of the disability rights perspective permeating the CRPD and will therefore not be analysed or challenged as such.

As mentioned above, the thesis aims at creating a new problem-based legal analysis of children's right to live within a family under one of the most recent human rights instruments. Therefore, the question of if and why a separation of a child from her or his family and a subsequent placement in a particular living arrangement is generally seen as a legitimate and reasonable alternative throughout the world will not be answered by the application of certain perspective or model in the current thesis.

The first section of the chapter will shortly describe the main models of understanding disability in the context of the CRPD. The second section will introduce parts of one model of understanding disability in the context of the CRPD, what Theresia Degener calls the "human rights model of disability".<sup>52</sup> The final part situates disability and age in the context of the CRPD.

### 3.1 Models of disability

In order to enable a discussion on the understanding of disability and age under the CRPD, it is essential to initially mention the main models of disability throughout disability studies. However, given that the core of the thesis concerns *age and* disability, the primary focus in this chapter is the section on CRPD's perspective on age and disability.

<sup>52</sup> The human rights model of disability is elaborated upon in; Degener T 'A Human Rights Model of Disability' in Blanck P and Flynn E (Eds.) *Routledge Handbook of Disability Law and Human Rights* (Routledge 2016) [hereinafter Degener, 2016].

There are a range of different models of disability and the impact and compliance of these models in understanding disability in the context of the CRPD could constitute a doctoral dissertation on their own. According to Anna Bruce, four of the main models which approach has influenced the understanding of disability at the international level are the “International Classification of Impairments, Disabilities, and Handicaps” (hereinafter “ICIDH”), the “International Classification of Functioning, Disability and Health” (hereinafter “ICF”), the “minority group model of disability” and the “social model of disability”.<sup>53</sup>

One model that is commonly referred to in disability law and human rights literature is the “medical model of disability”.<sup>54</sup> Rather than being a model used to understand disability under the CRPD, the medical model can be described as a way of “describing attitudes, tendencies, policies or measures which are disapproved of”.<sup>55</sup> The model regards the level of functioning of the individual as the problem. The impairment is therefore the main reason for exclusion and the solution to the problem – the disability – is seen as something that has to be treated, cured and rehabilitated by help of medical expertise.<sup>56</sup> It is argued that this model has been the main model influencing the understanding of disability in modern history.<sup>57</sup> The medical model is often described as the opposite to the social model.<sup>58</sup> The latter was, despite the lack of consensus, serving as the main approach to disability during the negotiations of the CRPD.<sup>59</sup> Out of the four approaches mentioned above, the social model and the ICF was the two main models figuring during the negotiations, with the social model being referred to the most.<sup>60</sup> However none of the approaches is explicitly referred to in the CRPD text itself.<sup>61</sup>

In contrast to the medical model, the social model sees the problem as the intersection between the level of functioning of the individual and the environment, rather than the impairment. The solution to this problem is that the society (state and civil society) adapts to the individual by eradicating social and physical barriers to enable inclusion of persons with disabilities.<sup>62</sup>

<sup>53</sup> Bruce, A *‘Which Entitlements and for Whom?: The Convention on the Rights of Persons with Disabilities and Its Ideological Antecedents’* (Lund University, 2014) [hereinafter Bruce, 2014] p. 16.

<sup>54</sup> Or individual model of disability.

<sup>55</sup> Bruce, 2014, p. 16, footnote 8.

<sup>56</sup> Degener, 2016, p. 33.

<sup>57</sup> Kayess R. and French P, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8 Human Rights Law Review [Kayess and French, 2008] p. 6.

<sup>58</sup> According to Theresia Degener, the medical model served as a deterrent during the negotiations of the CRPD; see Degener, 2016, p. 33; and Bruce, 2014, p. 101.

<sup>59</sup> See for instance Kayess and French, 2008, p. 7; and Degener, 2016, p. 33.

<sup>60</sup> Bruce, 2014, pp. 346-47.

<sup>61</sup> *Ibid*, p. 346.

<sup>62</sup> The social model of disability includes different theories stemming from the disability rights movement in the United Kingdom, see Kayess and French, 2008, p. 6. One of the founding fathers of the social model of disability is Michael Oliver, see for instance Oliver M *‘The Social Model of Disability: Thirty Years On, Disability and Society Disability & Society’* (2013 28:7).

One of the reasons for the lack of consensus concerning the social model during the negotiations was the problem of the sole focus on environmental barriers, which would mean that requirements relating the impairment of the individual would fall outside the scope of the CRPD.<sup>63</sup> During the negotiations, the social model was therefore understood as “environmental barriers to social participation, and that this focus is instead of, rather than a complement to, a focus on impairment.”<sup>64</sup> Accordingly, the social model has been criticised for lacking as a model of disability. As a response to this criticism, Theresia Degener suggest an alternative “human rights model of disability” which should be seen as an improvement to the social model (rather than a rejection) to be used as a tool to implement the CRPD.<sup>65</sup>

## 3.2 The human rights model of disability

There are many parts of a “human rights model of disability” or “human rights perspective on disability”. Degener addresses six different arguments to illustrate the difference between a human rights model and a social model of disability. The six arguments are; 1) impairment does not hinder human rights capacity; 2) the human rights model includes first and second-generation human rights; 3) the human rights model values impairment as part of human diversity; 4) the human rights model acknowledge identity issues; 5) the human rights model allows for assessment of prevention policy,<sup>66</sup> and; 6) the human rights model strives for social justice.<sup>67</sup>

One interesting aspect of Degener’s human rights model of disability is the argument that a human rights model of disability includes first and second-generation human rights and that the CRPD illustrates the indivisibility and interdependence of both sets of rights. Many of the articles in the CRPD cannot be said to belong solely to either civil and political or economic social and cultural rights.<sup>68</sup> For instance, article 19 on “Living independently and being included in the community” (which has no clear equivalent in other human rights instruments), could be traced back to be a civil right. However, the article also includes the right to community support services such as personal assistance, which in turn is seen as a social right. In this way, the social right ensures the realisation of the civil right, illustrating the indivisibility and interdependence between the two.<sup>69</sup>

A core aspect of Degener’s argument for the purpose of the current thesis is that the human rights model of disability acknowledges identity issues. She

<sup>63</sup> Bruce, 2014, p. 348.

<sup>64</sup> *Ibid*, p. 350.

<sup>65</sup> Degener, 2016, p. 32.

<sup>66</sup> Degener argues that “while the social model of disability is critical of prevention policy, the human rights model offers a basis for assessment when prevention policy can be claimed as human rights protection for disabled persons”, see Degener, 2016, p. 45.

<sup>67</sup> *Ibid*.

<sup>68</sup> *Ibid*, p. 37.

<sup>69</sup> *Ibid*.

argues that the social model of disability fails to cover all different experiences of oppression and neglects identity politics as a valuable component of both disability policy, as well as of emancipation.<sup>70</sup> On the contrary, a human rights model of disability recognise different layers of identity. These different layers of identity within the context of disability and rights are visible throughout the CRPD, particularly the intersection between disability and age.<sup>71</sup>

At its core, Degener argues that the CRPD is a codification of the human rights model of disability.<sup>72</sup> Consequently, the understanding of disability and age in the context of the CRPD mirrors Degener's human rights model of disability. This model, or "disability human rights perspective" permeates the entire Convention, as will be illustrated below.

### **3.3 Understanding of disability and age in the context of the CRPD**

The adoption of the CRPD is repeatedly described as a "paradigm shift" in the understanding of disability.<sup>73</sup> At large, the CRPD expresses perspectives and normative values that deal with disability, equality and rights. The shift with the adoption of the CRPD often refers to a rejection of the social welfare response or the medical model of disability to a social model of disability with a rights based approach to disability.<sup>74</sup> In essence, the adoption of the CRPD did not only provide entitlements to persons with disabilities, it also changed the way disability was understood.

Noticeable, the words "disability" and "persons with disabilities" cannot be found under the definitions in article 2 of the CRPD.<sup>75</sup> Despite the lack of a clear definition, a reference to "persons with disabilities" can be found in article 1(2) of the CRPD, reading as follow;

*[T]hose who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

Thus, there are five delimiting criteria to determine who falls within the meaning of a person with disability and thereby is covered by the CRPD. The criterions are; 1) having an "impairment"; 2) which is "physical, mental,

<sup>70</sup> Degener, 2016, p. 44.

<sup>71</sup> *Ibid*, pp. 41-42.

<sup>72</sup> *Ibid*, p. 49.

<sup>73</sup> See for instance Kayess and French, 2008, p. 3; and Degener, 2016, p. 48.

<sup>74</sup> Kayess and French, 2008, p. 3.

<sup>75</sup> Excluding definitions of disability and persons with disability was suggested both by States and the International Disability Caucus (IDC). While states were mostly concerned about the "distributive impact of such definitions", IDCs argued that including such definitions would result in them being externally imposed and risk disempowering persons with disabilities, see Kayess and French, 2008, p. 23.

intellectual or sensory”; 3) which is “long-term”; 4) which is “ha[d]”, and; 5) which “may”, in interaction with social barriers, create a relative disadvantage in participation in society.<sup>76</sup> The reference to persons with disabilities is open-ended which is also stressed by the article 1(1) outlining the purpose of the Convention as to ensure human rights to *all*<sup>77</sup> “persons with disabilities”.<sup>78</sup> In addition to determining who is covered, the fifth criterion importantly refers to the understanding of disability emphasising the social participation in the society rather than the individual impairment. The article also focuses on disadvantage rather than difference, which is an important social aspect linked to the understanding of disability.<sup>79</sup>

The meaning of “disability” could also be conceptualised by interpreting the detailed preamble of the CRPD. According to the preamble, disability is an evolving concept and state parties to the Convention recognise that;

*[D]isability results from the **interaction** between persons with impairments and **attitudinal and environmental barriers**<sup>80</sup> that hinders their full and effective participation in society on an equal basis with others[.]<sup>81</sup>*

The problem facing persons with disabilities is in the CRPD understood as restricted participation in society due to attitudinal and environmental barriers. This recognition further implies that those attitudinal and environmental barriers to social participation should be eradicated to ensure participation in the society on an equal basis with others. The CRPD expects the society to change or adapt to the individual instead the other way around. In this way, it could be argued that both preamble (e) and article 1 corresponds with what is described as the social model of disability mentioned above.<sup>82</sup> However, as elaborated upon by Bruce, CRPD: s mirroring of the social model is complicated,<sup>83</sup> and becomes further intricate by the fact that the social model is understood and defined differently between authors, making a comparison between different models of disability difficult.<sup>84</sup>

An example can however be illustrated by reference to article 1 and preamble (e) outlined above. For instance, while recognising the compatibility of article 1 and preamble (e) with the social model of disability,<sup>85</sup> Bruce stress that the provisions also recognise ““impairments” and not only “barriers” as factors of the “interaction” resulting in “disability””, and in this way reflect both a

<sup>76</sup> Bruce, 2014, p. 303.

<sup>77</sup> Emphasis added.

<sup>78</sup> Kayess and French, 2008, p. 23.

<sup>79</sup> Bruce, 2014, pp. 313-315.

<sup>80</sup> Emphasis added.

<sup>81</sup> Preamble (e), CRPD.

<sup>82</sup> Kayess and French, 2008, p. 23 and; Degener. 2016,

<sup>83</sup> Bruce, 2014, chapter 11. For conclusions, see in particular chapter 11.2.5.

<sup>84</sup> *Ibid*, p. 368.

<sup>85</sup> Describing “the depiction of the constituency in Article 1 through the social disadvantage experienced and the mentioning of barriers as instrumental to this [and] the corresponding construction of “disability” in Preamble (e) [...]” as closely resonating with the social model of disability, see Bruce, 2014, p. 366.

medical model and a social model of disability.<sup>86</sup> The references to “disability” / ”disabilities” in the CRPD are seen as “both restricted composite life opportunities *and* Impairment”.<sup>87</sup> Accordingly, in some aspects the social model is seen as lacking as a tool for understanding disability under the CRPD, but can be useful in others.<sup>88</sup> As mentioned above, the CRPD is described as “the human rights model of disability”<sup>89</sup> - an improvement of the social model – which also encompass some necessary elements of the medical model of disability, albeit modified, to ensure that “all persons with disabilities can exercise their human rights”.<sup>90</sup>

As with “persons with disabilities”, the CRPD does not define its references to “children with disabilities”. However, the preamble of the CRPD, which serves as the starting point for a conceptualisation of disability and age, recognises;

*[T]he difficult conditions faced by persons with disabilities who are **subject to multiple or aggravated forms of discrimination**<sup>91</sup> on the basis of [...] birth, age or other status[.]*<sup>92</sup>

Thus, the CRPD clearly recognises that individuals with disabilities might possess different “layers of identities” as Degener calls it, and thereby establishes an intersectionality perspective. The explicit reference to “multiple or aggravated forms of discrimination” referring to intersectionality is the first to appear in a UN human rights convention.<sup>93</sup> However, the intersectionality “concept” or “perspective” has been discussed throughout the realm of human rights long before the adoption of the CRPD.<sup>94</sup> At its core, the intersectionality concept – as understood generally in human rights law external to the CRPD - denies that identity can be dissected into “mutually exclusive categories of experience and analysis” and instead recognise that identity is a complex fusion of different categories.<sup>95</sup> In contrast to additive discrimination, intersectional discrimination “creates a new compound

<sup>86</sup> Bruce, 2014, p. 365.

<sup>87</sup> *Ibid*, p. 366.

<sup>88</sup> *Ibid*.

<sup>89</sup> Degener, 2016.

<sup>90</sup> Bruce, 2014, p. 366.

<sup>91</sup> Emphasis added.

<sup>92</sup> Preamble (p), CRPD.

<sup>93</sup> Bruce, 2014, p. 331.

<sup>94</sup> See for instance the work of Kimberlé Crenshaw, such as; Crenshaw K. ‘Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Politics and Antiracist Politics’ (1989) University of Chicago Legal Forum. According to Crenshaw, law needs to be informed by this intersectionality to ensure that certain people or marginalised groups who possess an interaction of different layers of identity risk falling between the “single axis” that discrimination law often creates.

<sup>95</sup> Smith B, ‘Intersectional Discrimination and Substantive Equality: A Comparative and Theoretical Perspective’ (2016) 16 *The Equal Rights Review* [Smith, 2016] p. 76. Intersectionality is closely linked to substantive equality, a concept often described as the goal to address persistent inequality, see Smith, 2016, p. 75.

subject” and reveal discrimination as “multiple or aggravated forms of discrimination”.<sup>96</sup>

Further, preamble (r) conceptualise disability and age by specifically addressing “children with disabilities” as subjects under the CRPD:

*[C]hildren with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child[.]*<sup>97</sup>

Preamble (p) and (r) of the Convention in this way recognise that that children with disabilities possess a multi-vulnerability due to their impairment and age, illustrating an intersectionality perspective. Given that the aim of applying an intersectional approach to law is to better identify and eliminate the power dynamics perpetuating systems of privilege and disadvantage,<sup>98</sup> the Convention has the potential to target one of the most vulnerable or least privileged group members, in this case children with disabilities.

Essentially, the perspective of disability and age – the acknowledgement of the two layers of identities – and the recognition of “children with disabilities” as a subject is evident by the mere existence of article 7; a stand-alone article on “Children with disabilities”. The article reads as follow:

- 1. States Parties shall take all necessary measures to ensure **the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.***
- 2. In all actions concerning children with disabilities, the **best interests of the child** shall be a primary consideration.*
- 3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their **views being given due weight in accordance with their age and maturity**, on an equal basis with other children, and to be provided with disability and age-appropriate **assistance** to realize that right.<sup>99</sup>*

Article 7 apply to all rights and freedoms of the Convention.<sup>100</sup> The first section refers to the general recognition that children with disabilities have equal rights with other children and the second section establishes the principle of the best interest of the child. The principle of the best interest of the child is modelled upon the same principle established in the CRC.<sup>101</sup> It is important to note that the principle is founded on a welfare approach to childhood<sup>102</sup> and the CRC has been criticised for relying on a medical model

<sup>96</sup> Smith, 2016, p. 80.

<sup>97</sup> Emphasis added.

<sup>98</sup> Smith, 2016, p. 75.

<sup>99</sup> Emphasis added.

<sup>100</sup> Bruce, 2014, p. 332.

<sup>101</sup> Article 3(1), CRC.

<sup>102</sup> See Broderick A ‘Article 7 Children with Disabilities’ in Della Fina V, Cera R and Giuseppe P (Eds.) *The United Nations Convention on the Rights of Persons with*



of disability.<sup>103</sup> Therefore, the principle risks being essentially paternalistic and not “rights-based”.<sup>104</sup> This weakness is however complemented by the third section of the article, which includes the principle of recognising the evolving capacities of the child and that children’s views should be given due weight in accordance with their age and maturity. In this way the third section addresses the difference between the rights of a child and the rights of an adult as being qualified autonomy and not a pure paternalistic view.<sup>105</sup> The qualified autonomy could also be interpreted from General principle 3(h) which recognise the “evolving capacities” of children with disabilities as well as the right to “preserve their identities”.

The key article for the purpose of the current thesis – article 23 – also highlights the interdependence between the child and his or her family in order to enjoy the equal right to family life.<sup>106</sup> For instance, the article obliges states to provide “services and support to children with disabilities and their families”<sup>107</sup>, prohibit separations of children from their family unless it is necessary in the best interest of the child, and prohibit separation “on the basis of a disability of either the child or one or both of the parents”.<sup>108</sup>

Conclusively, the CRPD recognises the intersection between disability and age and children with disabilities as compound subjects with entitlements equal to all other children. It also address the multi-vulnerability among children with disabilities since they are particularly exposed to different forms of abuse. Finally, the Convention highlights the interdependence between the child and his or her family. As will be demonstrated throughout legal analysis, article 23 on “Respect for home and the family” is shaped by this understanding of disability and age.

*Disabilities: A Commentary*, (2017 Springer International Publishing AG) [hereinafter Broderick, article 7, 2017] p. 207.

<sup>103</sup> *Ibid*, p. 197.

<sup>104</sup> *Ibid*, p. 207.

<sup>105</sup> Bruce, 2014, pp. 332-333.

<sup>106</sup> *Ibid*, pp. 334-335.

<sup>107</sup> Article 23(3), CRPD.

<sup>108</sup> Article 23(4), CRPD.

## 4 The obligation not to separate children without the agreement of the parents

Chapters four to seven are divided on a basis of different problem-based situations upon which the legal analysis of children's right to live within a family and corresponding state obligations is conducted. This first chapter concerns situations where the separation of children with disabilities from their families is enforced by the authorities without the agreement of the parents. Out of the provisions in article 23 on "Respect for home and the family", the provision in 23(4) – providing that states shall ensure that a child shall not be separated from their parents against their will – is the main provision to analyse here.

The legal analysis of article 23(4) is interpreted through, in particular, article 23(3), article 7 on "Children with disabilities" and article 19 on "Living independently and being included in the community". As indicated above, the analysis of articles 23, 7 and 19 also leads to other relevant provisions such as the CRPD Preamble, article 2 on "Definitions", and article 3 on "General principles". In this chapter, the main focus is on Preamble (r) and (x), article 2(3) in the definition of "discrimination on the basis of disability", 3(b) on non-discrimination, 3(c) on participation and inclusion, and 3(e) on equality of opportunity. Article 5(2) on "Equality and non-discrimination" is relevant since it prohibits all discrimination on the basis of disability and article 16(1-2) of the CRPD on "Freedom from exploitation, violence and abuse" is relevant because it regulates when the state has an obligation to act in cases of abuse or neglect of a child.

Initially, a few comments on the terms "home" and "family" found in the name of article 23 is necessary.<sup>109</sup> In addition to article 23, the term "home" also occurs in other relevant provisions such as article 16<sup>110</sup> and article 19<sup>111</sup>, but is not defined in the text of the Convention. The term has however been elaborated upon in relation to article 17 of the International Covenant on Civil

<sup>109</sup> Another key term for the purpose of this thesis is the reference to "particular living arrangement" in article 19. This, together with the term "institution" will however be dealt with under chapter seven "The obligation to provide alternative care and acceptable living arrangements" below.

<sup>110</sup> Article 16(1) of the CRPD reads as follows:

*States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.*

<sup>111</sup> Article 19(b) of the CRPD reads as follows:

*Persons with disabilities have access to a range of in-home, residential and other community support services [...].*

and Political Rights (hereinafter the “ICCPR”)<sup>112</sup> and article 8 in the ECHR<sup>113</sup> which can be applied *mutatis mutandis* to article 23.<sup>114</sup> According to the UN Human Rights Committee (hereinafter the “HRC”), home “is to be understood to indicate the place where a person resides or carries out his usual occupation.”<sup>115</sup> According to the ECtHR, the term “includes housing, business premises, dependencies of a building, caravans, and also homes built in contravention of applicable town planning regulations”.<sup>116</sup> The ECtHR thereby provides a broad understanding of the term, not only including current place of residence.<sup>117</sup>

The term “family” is not defined as such but is however found in the preamble of the CRPD, referred to as “the natural and fundamental group unit of society”.<sup>118</sup> Article 23 mentions the term in several paragraphs and also includes references to the “immediate family” and the “wider family”, which indicates that the Convention adopts a broad understanding to the term.<sup>119</sup> The HRC outlines that the term family shall “be given a broad interpretation to include all those comprising the family as understood in the society of the State party concerned.”<sup>120</sup> In addition, the ECtHR emphasise the need to refer to the “social conception” of the term family – *de facto* relationships – rather than *de jure* notion of a family.<sup>121</sup> The broad understanding of the term family covering different forms of relationship between adults and children is also emphasised in commentaries to the CRPD.<sup>122</sup>

<sup>112</sup> Article 17 on “arbitrary or unlawful interference with his privacy, family, home or correspondence”, United Nations General Assembly, International Covenant on Civil and Political Rights [hereinafter ICCPR], GA Resolution 2200A (XXI), United Nations, Treaty Series, Vol. 999, p. 171, 16 December 1966.

<sup>113</sup> Article 8 on the “right to respect for private and family life”, ECHR.

<sup>114</sup> Della Fina V ‘Article 23 on the respect for home and the in Della Fina V, Cera R and Giuseppe P (Eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, (2017 Springer International Publishing AG) [hereinafter Della Fina, article 23, 2017] p. 428.

<sup>115</sup> UN Human Rights Committee, CCPR General Comment No. 16: Article 17, The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation [hereinafter CCPR General Comment No. 16, 1988], 8 April 1988, para. 5.

<sup>116</sup> Della Fina, article 23, 2017, pp. 428-429.

<sup>117</sup> *Ibid*, p. 428 referring to ECtHR cases such as *Niemietz v. Germany*, App no. 13710/88, (ECHR 16 December 1992), *Demades v. Turkey*, App no. 16219/90, (ECHR 31 July 2003), *Buckley v. the United Kingdom*, App no. 20348/92, (ECHR 29 September 1996) and *Chapman v. the United Kingdom*, App no. 27238/95, (ECHR 18 January 2000).

<sup>118</sup> Preamble (x), CRPD. The same paragraph also recognise that the family “is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”. The paragraph includes the same wording as article 16(3) of the UN General Assembly, Universal Declaration of Human Rights (UDHR), 217 A (III), 10 December 1948.

<sup>119</sup> Article 23(5), CRPD.

<sup>120</sup> CCPR General Comment No. 16, 1988, para. 5.

<sup>121</sup> Della Fina, article 23, 2017, p. 430.

<sup>122</sup> See for instance Della Fina, article 23, 2017 and; Fiala-Butora J ‘Art. 23 Respect for Home and the Family’ in Bantekas I, Stein A and Michael Anastasiou D (Eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (2018 Oxford University Press) [hereinafter Fiala-Butora, article 23, 2018].

## 4.1 Best interest of the child

Article 23(4) provides for an extensive protection for children to live within a family (and not to be separated from their family) and reads as follow:

*States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.*

The obligation to “ensure” entails that the state has a positive obligation to ensure that a child is not separated from their parents without the agreement of the parents. The purpose of the paragraph is to protect against undue state involvement in the form of removing children from families. The only exception to the rule of non-separation under article 23(4) is when a separation is considered to be “necessary for the best interests of the child”. In addition there is the requirement of lawfulness – the removal has to be taken in accordance with national law, by the competent authorities. It must also be subject to judicial review. Finally, in no case can disability – of either the child or the parent – be the reason for family separation without the agreement of the parents. Accordingly, all separations of children from their families are not prohibited.

Even if a decision to separate a child from their family is not based on the disability of the child, is in accordance with national law and procedure and is subject to judicial review, the separation of the child still needs to be in accordance with the criteria “in the best interest of the child”. In a situation where the authorities have taken a decision to remove a child, such a decision must therefore be in accordance with the best interest of the child in order to be lawful under the CRPD.

Article 7 of the CRPD concerning children with disabilities is intrinsically linked to article 23. It is of outmost importance when interpreting the right of children to family life because it emphasises the specific perspective of children’s rights.<sup>123</sup> Article 7(2) reads as follows:

*In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.*

Article 7(2) echoes the best interest principle found in article 23(4) and indicates the importance of this principle in all actions covered by the CRPD. While article 7(2) is relevant generally for all rights and obligations throughout the CRPD, article 23(4) is focused particularly on the best interest

<sup>123</sup> See Broderick, article 7, 2017, p. 200.

principle in cases of separation. It is evident that a separation is only permissible when conducted in the best interest of the child.

The rights of children with disabilities including the right to family life in article 23<sup>124</sup> and article 7<sup>125</sup> of the CRPD are modelled upon the provisions in the CRC.<sup>126</sup> Given this close connection between article 3(1) in the CRC and article 7(2) of the CRPD, the interpretation by the CRC Committee is relevant when interpreting the best interest of the child as well as children's right to family life. The CRPD Committee has not itself provided any guidance on the best interest principle, but they have referred to the interpretation of the CRC Committee, emphasising that the concept shall be applied to children with disabilities.<sup>127</sup> The CRC Committee has observed that "[t]he best interests of the child is a dynamic concept that encompasses various issues which are continuously evolving"<sup>128</sup> and that it is a threefold concept consisting of a substantive right, a fundamental interpretative legal principle, and a rule of procedure.<sup>129</sup> Most importantly, the CRC Committee has affirmed that "[c]hildren with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects."<sup>130</sup>

Accordingly, the CRC Committee establishes that the best interest of the child, including children with disabilities, is to live with their own family.

<sup>124</sup> Article 9(1-3) of the CRC reads as follow:

*1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.*

*2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.*

*3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests.*

<sup>125</sup> Article 3(1) of the CRC reads as follow:

*1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.*

<sup>126</sup> However, while the CRC emphasise a "medicalised or welfare approach to disability"; see Broderick, article 7, 2017; the CRPD in contrast recognise disability as a result from the "interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."; see preamble (e), CRPD.

<sup>127</sup> CRPD Committee, General Comment No. 6: Article 5: equality and non-discrimination [hereinafter CRPD General Comment No. 6, 2018], UN doc: CRPD/C/GC/6, 9 March 2018, para 38.

<sup>128</sup> United Nations Committee on the Rights of the Child [hereinafter CRC Committee], General comment No. 14: Article 3(1): on the right of the child to have his or her best interests taken as a primary consideration [hereinafter CRC General Comment No. 14, 2013], UN doc: CRC /C/GC/14, 29 May 2013, para 11.

<sup>129</sup> CRC General Comment No. 14, 2013, para 6.

<sup>130</sup> CRC Committee, General comment No. 9: The rights of children with disabilities [hereinafter CRC General Comment No. 9, 2006], UN doc: CRC/C/GC/9, 27 February 2007, para. 41.

Consequently, and as indicated above, any separation of a child from her / his family must be done in accordance with the best interest principle – which as a rule is to live within their family. The point of departure must therefore always be for a child with disabilities to live within their own family in accordance with the best interest principle. However, this does not necessarily mean that a separation can never be in the best interest of the child. The interpretation of article 23(4) and the best interest principle risks resulting in a catch 22, since it can both mandate and forbid separations of children from their families. The best interest principle can be used both to legitimise a separation, but also as an argument against a separation, since the best interest of a child as a rule is to live within a family.

The best interest principle and the *equal* right to family life runs parallel to each other, and informs each other. Crucially, the equality aspect is measured against the life, interests and rights of other children – which is to live and grow up in their own family. Consequently, a core aspect of children’s life and rights is the right to live within a family. This informs not only what equality for children is, but also the best interest principle. Just as article 23(3) gives equal right particularly to family life, article 7(1) underscores the importance of equal rights for children of all rights and freedoms in the CRPD on an equal basis with other children. Article 7(2) is also inextricable linked to children’s equal enjoyment of rights in article 7(1). The equal right for children with disabilities is emphasised in the preamble as one of the core objectives of the CRPD.<sup>131</sup> The equal right to family life is further analysed in section 4.4.<sup>132</sup> and in chapter six.

## **4.2 Circumstances under which a separation is “in the best interest of the child”**

According to the analysis above, the only limitation in article 23(4) to the right to family life – instances where separation might be permissible – is when it is conducted in the best interest of the child. Article 23(4) does not however outline what kind of harm needs to be present for a legitimate separation to be conducted. Instead, the only point of reference is the best interest principle. Neither does article 23(4) outline any specific standard or threshold for when a separation can be considered legitimate or even required.<sup>133</sup> Therefore, the most difficult part of this analysis is to establish what kind of harm tips the scale so that it is no longer in the best interest of the child to remain with his / her family, making a separation permissible.

<sup>131</sup> Preamble (r), CRPD.

<sup>132</sup> The chapter includes an analysis of “discrimination on the basis of disability” emphasising that disability cannot be a reason for any separation, as outlined in article 23(4).

<sup>133</sup> Article 9(1) of the CRC, on which article 23(4) is modelled upon, outlines that a determination of whether or not to separate the child from her or his parents may be necessary in a case involving “abuse or neglect” of the child by their parents.

A contextual interpretation of article 23(4) leads to article 23(3) which contains the closest reference to the different kinds of harm the right to family life aims to prevent:

*States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*

The article includes reference to different kinds of harm – “concealment”, “abandonment” “neglect” and “segregation” of children with disabilities – but in the primary context of improving the living conditions for the family by service and support. Among these, while the words abandonment and concealment (and obviously segregation) speak against segregation, the word neglect speaks to the kind of situation that could be a legitimate reason for separation. In addition to article 23(3), article 16(1) on freedom from exploitation, violence and abuse of the CRPD generally conceptualise the kinds of harm that would make a separation legitimate. The context here is state action generally to avoid harm of adults and children with disabilities. Article 16(1) obliges states to “take all appropriate legislative, administrative, social, educational, and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse”.

State parties are obliged to protect persons with disabilities (including children) from “all forms of exploitation, violence and abuse”. Among these forms of harm, the word “abuse” indicates the least severe kind of situation that could be a legitimate reason for separation under article 16. Conclusively, both articles 23(3) and 16 include different kinds of harm that the right to family life aims to prevent. Thus, determining whether a separation is legitimate or not points towards the two words “neglect” and “abuse”. Accordingly, the CRPD provides for a high threshold for states to intervene in order to make a separation legitimate. An interpretation of the ordinary meaning of the word “neglect” in article 23(3) would however indicate a lower threshold than the word “abuse” in article 16. Since separations of children from their family is a very intrusive measure this indicates that the higher threshold on the severity of harm found in article 16 is more suitable for determining when a separation is legitimate. The high threshold on the severity of harm should be read in conjunction with the state obligation to provide support to children with disabilities and their families found in both article 23(3) and 16(2).

While article 16(1) conceptualises the kinds of harm that would legitimise a state interference, article 16(2) adds the obligation to take preventive measures and to provide support to persons with disabilities and their families to avoid any harm. Article 16(2) obliges states to: “take all appropriate

measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, [...]. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.” Article 16 therefore provides the state obligation to both support families to prevent harm and the obligation to protect children from harm, indirectly through e.g. separation from their family as envisaged in article 23(4). Clearly, both article 23(3) and article 16 have strong links to the prevention of harm and the obligation to provide assistance to families in order to care for their child. The strong obligation to provide adequate assistance supports the high threshold for states to intervene with the right to family life through separation. Instead, the main aim must be to support families through support and assistance in order to avoid harm such as neglect and / or abuse, which in turn risks actualising separation.

The CRPD Committee does not give any guidance on how these thresholds for the kinds of harms or the severity of harms should be interpreted in relation to separation. As already mentioned, the best interest of the child principle in the CRPD is closely related to the CRC, therefore, the general comments from the CRC Committee can be used to aid interpretation of the best interest principle here. The CRC Committee has emphasised that any separation can “only occur as a last resort measure” and should not be conducted “if less intrusive measures could protect the child” in order to be in accordance with the best interest principle.<sup>134</sup> Accordingly, the CRC Committee establishes that a separation is only permitted as an exception – a last resort – after all other means, including adequately providing for the family, have been exhausted. The strong emphasis on the obligation to provide assistance in the CRPD (as discussed more in detail under chapter five and six below) indicates that less intrusive means must be exhausted before separation is considered.

The choice to separate the child can be made before any harm has occurred or after the harm already happened. Articles 23(3) and 16(1) does not give any guidance in this regard, and the CRPD Committee has not taken a stand. The issue has however been discussed by the CRC Committee in the context of the best interest principle. According to the CRC Committee, an assessment of the best interest principle requires decision-making authorities to assess “the possibility of future risk and harm”.<sup>135</sup> However, the CRC Committee further emphasise that “[g]iven the gravity of the impact on the child of separation from his or her parents, such separation should only occur [...] when the child is in danger of experiencing imminent harm or when otherwise necessary”.<sup>136</sup> A specific conclusion on at what point a separation

<sup>134</sup> CRC General Comment No. 14, 2013, para 61.

<sup>135</sup> *Ibid.*, para 74. The CRC Committee also stress that an assessment of the best interest principle includes the state obligation to “ensure the child such protection and care as is necessary for his or her well-being”, see para 71; and that ““protection and care” must also be read in a broad sense, since their objective is not stated in limited or negative terms (such as “to protect the child from harm”), but rather in relation to the comprehensive ideal of ensuring the child’s well-being and development”, see para 72.

<sup>136</sup> CRC General Comment No. 14, 2013, para 61.



is legitimate must be analysed on a case by case basis, and is therefore not possible to establish in the current thesis. Generally however, it must be stressed that the risk of harm must be imminent in order for the separation to be justified, due to the intrusiveness of such state intervention.

To conclude, the legal analysis above suggest that the kind of harm that needs to be present for a legitimate separation to be conducted might be drawn from the words found in article 23(3), “neglect”, and article 16(1- 2), “abuse”. The risk of harm – any form of neglect and abuse – must arguably also be imminent in order for a separation to be in compliance with the CRPD. An interpretation of the ordinary meaning of the two words leads us to different thresholds, where “neglect” could be seen as lower than “abuse”. The high intrusiveness of a separation of children with disabilities from their family however favours a high threshold, like the one found in article 16. The high threshold for states to intervene in family life through separation is further supported by the strong obligation to provide adequate assistance to prevent any harm in the first place. The intrusiveness of a separation is also linked to the best interest of the child as being able to live within a family, which in turn is informed by the equal right to family life.

Accordingly, the point of departure is that the best interest of the child is to live within a family and any separation of a child negates this right. The only potential limitation in article 23(4) to the enjoyment of the right to family life is if a child is facing harm in terms of neglect and / or abuse or in any other way face imminent risk of such harm. A decision to separate the child from their family must therefore address both the severity of the harm and the risk of such harm.

In a situation where the parents actually are unable to take proper care of their child, which may amount to neglect (according to article 23(3)) and in some cases also abuse (according to article 16), a separation can be conducted in accordance with the best interest principle despite the heavy emphasis on the right of the child to remain in their own family.

However, if any (risk of) neglect or abuse is due to the lack of assistance to the parents to care for their child, the separation could have been avoided with adequate assistance. Such a situation would therefore comprise both an analysis of whether the separation was in the best interest of the child or not (as outlined above), as well as an analysis of necessary assistance – which will be analysed in chapter six below.

### **4.3 Procedural requirements and lawfulness of a decision to separate children from their parents**

In addition to the material condition – that any separation decision has to be in accordance with the best interest of the child – the separation decision also

actualises requirements of procedure and lawfulness. Article 23(4) prohibits any separation of a child from their parents, except when “competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child”.

The provision prescribes that any separation without the agreement of the parents must be conducted “in accordance with the applicable law”, and thereby establishes the requirement of lawfulness. As part of the requirement of lawfulness, the decision must be taken in accordance with the applicable procedure by the competent authorities. There is also the requirement that such a decision must be subject to judicial review.

### *Lawfulness*

The requirement of lawfulness and procedure in article 23(4) establishes a range of requirements that need to be fulfilled in order to justify any restriction of the right to family life. All requirements and procedural guarantees that needs to be ensured are not however explicit in the article, but is implicit in the substantive right to family life. Procedural requirements are particularly important in relation to article 23(4) since the material right is about the process to separate children from their parents and subsequently place children in a particular living arrangement. In order to ensure the effective realisation of the substantive right (to family life), there must be a procedure in place to ensure that right. A situation where a child has been separated from their parents might therefore comprise of both a material problem (with a separation and the reasons behind the separation), as well as a problem with the lawfulness of the decision as such. Initially, it is important to recognise that being a child combined with having an impairment might result in a double vulnerability when it comes to the requirement of lawfulness and procedure in separation cases.

The CRPD Committee does not provide any guidance with regard to the requirement of lawfulness in article 23(4). Therefore, the question of what kind of legislation that can be seen as adequate or even existing with regard to such an intrusive measure as separation of children from their parents is not addressed by the CRPD Committee. However, international human rights law, specifically the case law from the ECtHR, outlines some general requirements on lawfulness which are relevant to the rights in most human rights conventions.<sup>137</sup> In order to gain more detailed guidance on lawfulness, it is therefore relevant to look at the ECHR and the case law of the ECtHR. The justification of restrictions – lawfulness – is throughout ECtHR case law divided into sub-requirements; the requirement of a “basis is domestic law”<sup>138</sup>; the requirement of accessibility of the legal basis; the requirement of non-arbitrariness and procedural due care.<sup>139</sup> Elements of foreseeability, non-

<sup>137</sup> Gerards J *‘General Principles of the European Convention on Human Rights’* (2019 Cambridge University Press) [hereinafter Gerards, 2014] p. 198.

<sup>138</sup> According to the CRPD “in accordance with the applicable law”.

<sup>139</sup> Gerards, 2014, p. 198.

arbitrariness and certain procedural safeguards are linked and used in conjunction in order to determine the lawfulness of an interference.<sup>140</sup>

*In accordance with applicable law*

The requirements that a decision has “basis in domestic law” – is in the CRPD referred to as the requirements that the decision being taken is “in accordance with applicable law”. It generally means that a restriction must be lawful (under national law) in order to be justified. Obviously, in order to be in accordance with this first requirement, there must first of all exist a legal provision in the national law. On a general level, the ECtHR most often follow the national court’s assessment on the lawfulness of the applicable legislation.<sup>141</sup> One could assume that the CRPD Committee might take a more progressive approach than the ECtHR in this regard.<sup>142</sup> Clearly, there are normative synergies between the ECHR and the CRPD,<sup>143</sup> even though there are differences with regard to the scope of application of the two instruments.<sup>144</sup> Since its adoption, the CRPD has influenced the case law of the ECtHR in its interpretation of disability rights.<sup>145</sup> It is however the CRPD Committee that has assumed the leading role in the protection of the rights of persons with disabilities.<sup>146</sup> Commentators mostly refer to the CRPD Committee as a body “widening the protection provided for persons with disabilities” and to the ECtHR as following the (more progressive) path taken by the CRPD Committee.<sup>147</sup> In this light, it is likely that the CRPD Committee will be slightly more radical in its assessment on the lawfulness of the national application of law.<sup>148</sup>

<sup>140</sup> Gerards, 2014, p. 214.

<sup>141</sup> *Ibid.*, p. 203.

<sup>142</sup> While most of the literature on the relationship between the ECHR and the CRPD concerns the ECtHR’s interpretation of the CRPD and the decisions, guidelines and general comments of the CRPD Committee, not much have been written on how the CRPD Committee in turn interprets the ECHR; see for instance; Broderick A, ‘The United Nations Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights: A Tale of Two Halves Or a Potentially Unified Vision of Human Rights’ (2018) 7:2 Cambridge International Law Journal [hereinafter Broderick, 2018] and; Favalli S, ‘The United Nations Convention on the Rights of Persons with Disabilities in the Case Law of the European Court of Human Rights and in the Council of Europe Disability Strategy 2017–2023: ‘from Zero to Hero’ (2018) 18:3 Human Rights Law Review [hereinafter Favalli, 2018].

<sup>143</sup> However, there are clear normative gaps between the ECHR and the CRPD such as legal capacity, see for instance Favalli, 2018, p. 537.

<sup>144</sup> Broderick, 2018, p. 223.

<sup>145</sup> In the context of Council of Europe, see for instance Favalli, 2018, p. 537.

<sup>146</sup> Favalli, 2018, p. 537.

<sup>147</sup> *Ibid.*

<sup>148</sup> See CRPD Committee, H.M. v. Sweden [hereinafter H.M. v. Sweden, 2012], Communication No. 3/2011, Views adopted by the Committee at its Seventh Session, 16-27 April 2012, UN doc: CRPD/C/7/D/3/2011, 21 May 2012. The CRPD Committee considered the application of the Swedish Planning and Building Act and challenged the national application of the law by stating that it allowed “for departure from the development plan, and that it can thus accommodate, when necessary in a particular case, an application for reasonable accommodation aimed at ensuring to persons with disabilities the enjoyment or exercise of all human rights on an equal basis with others and without any discrimination”, see para 8.5.

### *Accessibility and foreseeability*

The requirement of accessibility of the legal basis stems from the ECtHR landmark decision *Sunday Times v. the United Kingdom* which introduced the standard of law being “adequately accessible” as well as the standard that the law must be formulated with “sufficient precision” in order to be regarded as law.<sup>149</sup> The accessibility standard can be met in many different ways, and states often have a leeway in describing how certain laws are accessible to the citizens. The standard set by the ECtHR can therefore not be considered particularly strict.<sup>150</sup> The standard of foreseeability refer to the fact that one must be able to foresee the consequences of one’s action.<sup>151</sup> The circumstances in each specific case will obviously be decisive for a determination of whether or not the legislation in question can enable the individual to regulate her / his conduct.<sup>152</sup> Generally, the ECtHR recognises the need for legislation to be vague and general. At large, the case law of the ECtHR suggests that the standard of foreseeability of law can be met quite easily if individuals can reasonably be expected to know how it will be applied to them.<sup>153</sup> It is however important to emphasise that “the level of precision required of domestic legislation depends to a considerable degree on the content of the law in question, the field it is designed to cover, and the number and status of those to whom it is addressed”.<sup>154</sup> Based on the above requirements on accessibility and foreseeability, the level of precision required of national legislation is arguably quite high, given the severity of the interference in question, the importance of the right to family life and the potentially vulnerable situation the family is in. This requirement will therefore enable an evaluation of whether or not the national legislation in question is too general and / or vague, which could give the local authorities too wide a discretion with regard to the separation of children with disabilities from their family as well as with regard to the placement of the child in a particular living arrangement.

### *Arbitrariness and procedural safeguards*

The requirements of accessibility and foreseeability can also sometimes border the requirement of absence of arbitrariness.<sup>155</sup> Thus, it is not enough that the law exists and is “adequately accessible” and formulated with “sufficient precision”, but it must also contain a certain quality that could guarantee the absence of arbitrariness.<sup>156</sup> The ECtHR has referred to elements of arbitrariness as a separate element of the test of lawfulness.<sup>157</sup> At the same time, the requirement of non-arbitrariness is closely related to the overall lawfulness of an interference.<sup>158</sup> In most ECtHR cases however, the

<sup>149</sup> *Sunday Times v. the United Kingdom*, App no 6538/74 (ECHR 26 April 1979), para 48.

<sup>150</sup> Gerards, 2014, pp. 203-205.

<sup>151</sup> *Sunday Times v. the United Kingdom*, App no 6538/74 (ECHR 26 April 1979), para 49.

<sup>152</sup> Gerards, 2014, p. 205.

<sup>153</sup> *Ibid*, p. 209.

<sup>154</sup> *Ibid*, p. 206.

<sup>155</sup> *Ibid*, p. 212.

<sup>156</sup> *Ibid*, p. 213.

<sup>157</sup> *R.Sz. v. Hungary*, App no 41838/11 (ECHR 2 July 2013), para. 36.

<sup>158</sup> Gerards, 2014, pp. 212-213.

requirement of absence of arbitrariness is connected to procedural safeguards.<sup>159</sup>

The ECtHR refers to the requirement of having a procedural infrastructure at the national level to ensure the absence of arbitrary application of national legislation, and thereby also ensure the rights contained in the ECHR.<sup>160</sup> Most of the ECtHR case law in this area concerns interferences such as surveillance, interception of communications or other measures taken in secret.<sup>161</sup> On a general level, the ECtHR has made clear that the mere existence of a procedural infrastructure – and qualitative legislation – is not always enough to justify a restriction. Rather, “the manner in which all these guarantees have been applied in the particular circumstances of the case” is relevant to determine the lawfulness of a restriction.<sup>162</sup>

As already mentioned, the different sub-requirements of lawfulness are interconnected. The compatibility of these requirements can also be seen as part of the compliance with the so called “procedural positive obligations” found in the case law of the ECtHR.<sup>163</sup> Article 8 on the right to family life of the ECHR includes legal standards that are relevant when determining whether a certain procedure could be considered arbitrary or amount to a violation of the procedural positive obligations.<sup>164</sup> In short, when determining whether a substantive right of the ECHR has been violated (here article 8 on children’s right to family life) the ECtHR takes into consideration procedural shortcomings by the national authorities. A number of procedural positive obligations have been established by the ECtHR. This includes procedural guarantees for individuals such as; the procedure for investigation; the availability of remedies; and the right to be heard before the decision would take place.<sup>165</sup>

#### *Decision-making processes and the right to be heard*

As mentioned above, the CRPD Committee does not provide any specific guidance with regard to the requirements of lawfulness and quality of procedure in article 23(4). It is therefore hard to comprehend the kind of process that the CRPD Committee would deem adequate in relation to such an intrusive measure as the separation of children from their parents (and subsequently the placement of the child in a particular living arrangement). It is however likely that the CRPD Committee would emphasise the importance

<sup>159</sup> Gerards, 2014, p. 214.

<sup>160</sup> *Ibid.*

<sup>161</sup> *Ibid.*, p. 214-215.

<sup>162</sup> *Ibid.*, p. 216.

<sup>163</sup> *Ibid.*, p. 219.

<sup>164</sup> ECHR does provide an obligation of states to secure the practical and effective protection of the rights and freedoms in the ECHR see article 1 of the ECHR. Through this obligation, the ECtHR has established procedural layers of the substantial rights for instance the right to family life under the article 8, see Brems E ‘Procedural Protection: An examination of procedural safeguards read into substantive convention rights’ in Brems E and Gerards J (Eds.) *Shaping Rights in the ECHR: the role of the European Court of Human Rights in determining the scope of human rights* (2013 Cambridge University Press) [Brems, 2013], pp. 160-161.

<sup>165</sup> Brems, 2013, pp. 144-154.

of participation of interested persons (in this case both the child and the parents) in such a procedure, evaluating if the individuals concerned have been properly involved.<sup>166</sup>

One procedural guarantee that is key in any decision-making processes concerning children is the right to be heard, which is outlined in article 7(3) of the CRPD and reads as follows:

*States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.*

Article 7 thus includes a procedural aspect with regard to the right to be heard in matters affecting children with disabilities. The requirement in article 23(4) that a separation must be “in accordance with applicable law and procedure” read in conjunction with article 7(3) introduces a requirement to enable the child to express their view with regard to the separation, and for the competent authorities to take the child’s view into consideration when deciding on what is necessary according to the best interest of the child principle. The right to be heard is therefore also part of the best interest of the child principle. The CRPD Committee stresses that the best interest of the child “should be used to ensure that children with disabilities are informed, consulted and have a say in every decision-making process related to their situation”.<sup>167</sup> States must also ensure that “the will and preferences of children with disabilities are respected on an equal basis with other children”.<sup>168</sup> Accordingly, and as established by the CRC Committee, the best interest of the child is a rule of procedure, in addition to being a substantive right and a fundamental interpretative legal principle.<sup>169</sup> The CRC Committee further emphasises that – in procedures concerning children’s right to family life – the authorities need to ensure that the children’s views are given due weight in accordance with their age and maturity.<sup>170</sup> It is of course important to notice that it might exist cases where the right to be heard is not possible to invoke. However, in cases where it is at all possible to hear the child, this must be done and be given weight in the decision in order to comply with the CRPD.

In cases concerning separation the ECtHR has, like the CRPD Committee, also emphasised the centrality of the best interest of the child as well as the

<sup>166</sup> The CRC Committee has expressed concern “at the fact that children with disabilities are not often heard in separation and placement processes”, CRC General Comment No. 9, 2006, para 48.

<sup>167</sup> CRPD General Comment No. 6, 2018, para 38.

<sup>168</sup> CRPD Committee, General Comment No. 1: Article 12: equal recognition before the law [hereinafter CRPD General Comment No. 1, 2014], UN doc. CRPD/C/GC/1, 11 April 2014, para 36.

<sup>169</sup> CRC General Comment No. 14, 2013, para 6.

<sup>170</sup> Article 7(3) and also emphasised by CRPD General Comment No. 1, 2014, para 36.

participation of children in the procedure.<sup>171</sup> In these cases, the ECtHR has stressed the timeliness of the local authority's decision making process and related proceedings in its assessment.<sup>172</sup> In addition to the procedural positive obligations, the ECtHR has established certain implied procedural guarantees driven from the positive obligation to provide fair procedure. An implied procedural guarantee can for instance be the motivation of a decision. Another implied procedural guarantee used by the ECtHR is the overall fairness of the decision-making procedure which includes the standard of a practical and effective right of procedure.<sup>173</sup> In the ECHR context, the ECtHR analyse the relevant procedural safeguards, such as those mentioned above, and conclude whether or not the decision-making processes in the specific case meet the requirement of lawfulness.<sup>174</sup> As already mentioned, these general requirements on lawfulness established by the ECtHR are relevant to the rights in most human rights conventions,<sup>175</sup> and would therefore also be relevant in order to determine whether a separation- and / or placement-decision is lawful.

Relating to quality of the procedure in cases of separation, the CRC Committee stress the procedural state obligation to guarantee that “the situation of the child and his or her family has been assessed, where possible, by a multidisciplinary team of well-trained professionals with appropriate judicial involvement” in line with the best interest of the child by “ensuring that no other option can fulfil the child's best interest”.<sup>176</sup> This is closely related to the obligation of the state to provide assistance, discussed below under chapter five.

#### *Procedural review*

As mentioned above, the ECtHR has established a number of procedural positive obligations, procedural review being one. It is generally stated in ECtHR case law, that the quality of the decision making process matters for the ECtHR's review. If a decision has been properly prepared through deliberation and an open or transparent decision-making process, the ECtHR may be more acceptable and conclude that such a decision is in conformity with the ECHR.<sup>177</sup> On the contrary, if a specific case would show a lack of procedural due care, the ECtHR might take it into account to determine the overall reasonableness of the interference.<sup>178</sup> Just as the ECtHR considers the overall quality of the procedure (including quality of legislation and the existence of a procedural infrastructure) in its review, it is likely that the

<sup>171</sup> Brems, 2013, p. 150; referring to *Saviny v. Ukraine*, App no 39948/06 (ECHR 23 December 2008), para 51.

<sup>172</sup> Brems, 2013, p. 151; referring to *W. v. UK*, App no. 9749/82 (ECHR 8 July 1987), para 65.

<sup>173</sup> *Airey v. Ireland*, Series App no. 32 (ECHR 9 October 1979), para 24.

<sup>174</sup> *Dragojevic v Croatia*, App no. 68955/11 (ECHR 15 January 2015), para 83; *Big Brother Watch and others v. the UK*, App. nos. 58170/13, 62322/14 and 24960/15 (ECHR 13 September 2018), para 307.

<sup>175</sup> Gerards, 2014, p. 198.

<sup>176</sup> CRC General Comment No. 14, 2013, para 64.

<sup>177</sup> Gerards, 2014, p. 258.

<sup>178</sup> *Ibid*, p. 259.

CRPD Committee will take the same aspects into consideration when determining the overall lawfulness of a restriction of the right to family life.

Conclusively, article 23(4) of the CRPD includes the requirement of lawfulness and procedure in addition to the material condition that any separation decision has to be in accordance with the best interest of the child. It is important to emphasise that the lawfulness of a decision through the procedural leg of article 23(4) would be addressed and evaluated together with a material analysis. Here, the range of requirements outlined above could be addressed in order to argue that a restriction of the right to family life is not justified. The question of the leeway of discretion in the national legislation and what kind of process that can be considered adequate is key to evaluate the effective realisation of the equal right to family life for children with disabilities. It can be concluded that the requirement of lawfulness are specifically important in relation to article 23(4) since the material right is largely about the process to separate children from their parents.

#### **4.4 Separation based on the child's impairment as violating the right to non-discrimination**

The last sentence in article 23(4) relates to “discrimination on the basis of disability” and reads as follow:

*In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.*

Article 23(4) is unambiguous with regard to the fact that disability can never be a reason for separating children from their parents and consequently the authorities cannot base a decision on separation on the child's disability.<sup>179</sup> The preamble of the CRPD recognizes that “discrimination on the basis of disability is a violation of the inherent dignity and worth of the human person”<sup>180</sup> and article 5(2) emphasise that all discrimination on the ground of disability is prohibited.<sup>181</sup> Article 2(3) defines discrimination on the basis of disability as:

*[A]ny distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental*

<sup>179</sup> The last sentence in article 23(4) is considered to be an anti-discrimination provision, and was included already by the Working Group's draft Convention in 2004; See Draft Article 14 – Respect for Privacy, the Home and the Family, A/AC.265/2004/WG/1, Annex I; as mentioned in Della Fina, article 23, 2017, p. 431.

<sup>180</sup> Preamble (h), CRPD.

<sup>181</sup> Article 5(2), CRPD.



*freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation [.]*

Therefore, a decision to separate a child from their family without the agreement of the parents, based on the disability of the child (whether explicit or implicit) is a clear violation of the CRPD when interpreted in accordance with the ordinary meaning of the text and in line with the object and purpose of the CRPD, which is the right of children with disabilities to enjoy the right to family life on an equal basis with other children; namely to live within a family.<sup>182</sup>

The reference to “all forms of discrimination” in article 2(3) includes any type of discrimination on the ground of disability.<sup>183</sup> Direct discrimination, stemming from the formulation “any distinction, exclusion or restriction” is “when a person is treated less favorable than another similarly situated person because of a particular characteristic, unless there is an accepted justification for the difference of treatment”.<sup>184</sup> In general, it is quite unlikely that the national authorities would base a decision explicitly on the child’s impairment or diagnosis (direct discrimination) but would probably rather, at least explicitly, rely on the neutral criteria found in article 23(4); namely the “best interest of the child”. When the criteria of the best interest of the child is used to measure the parental abilities to care for their child's needs, it is more likely that the authorities’ reasoning in a specific case amounts to indirect discrimination by letting ideas or presumptions about the impairment of the child guide the decision.

Indirect discrimination is not mentioned as such in the CRPD, but could be read from the definition in article 2(3) as any distinction, *exclusion or restriction* “which has the purpose or effect” on the enjoyment or exercise of rights. Indirect discrimination “originate[s] from a differentiation on the basis of an apparently neutral criterion” [in this case the best interest principle] “which has the effect where the members of a group protected by non-discrimination law are disadvantaged compared to the members of another group, and no objective justification can be shown to exist for the applied criterion”.<sup>185</sup> It is likely that explicit or implicit ideas of what is in the best interest of the child and / or the child’s needs is based on assumptions or stereotypes that are closely connected to the child’s impairment or diagnosis. In such a case it might be possible to show that particular aspects of the child’s needs deemed central to the best interest principle are over-represented among children with disabilities – or alternatively not relevant or even true – which would potentially result in indirect discrimination. However, in order to argue indirect discrimination these aspects must be without “objective and

<sup>182</sup> See for instance Preamble (x), CRPD.

<sup>183</sup> Cera R ‘Article 2 Definitions’ in Della Fina V, Cera R and Palmisano G (Eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, (2017 Springer International Publishing AG) [hereinafter Cera article 2, 2017] p. 112.

<sup>184</sup> *Ibid.*

<sup>185</sup> *Ibid.*

reasonable justification”,<sup>186</sup> i.e. amount to irrelevant aspects of the child’s best interests. This would need to be assessed in each individual case depending on the circumstances.

To conclude, a contextual analysis of article 23(4) in line with article 2(3) and article 5(2) emphasises the fact that a separation of a child from her or his family against the parents’ agreement, based on the disability of the child in any of the manners outlined above, is a clear violation of the CRPD. This is also confirmed by the CRPD Committee stating that “separation of a child from his or her parents based on the disability of the child or parents or both is discrimination and in violation of article 23”.<sup>187</sup>

<sup>186</sup> See for instance *H.M. v. Sweden*, 2012, para 8.3 “[t]he right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.”

<sup>187</sup> CRPD General Comment No. 6, 2018, para 61.

## **5 The obligation to provide adequate assistance as a prerequisite for the enjoyment of the right to live within a family**

As established above, a decision to separate a child from their family without the agreement of the parents may or may not be in the best interest of the child at the moment of separation. Disregarding the question of whether the decision at the time of separation was correct for a moment, the next question to consider is how such situations can occur. It might be situations where children are separated from their parents and that this separation derives partly or entirely from the fact that the family has not been provided with adequate assistance in order to take care of their child. This chapter therefore aims to address the underlying reason for a separation – whether or not the state has provided the family with necessary assistance.

The denial to provide assistance is potentially a violation in itself, even before any separation is in question.<sup>188</sup> However, the denial to provide assistance is conceptualised throughout the thesis as rendering the separation as such a violation. Therefore, the primary purpose of the following section is to establish the legal link, the interaction, between the obligation to provide assistance and the right to family life.

The question explored here is whether the separation of children with disabilities from their parents result in a denial of the right to family life under the CRPD, when this outcome derives partly or entirely from the denial of assistance to the parents in caring for the child. The legal analysis is based on a situation where the separation is enforced by the authorities without the agreement of the parents – partly or entirely due to the lack of adequate assistance to the parents in caring for their child.

This includes a legal analysis of the provisions in article 23(3) – providing that states shall provide services and support to children with disabilities and their families – and 19(b) obliging states to ensure that persons with disabilities have access to support services and specifically providing for the right to personal assistance. The legal analysis of article 23 is interpreted through article 7 on “Children with disabilities”. The analysis of articles 23, 19 and 7 also leads to other relevant provisions such as General principles 3(c) on participation and inclusion, and 3(e) on equality of opportunity.

<sup>188</sup> This will however require a thorough analysis of the concept of “progressive realization” which, for the purpose of this thesis, is not part of the analysis, see section 1.2. “Delimitations” above.

Article 16(1-2) of the CRPD on freedom from exploitation, violence and abuse is relevant because it regulates when the state has an obligation to act in cases of abuse or neglect of a child and specifically outlines the state obligation to take measures to prevent violence and abuse by ensuring assistance and support for persons with disabilities and their families.

## 5.1 The obligation to provide assistance

The provision in article 23(3) is key in order to establish the link between the obligation to provide assistance and the right to family life for children with disabilities. As mentioned above, the provision in 23(3) begins by establishing the important provision of children's equal right with respect to family life, which – as will be argued below – essentially is to live within a family like other children.<sup>189</sup> The article continues by establishing that:

*[W]ith a view to realizing these [equal rights with respect to family life], and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*

Article 23(3) explicitly obliges the states to undertake services and support to children with disabilities and their families in order to prevent segregation, and to provide early and comprehensive information to families raising children with disabilities. Article 23(3) therefore provides two different obligations; the obligation to provide services and support and the obligation to inform about such services. These can be violated separately.<sup>190</sup> The failure of providing “early and comprehensive” information about the available assistance is contrary to article 23(3). If however there is no such assistance available, there is of course nothing to inform about. Interpreting article 23(3) together with 23(4), 23(3) indicates an obligation of the state to provide the necessary support (for instance assistance) to the family in order to prevent a separation.

To further strengthen this link article 19(b) on “Living independently and being included in the community” can be invoked. The right to family life for children with disabilities contained in article 23 is intimately linked with article 19 and the right to live independently in the community.<sup>191</sup> Article 19 provide the right of persons with disabilities to live independently and have choices equal to others. The article is founded on the core that all human

<sup>189</sup> Children's equal right to family life will be further analysed in section 6.1. below.

<sup>190</sup> Fiala-Butora, article 23, 2018, see chapter 8 on paragraph 3. In addition, Fiala-Butora stress that the lack of funds does not exempt states from their obligations under paragraph 3. To review the effective allocation of resources, states parties are required to collect disaggregated data on the support provided.

<sup>191</sup> CRPD General Comment No. 5, 2017, para 87.

beings are born equal in dignity and rights and all life is of equal worth.<sup>192</sup> In this way, the article is linked to all situations and activities in life, including the core aspect of children's equal right to family life. As mentioned above, the equality aspect is measured against the life, interests and rights of other children. Article 19 could therefore function as a platform to enjoy other rights<sup>193</sup> – which in this case is the right to live and grow up in their own family. The obligation in article 19(b) reads as follow:

*Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.*

Thus, in addition to article 23(3), article 19(b) outlines an obligation for states to provide adequate support, and particularly outlines “personal assistance necessary to support living and inclusion in the community”. While article 23(3) entails a more exact obligation to provide adequate support specifically aimed towards avoiding separation, article 19(b) adds specifically the obligation to provide personal assistance with the aim of ensuring independent living for persons with disabilities (including children) on an equal basis with others, including having choices equal to others.

General principle 3(e) of the CRPD emphasises that children with disabilities should have equal opportunities as others.<sup>194</sup> Accordingly, the obligation to ensure the equal right to family life stresses that children with disabilities should have the same opportunities and access to family life as other children, which is to live within a family. Further, General principle 3(c) emphasises the importance of full and effective participation and inclusion in society. The right to live in a family is essential in order for children with disabilities to be included and to participate in the society as other children do.<sup>195</sup> An interpretation of the object and purpose of the CRPD in line with articles 23(3) and 19(b) therefore stress the importance of a child with disabilities to live within their own family.

Accordingly, a contextual interpretation of article 23(3) suggests that state parties to the CRPD have extensive obligations to provide adequate assistance to prevent family separation and thereby ensure the right to family life. Consequently, a denial of assistance undermines children's right to live within a family and might result in a potential violation of the equal right to family life.

<sup>192</sup> CRPD General Comment No. 5, 2017, para 2. Article 19 does not have an equivalent in other human rights law treaties and was a response to the “institutionalization” of persons with disabilities. See Degener, 2016, p. 37.

<sup>193</sup> Fiala-Butora J, Rimmerman A and Gur A ‘Art.19 Living Independently and Being Included in the Community’ in Bantekas I, Stein A and Michael Anastasiou D (Eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (2018 Oxford University Press) [hereinafter Fiala-Butora, article 19, 2018] see chapter 1.

<sup>194</sup> As emphasised in General principle 3(e), CRPD.

<sup>195</sup> As emphasised in General principle 3(c), CRPD.

## **5.2 The obligation to prevent neglect and / or abuse through the provision of adequate assistance**

As indicated in section 4.2. above, it might be the case that a decision to separate the child is due to the fact that the child needs protection (in the best interest of the child) because of actual or potential neglect or abuse, where an alternative to separation is no longer feasible as an immediate solution. However, the underlying reason for such a separation might be a result of the state's failure to provide adequate support in the first place.

In cases of abuse, states have an obligation / mandate to act, stemming from article 16, as established above. Article 16(1) obliges states to take all appropriate measures to protect children with disabilities, also within the home, from all forms of exploitation, violence and abuse. Article 16(2) specifically outlines the state obligation to take measures to prevent violence and abuse by ensuring for instance age-sensitive assistance and support for persons with disabilities and their families and caregivers. This provision further strengthens the state's obligation to provide early and adequate assistance in order to prevent neglect and abuse.

It is evident that the state has extensive obligations with regard to the provision of adequate assistance to prevent neglect and abuse, long before any separation may be in question. In other words, the right to family life is dependent and intrinsically linked to the right to adequate service and support. In a situation where the provision of adequate assistance could have prevented the potential neglect and consequently also the separation, the unfulfilled obligation to provide adequate assistance would also erase the only legitimate ground (according to the best interest principle) for separation.

Whether the separation was necessary or not at the time, the separation of the child from their parents due to the lack of adequate assistance violates article 23(3). Further, interpreting article 19(b) including the specific right to personal assistance in line with article 23(3) ensuring the core aspects of children's equal rights with respect to family life, suggests an even stronger obligation on states to provide the necessary support in order to enable children to live with their parents and prevent separation. A separation due to the denial of assistance would therefore also be contrary to article 19(b). Further, children's equal right to family life is a core aspect in both article 23(3) and article 7 stressing the state obligation to ensure that children with disabilities have the right to live with their own family like other children do. Conclusively, denying the family adequate assistance to prevent separation and ensure the right to family life is contrary to the object and purpose of the Convention and violates article 23(3), article 19(b) and article 7. Any such separation which could have been avoided by providing adequate assistance in order to prevent neglect and abuse is also contrary to article 16(1-2) of the CRPD.

This reading of article 19 is in line with the CRPD Committee general comment addressing article 19, stating that the denial of adequate support is a major concern and a threat to the right of children with disabilities to family life.<sup>196</sup> Thus, the CRPD Committee clearly recognise that the right to family life is dependent and intrinsically linked to the right to adequate service and support as discussed above. To further emphasise this link, the CRPD Committee outlines that since “the absence of community-based support and services may create financial pressures and constraints for the family of persons with disabilities; the rights enshrined in article 23 are essential to prevent children from being taken away from their families and being institutionalized, as well as to support families in community living.”<sup>197</sup> Given that the aim of the support services in article 19(b) is inclusion within the community, the CRPD Committee stress that “any institutional form of support services which segregates and limits personal autonomy is not permitted by article 19(b)”.<sup>198</sup>

Most importantly, the CRPD Committee emphasises when addressing article 19 with specific regard to children that “the core of the right to live independently and be included in the community entails a right to grow up in a family”.<sup>199</sup> Realistically, the right to assistance is a support service provided by state funds, where the placement in particular living arrangements are sometimes argued to be more favourable from an economic point of view. However, the CRPD Committee has been clear on the point that arguments from states such as the fact that other options than institutions are too costly are reasonings contrary to article 19.<sup>200</sup> In line with the analysis above, the position of the CRPD Committee on article 19 is consequently very clear, explicitly stressing that the core of the right of the child to live independently in the community entails a right to grow up in a family. Together, this suggests that the separation of a child from her or his parents partly or wholly due to the lack of adequate assistance would be a violation of article 19 and article 23.

Accordingly, a separation without the agreement of the parents necessitates both the analysis of whether the separation was in the best interest of the child, as well as the analysis of whether the necessary assistance was provided. It is clear from the analysis above that the best interest of the child with disabilities under the CRPD is first and foremost to live with their family. In addition, the CRC Committee in addressing the best interest principle stresses that

<sup>196</sup> See for instance CRPD Committee, Concluding Observations on the initial report of Slovakia, UN doc. CRPD/C/SVK/CO/1, 17 May 2016, para on article 23.

<sup>197</sup> CRPD General Comment No. 5, 2017, para 87. This is also linked to acceptable living arrangements analysed in chapter seven below.

<sup>198</sup> CRPD General Comment No. 5, 2017, para 30.

<sup>199</sup> *Ibid*, para 37.

<sup>200</sup> *Ibid*, para 21. Alternatives to the placement within a family or family setting in accordance with article 23(5) will be analysed in chapter seven below. The CRPD Committee also stresses in relation to article 19 that adequate and age-sensitive support services for girls and boys is of particular importance; para 75. So is the need to “provide support, information and guidance to families (article 23) to prevent institutionalization of children with disabilities”; para 75.

“separation may be considered only in cases where the necessary assistance to the family to preserve the family unit is not effective enough to avoid a risk of neglect or abandonment of the child or a risk to the child’s safety”.<sup>201</sup> Thus, the best interest principle presupposes adequate support to prevent harm such as neglect or abandonment. The CRC Committee further establishes the fact that the best care for children with disabilities is provided within their own family, but that this is dependent on adequate support to the family to care for their child.<sup>202</sup>

As the child’s and the parents’ right to family life is dependent and intrinsically linked to the right to adequate service and support as stated above, the denial of support would constitute a violation of article 23(3) as well as article 19(b). Even though the separation might have been implemented in the best interest of the child to prevent abuse and neglect – it has not been conducted as a last resort measure if less intrusive means at an earlier stage was applicable, such as adequate assistance. In order to argue for a violation of articles 23 and 19, a successful case would have to establish the link between denial of assistance and separation. Finally, any separation that could have been avoided by providing adequate assistance in order to prevent neglect and abuse could also be argued as contrary to article 16(1-2) of the CRPD.

### **5.3 The obligation to facilitate family reunification through the provision of adequate assistance**

The obligation to facilitate family reunification is relevant after a separation has been conducted, irrespective of whether or not the separation was legitimate in the first place. There is no provision in the CRPD with regard to the obligation to facilitate family reunification and the CRPD Committee does not provide any guidance on the issue. Even though the CRPD does not specifically address the issue of family reunification, international human rights law outlines some general requirements on family reunification that could be relevant for the interpretation of the right to family life in the CRPD. In the CRC, the provisions concerning family reunification are focused on either refugee children<sup>203</sup> or children with parents living in another contracting state.<sup>204</sup> In relation to the guidance with respect to the CRC Committee, they have recognised the value of the family in relation to migration, stressing that the “preservation of the family unit should be taken into account when assessing the best interest of the child in decisions on family reunifications”.<sup>205</sup> This is echoed on a general level and not specifically in relation to migration, in the General Assembly Resolution on

<sup>201</sup> CRC General Comment No. 14, 2013, para 73.

<sup>202</sup> CRC General Comment No. 9, 2006, para. 41.

<sup>203</sup> Article 22(2), CRC.

<sup>204</sup> Article 10(1), CRC.

<sup>205</sup> CRC General Comment No. 14, 2013, para 66.



the Rights of the Child which encourage states to take “actions to achieve family reunification unless it is not in the best interests of the child”.<sup>206</sup>

In order to gain more detailed interpretative guidance on family reunification, it is relevant to look at other international human rights law sources such as the ECHR and in particular the case law of the ECtHR. Through its case law, the ECtHR establishes an obligation on state parties to facilitate family reunification under article 8 on the right to family life of the ECHR. Briefly, from the perspective of the rights of the child and the parents, the ECtHR emphasises (in line with the position of the CRC Committee noted above) that the separation of the family is the most drastic measure a state can take. It cannot be applied if the situation can be solved by measures that are less drastic than an actual removal of the child.<sup>207</sup> The ECtHR has also held that a guiding principle in decisions to separate children from their parents is its temporality,<sup>208</sup> and that a decision to separate a child from her / his parents and the placement of a child in care “should normally be regarded as a temporary measure, to be discontinued as soon as circumstances permit”.<sup>209</sup> More specifically, the ECtHR has stated that “[t]he positive duty to take measures to facilitate family reunification as soon as reasonably feasible will begin to weigh on the competent authorities with progressively increasing force as from the commencement of the period of care, subject always to its being balanced against the duty to consider the best interests of the child.”<sup>210</sup>

Accordingly, where the child’s right to live within a family is limited on the ground of the best interest of the child due to harm or risk of harm (which is linked to the denial of assistance to the parents), any separation should be approached as a temporary measure. The moment the decision is taken the work to facilitate reunification must commence in order to be in conformity with the CRPD. As established above, the prevention of separation is dependent and intrinsically linked to the right to adequate service and support. This link to the provision of adequate assistance remains part of the state obligation to facilitate family reunification. Consequently, just as the state has an obligation to prevent separation and the obligation to provide assistance is part of that, the obligation to provide assistance will be part of the obligation of reunification. In order to outline a thorough line of argumentation for family reunification, an examination of each individual case is needed.

<sup>206</sup> GA Res, Rights of the child, 2020, para 27. The resolution may be used as a source of interpretation of the obligation to facilitate family reunification.

<sup>207</sup> *Wallová and Walla v. the Czech Republic*, App. No. 23848/04 (ECHR, 26 October 2006).

<sup>208</sup> *Hokkanen v Finland*, App. No 19823/92 (ECHR, 23 September 1994), para 66.

<sup>209</sup> *Saviny v. Ukraine*, App no 39948/06 (ECHR 23 December 2008), para 52.

<sup>210</sup> *K and T v Finland*, App. No 25702/94 (ECHR 12 July 2001), para 178.

## 6 The obligation not to segregate children from their family irrespective of the parents' agreement

A separation of a child from her or his family does not always have to be conducted against the explicit contestation of the parents. On the contrary, in many cases children are separated from their parents with the agreement (even though reluctant) of the parents or even at their initiative. In contrast to a situation where the separation is enforced by the authorities against the explicit contestation of the parents (see chapter four above), the legal analysis in the following chapter have been tailored to the fact that no such explicit contestation from the parents exist.

Even though article 23(4) is concerned with direct state involvement in removing children from families as discussed in chapter four above, it might be possible to argue that the state interfered with the parents' "will" in other ways than forcibly separating children from their family.<sup>211</sup> Consequently, the denial of adequate support to children with disabilities to remain in the family could be seen as an interference with the parents' will even though the parents did not contest to the segregation, if they saw no other alternative. In other words, such separation could be seen as conducted by *de facto* force by the authorities. However, a thorough examination of the meaning of "against their will" in article 23(4) is not part of this analysis since it would render the scope of the thesis too extensive. Further, based on the legal analysis above, the assessment is that article 23(4) in its entirety specifically address circumstances where the authorities have taken a decision against the parents' explicit contestation. It is therefore assumed that article 23(4) might be hard – however not impossible – to apply in a successful manner where the parents have agreed to the separation. Instead, the provision in 23(3) – providing that states shall ensure that children with disabilities have equal rights with respect to family life – is the main provision to analyse when a segregation is conducted with the (reluctant) agreement of the parents.

It is important to note that the term "separation" is only used in paragraph 23(4) "a child shall not be *separated* from his or her parents against their will",<sup>212</sup> and not in paragraph 23(3) which instead refer to the prevention of "concealment, abandonment, neglect and *segregation* of children with disabilities".<sup>213</sup> This legal difference is emphasised by using the expression "*segregation* from the child's family" (in accordance with 23(3)), instead of using the expression "separation from the child's family". The legal analysis

<sup>211</sup> Fiala-Butora, article 23, 2018, chapter 9 on paragraph 4.

<sup>212</sup> Emphasis added.

<sup>213</sup> Emphasis added.

of article 23(3) is interpreted through, in particular, article 7 on “Children with disabilities” and article 19 on “Living independently and being included in the community”. The analysis of article 23(3) also leads to other relevant provisions such as the CRPD Preamble (r) and (x), General principle 3(c) on participation and inclusion, and 3(e) on equality of opportunity.

## **6.1 The obligation to ensure the *equal* right to live within a family**

Instead of relying on article 23(4), the core legal response to a situation where the segregation is conducted with the agreement of the parents is the *equal* right of a child with disabilities to live within a family. Article 23(3) provides for an extensive protection for a child’s equal right to live within a family (and not to be segregated from their family) and reads as follows:

*States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*

While article 23(4) discussed in chapter four recognises both the right of the child as well as the right of the parents, article 23(3) is tailored specifically to protect children’s right to family life. The right to family life under article 23 is not the creation of a new right, instead the *equal* right to family life relates to the fact that the right must be accessible for all – including children with disabilities – and not only for persons without disabilities. At the same time as article 23(3) outlines the equality aspect of the right to family life, it also refers to the prevention of segregation of children with disabilities through the provision of services and support to children with disabilities and their families. Consequently, the prevention of segregation and the equal right to family life are linked in article 23(3) itself. The equal right to family life is therefore legally connected to the provision of adequate assistance in order for families to care for their children in their home and thereby exercise their right to family life in practise.

Article 7 of the CRPD concerning children with disabilities is intrinsically linked to article 23. Just as article 23(3) gives equal rights particularly to family life, article 7(1) underscores the importance of enjoyment for children of all rights and freedoms in the CRPD on an equal basis with other children. The equal right for children with disabilities is also emphasised in the preamble as one of the core objectives of the CRPD.<sup>214</sup> Further, the preamble refers to the family as “the natural and fundamental group unit of society” which is entitled the protection by society and the state. The same provision

<sup>214</sup> Preamble (r), CRPD.

also stresses that “persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.<sup>215</sup> Accordingly, the object and purpose of the Convention emphasise the importance of protecting the family unit through necessary assistance to ensure the *equal* enjoyment of rights, here, the equal right to family life for children with disabilities.

Crucially, the equality aspect is measured against the life, interests and rights of other children – which is to live and grow up in their own family. Consequently, a core aspect of children’s life and equal rights is the right to live within a family. General principle 3(e) of the CRPD emphasise that children with disabilities should have the equal opportunities as others.<sup>216</sup> Accordingly, the obligation to ensure the equal right to family life for children with disabilities translates into the right to live within a family. Further, General principle 3(c) emphasise the importance of full and effective participation and inclusion in society. The right to live in a family is essential in order for children with disabilities to be included and to participate in the society as other children do.<sup>217</sup> An interpretation of the object and purpose of the CRPD in line with article 23(3) therefore stresses the importance for a child with disabilities to live within their own family as other children do.

## **6.2 The obligation to provide adequate assistance as a prerequisite for the *equal* enjoyment of the right to live within a family**

As established above, the denial of assistance is potentially a violation in itself, even before any separation or segregation may be in question.<sup>218</sup> However, the lacking assistance is conceptualised as rendering the consequent segregation a violation. To repeat, in a situation where the denial of assistance is the reason for the separation / segregation from the child’s family, the interpretation of the right to adequate assistance in article 23(3) and the right to personal assistance in article 19(b) in support of the right to live within a family is relevant.

When a segregation has been conducted with the agreement of the parents, the question that has to be examined is whether it exist a link between the segregation (resulting in a denial of the right to family life) and a potential lack of assistance. This legal link is of particular importance in a situation

<sup>215</sup> Preamble (x), CRPD.

<sup>216</sup> As emphasised in General principle 3(e), CRPD.

<sup>217</sup> As emphasised in General principle 3(c), CRPD.

<sup>218</sup> This will however require a thorough analysis of the concept of “progressive realization”. An analysis that would render the scope of this report too extensive, see chapter 1.2. on “Delimitations”.

where a segregation has been conducted with the agreement of the parents in order to establish a violation. This is due to the fact that the segregation is not contested as such by the parents, and is therefore harder to pursue as a violation of article 23(4) as being against the “will” of the parents (see above under chapter six). Only when this link is established can the denial of assistance be conceptualised as a breach of the obligation to prevent segregation / separation. As concluded in section 5.1., a denial of assistance would by extension result in a denial of the *equal* right to family life. The equal right to family life is thus legally connected and dependent on the provision of adequate assistance in order for families to care for their child in a common home and thereby exercise the right in practise.

To summarise the analysis under chapter five above, a segregation of the child from their parents (with the reluctant agreement of the parents) due to the lack of adequate assistance violates article 23(3) since it is against the equal right to family life. Further, segregation due to the denial of assistance would also be contrary to article 19(b) since it is contrary to the right to live independently in the community – which for a child is to live within a family. Denying the family adequate assistance to prevent segregation and ensure the right to family life therefore violates article 23(3) and article 19(b) even though the parents agreed to the segregation. Any such segregation that could have been avoided by providing adequate assistance in order to prevent potential neglect and abuse is also contrary to article 16(1-2) of the CRPD. Finally, this legal link between the denial of assistance and the segregation would have to be established in order to argue for a violation of articles 23 and 19 in a particular case.

In a situation where the parents have agreed to a segregation, the reference to the state obligation to provide “early and comprehensive” information in article 23(3) is particularly relevant. The obligation in article 23(3) to inform about services and support can be violated separately from the obligation to provide such services (see chapter five above). Therefore, any information given to the parents before they took the final decision to agree to the segregation is of particular interest. The state must provide sufficient information about the availability of support – for instance support as personal assistance – to ensure that parents know about the existence of such support and can take it into consideration before consenting to any other support alternatives, such as placement in particular living arrangement. Insufficient information should be seen as a state failure which might amount to a violation of article 23(3).<sup>219</sup> Withholding information about available support might even be “the result of wilful neglect, with the aim of saving resources of a local municipality that would have to fund these services”.<sup>220</sup> Further, the CRPD Committee has expressed concern over the fact that “parents of children with disabilities encounter obstacles to gaining access to specific support for exercising their parental responsibilities and preventing

<sup>219</sup> Fiala-Butora, article 23, 2018, chapter 8.

<sup>220</sup> *Ibid.*

abandonment”.<sup>221</sup> It might therefore be the case that certain support services exist, but parents to children with disabilities might have difficulties in accessing them.<sup>222</sup>

Finally, the obligation to facilitate family reunification is relevant after segregation has been conducted, irrespective of whether or not the separation / segregation was conducted with the (reluctant) agreement of the parents (see section 5.3. above). Any segregation should be approached as a temporary measure and the work to facilitate reunification must commence the moment the decision is taken, in order to be in conformity with articles 23(3) and 19(b). As stated above, just as the state has an obligation to prevent separation and the right to assistance is part of that, the right to assistance will be part of reunification. Thus, the legal link to the provision of adequate assistance remains part of the state obligation to facilitate family reunification. Consequently, any segregation of the child from their parents should be remedied by the provision of adequate support. Even though the child is no longer with their parents, the right to family life remains relevant.

### 6.3 The best interest of the child

In contrast to article 23(4), article 23(3) does not include a specific reference to the best interest principle in the context of the equal right to family life. However, as established above, article 7(2) refers to the best interest of the child as a primary consideration. Article 7(2) is relevant generally for all rights and obligations throughout the CRPD which indicates the importance of the best interest of the child principle in all actions covered by the CRPD, including article 23(3). Article 7(2) is also inextricably linked to children’s equal enjoyment of rights in article 7(1). The analysis of the best interest of the child in the previous chapter concludes that the best interest of the child is – as a rule – to live within a family and that this overlaps with children’s equal right to family life.

While the CRPD Committee has not itself provided any guidance on the best interest principle, they have referred to the interpretation of the best interest principle by the CRC Committee to be applied to children with disabilities.<sup>223</sup> The CRC Committee has affirmed in relation to the best interest of the child that “[c]hildren with disabilities are best cared for and nurtured within their own family environment *provided that the family is adequately provided for in all aspects*”<sup>224</sup> and that “community-based support to families with children with disabilities” must be available in order to guarantee enjoyment of the right to family on an equal basis with others.<sup>225</sup> The CRC Committee thus

<sup>221</sup> CRPD Committee, Concluding Observations: Thailand, UN doc. CRPD/C/THA/CO/1, 12 May 2016, para 43. As referred to in Fiala-Butora, article 23, 2018, chapter 8.

<sup>222</sup> Fiala-Butora, article 23, 2018, chapter 8.

<sup>223</sup> CRPD General Comment No. 6, 2018, para 38.

<sup>224</sup> CRC General Comment No. 9, 2006, para. 41. Emphasis added.

<sup>225</sup> CRPD Committee, Concluding Observations: Ethiopia, UN doc. CRPD/C/ETH/CO/1, 4 November 2016, para 49 and 50: as referred to in Fiala-Butora, article 23, 2018, chapter 8.

reaffirms the link between the best interest of the child, the prevention of segregation through assistance and the equal right to family life. The state obligation to ensure the best interest of the child thus cannot be fulfilled without the provision of adequate assistance. This is further emphasised by the CRC Committee stating that any segregation of a child from her or his family can “only occur as a last resort measure” and should not be conducted “if less intrusive measures could protect the child”, in order to be in accordance with the best interest principle.<sup>226</sup> Accordingly, a segregation of a child from their family in the best interest of the child can only be conducted as a last resort after all other means – including adequately providing for the family – have been exhausted.

Conclusively, a contextual interpretation of article 23(3) on children’s equal right to family life in conjunction with article 7(2) on the best interest of the child which is inextricable linked to children’s equal enjoyment of rights in article 7(1), suggests that the best interest of the child is to live within a family with the assistance they require in order for families to care for their child and for children to exercise their right to family life in practise. Both the CRPD and the CRC Committee have reaffirmed the link between the best interest of the child principle and the provision of adequate assistance. A segregation due to the lack of adequate assistance violates article 23(3) since it is against the best interest of the child as well as the equal right to family life, even though conducted with the reluctant agreement of the parents. Any such segregation that could have been avoided by providing adequate assistance is also contrary to article 16(1-2) of the CRPD, in as much as it is coupled with neglect and abuse.

<sup>226</sup> CRC General Comment No. 14, 2013, para 6.

## **7 The obligation to provide alternative care and acceptable living arrangements**

Even if a separation / segregation is deemed necessary in the best interest of the child and has been conducted in conformity with the necessary safeguards and in accordance with the provisions in articles 23(3-4) and 19(b), an examination of the state obligation to provide for alternative care within the wider family or within in a family setting is required. The main provision to analyse in this regard is article 23(5), obliging states to provide alternative care within the wider family or within in a family setting. Article 23(5) is central to establish what a “family setting” means and to establish which alternative living arrangements to the family that are in conformity with the CRPD. Article 19(a) on “Living independently and being included in the community” is also relevant here since it obliges states to ensure that individuals can choose their place of residence and not be obliged to live in particular living arrangements. Article 19 is used to interpret article 23(5) in support of the right to live within a family.

### **7.1 Alternative care within the wider family or in a family setting**

If a separation or segregation of a child from their family should be considered necessary in the best interest of the child and not conducted due to the lack of assistance, article 23(5) provides strong obligations on states to provide alternative care and reads as follow:

*States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.*

Accordingly, a state shall undertake “every effort” to provide care first of all within the wider family and as a second choice in a family setting. The question that arises here is whether the state has any other option than a placement within the wider family or in a family setting. The wording of the article explicitly outlines the wider family as well as a family setting as alternatives, but at the same time it does not explicitly prohibit a placement in another kind of living arrangement.



When interpreting article 23(5), it is of importance to recall the preamble of the Convention. State parties to the CRPD have expressed their belief that “the family is the natural and fundamental group unit of society [which] is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.<sup>227</sup> State parties to the CRPD have also recognized that “children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children”.<sup>228</sup> Accordingly, a contextual interpretation of article 23(5) suggest that a placement of a child in any other setting than the wider family or in a family setting does not correspond to the object and purpose of the CRPD and narrows the scope for exceptions significantly. In addition, the main purpose of adding the provision in article 23(5) was to prevent “any form of institutionalization of children with disabilities”.<sup>229</sup> Based on this, it seems to be a feasible argument that irrespective of whether the separation was in the best interest of the child, anything that is not a family – from institutions to groups homes – is a form of institutional care which would undermine not only the child’s right to family life but also the object and purpose of the CRPD.

Accordingly, the state obligation to undertake “every effort” must be interpreted as the obligation of the state to provide continuous adequate assistance (alternative care) to the “other” family outlined in article 23(5) when this cannot be conducted within the child’s own family. Interpreting article 23(5) in conjunction with article 19 arguably indicates that the reference to “every effort” in article 23(5) relates to alternative care, and is not an exception to a placement within the wider family, or in a family setting. Thus, an analysis of article 23(5) suggests that the only acceptable living arrangement for children with disabilities is within a family, and anything else is to be considered a violation of article 23(5).

## **7.2 Acceptable living arrangements and the legality of the placement of children with disabilities in anything else but a family**

According to article 23(5) a placement of a child with disabilities in anything else but within a family is to be considered a violation of the Convention. What this section explores is the question of whether already existing living arrangements (see chapter two above), live up to the requirements of “family setting” or whether they have institutional characteristics and consequently

<sup>227</sup> Preamble (x), CRPD.

<sup>228</sup> Preamble (r), CRPD.

<sup>229</sup> Della Fina, article 23, 2017, p. 436. The prevention of any form of institutionalisation of children also connects to the question of institutions, discussed in section 7.2. below.

are unacceptable under article 19 of the CRPD. As outlined above, article 19 of the CRPD emphasises the equal right of all persons with disabilities to live in the community, with choices equal to others. Article 19 obliges states to take measures to facilitate the full enjoyment of the right to live independently in the community. Article 19(a) specifies this end as follows:

*Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.*

Article 19(a) thus includes both a positive obligation concerning the choice where to live and a negative obligation not to be obliged to live in a particular living arrangement. It is essential to clarify that the CRPD outlines what is required, not what is prohibited. The word “institution” is therefore not included in the CRPD. The title of article 19 instead refers to “living independently” and article 19(a) refers to “particular living arrangement”. “Living independently” was also one of the most-debated issues of article 19 during the negotiations of CRPD.<sup>230</sup> In order to determine what an acceptable living arrangement under the CRPD is, it is therefore important to identify the delimitation (the definition) of an acceptable “particular living arrangement” and “family setting”. An indication of where to draw this line could be found in the definition of “living independently”, “independent living arrangements” and “institutions” in article 19 by the CRPD Committee.

According to the CRPD Committee, “Independent living” refers to the fact that persons with disabilities are “provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives”, for instance where to live and with whom.<sup>231</sup> This is of particular relevance with regard to children. The choice is about both children and their parents, where the parents will make the final choice of residence for the child unless the child risks imminent harm such as neglect and / or abuse. It is important to note however that children do not have a choice in the same sense as adults, but it is assumed that the decision of children concerning where and with whom they live is within a family, in order to be on an equal basis with other children (and their assumed choices). As the CRPD considers the family as the natural and fundamental group unit of society, this must be the starting point for the analysis of what can be considered as an acceptable “independent living arrangement” for children in line with article 19.

In contrast to the text of the CRPD, the CRPD Committee outlines both what is required and what is prohibited. With regard to the definition of “independent living arrangements” the CRPD Committee more or less equates living arrangements contrary to the CRPD with “institutions”. For

<sup>230</sup> Palmisano G ‘Article 19 Living Independently and Being Included in the Community’ in Della Fina V, Cera R and Giuseppe P (Eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, (2017 Springer International Publishing AG) [hereinafter Palmisano, article 19, 2017] p. 356.

<sup>231</sup> CRPD General Comment No. 5, 2017, para 16(a).

instance, the CRPD Committee states that “obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision [...]”, are all defining elements of institutions or institutionalisation.<sup>232</sup> A number of these elements of institutions or institutionalisation established by the CRPD Committee could all be argued to be actualised in a range of examples throughout the world today, however, obviously to different extent depending on each individual case. With regard to children, the major difference between living in a family and in a particular living arrangement is arguably the replacement of the parents by employed staff in everyday situations.

According to the Committee, the size and name of the living arrangement is irrelevant - whether it is a large-scale institution or a smaller group home or even individual homes - if elements of institutions or institutionalisation is evident.<sup>233</sup> Furthermore, the CRPD Committee has clarified that “institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions”.<sup>234</sup> The CRPD Committee has called for deinstitutionalisation, specifically of children,<sup>235</sup> and has gone as far as calling for the abolishment of the institutionalisation of children of any age.<sup>236</sup> The de-institutionalisation must also include all children, no matter what their impairments.<sup>237</sup> Seemingly, the CRPD Committee equates living arrangements contrary to the CRPD with institutions and the concept of institutions with the violation of the Convention.

Importantly, the CRPD Committee stresses that “[f]amily-like” institutions are still institutions and are no substitute for care by a family”.<sup>238</sup> Group homes – no matter if they are large or small – “are especially dangerous for children, for whom there is no substitute for the need to grow up with a family”.<sup>239</sup> The definition of independent living arrangements for children with disabilities in line with article 19 must therefore be interpreted to mean the right to live within a family. In contrast, an unacceptable living arrangement is used to describe anything that is not a family setting. Thus,

<sup>232</sup> CRPD General Comment No. 5, 2017, para 16(c).

<sup>233</sup> *Ibid.*

<sup>234</sup> *Ibid.*

<sup>235</sup> See CRPD Committee, Concluding Observations: Lithuania, UN doc. CRPD/C/LTU/CO/1, 11 May 2016, para 39; as referred to in Fiala-Butora, article 19, 2018, chapter 3.2.

<sup>236</sup> CRPD Committee, Concluding observations on the initial report of Guatemala, UN doc. CRPD/C/GTM/CO/1, 30 September 2016, para 54(d).

<sup>237</sup> CRPD Committee, Concluding Observations: El Salvador, UN doc. CRPD/C/SLV/CO/1, 8 October 2013, para 42, as referred to in as referred to in Fiala-Butora, article 19, 2018, chapter 3.2.

<sup>238</sup> CRPD General Comment No. 5, 2017, para 16(c).

<sup>239</sup> *Ibid.*

irrespective of the level of fulfilment of the criteria of “institutions” above, many existing particular living arrangements for children with disabilities throughout the world today cannot be considered to be “a family” and consequently amount to unacceptable living arrangements in the view of the CRPD Committee.

The CRPD Committee has also called upon state parties to replace institutionalisation of children with disabilities with measures “to promote their adoption or placement in foster care and ensure that foster families receive the requisite support for their care”.<sup>240</sup> The state obligation to ensure that foster families receive adequate support for their care is thus linked to the right to grow up within a family.<sup>241</sup> The only alternatives to the replacement in the immediate family emerge as foster care or adoption.<sup>242</sup> Thus, according to the CRPD Committee, anything but a family is unacceptable for children with disabilities. Consequently, any other form of living arrangements are unacceptable and violates article 19 of the Convention.

Conclusively, it can be argued that the most of the particular living arrangements existing today can automatically be considered contrary to both a contextual analysis of the requirement “family setting” in article 23(5), and the position of the CRPD Committee on article 19 which – as outlined above – is very clear.<sup>243</sup> As a placement of a child with disabilities in a living arrangement described above cannot be considered a family, such placement violates the right to family life and is contrary to both articles 23 and 19. Thus, the mere placement of a child in a non-family setting would be contrary to both article 23 and article 19, no matter how justifiable the separation as such was.<sup>244</sup>

In this regard, the General principle 4(1d) of the CRPD also outlines the state obligation to “refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention”. Given the legal analysis on children’s right to family life and the position of the CRPD Committee, a placement of a child with disabilities in any other setting than within a family is to engage in an act or practice inconsistent with the CRPD. State parties to the Convention must therefore refrain from placing a child with disabilities in any other living arrangements than within a family.<sup>245</sup>

<sup>240</sup> CRPD Committee, Concluding observations on the initial report of Guatemala, UN doc. CRPD/C/GTM/CO/1, 30 September 2016, para 58(d).

<sup>241</sup> *Ibid.*

<sup>242</sup> Fiala-Butora, article 23, 2018, chapter 10 on paragraph 5.

<sup>243</sup> CRPD General Comment No. 5, 2017, para 16. Furthermore, the High Commissioner for Human Rights on Mental Health stress the fact that “institutional care in early childhood has such harmful effects that it should be considered a form of violence against young children”, see OHCHR, 2017, para 58.

<sup>244</sup> For instance, it would not matter if the preceding separation / segregation was due to the lack of assistance to care for the child within the family.

<sup>245</sup> Article 4(1d), CRPD.

# **8 The scope and strength of the right for children with disabilities to live with their families under the CRPD**

The main aim of the thesis has been to interpret children's right to live with their family and to highlight a global problem where children with disabilities are separated from their families and placed in particular living arrangements. Consequently, the legal analysis seeks to ascertain and understand the scope and strength of children's right to live with their family and corresponding state obligations established under the CRPD. At its core, the thesis attempts to create a new problem-based legal analysis of children's right to live within a family with the purpose of providing literature to contribute to a better protection of this right. This final chapter address the overarching research question which is formulated as "What is the scope and strength of the right for children with disabilities to live with their families under the CRPD" and is divided on the basis of each sub-question.

## **8.1 The significance of parents' agreement to separation and / or segregation for state obligations**

As have been illustrated in chapters four to six, there are a number of legal differences between a separation conducted under the explicit contestation of the parents and a segregation conducted with an agreement of the parents to separate the child from their family. The core of this difference lies within the applicability of either the provision in 23(4) – providing that states shall ensure that a child shall not be separated from their parents against their will, or the provision in 23(3) – providing that states shall ensure that children with disabilities have equal rights with respect to family life.

### *The obligation not to separate without the agreement of the parents*

The analysis in chapter four is based on a situation where the separation is enforced by the authorities without the agreement of the parents and the legal analysis are consequently based on the provision in article 23(4). The legal analysis reveals that the only potential limitation to the provision in 23(4) is if a separation is conducted in accordance with the best interest of the child principle. The interpretation of article 23(4) and the best interest principle however risks resulting in a catch 22, since it can both mandate and forbid separations of children from their families. However, the point of departure in cases concerning separation without the agreement of the parents should be that the best interest of the child is – as a rule – to live within their family.

The best interest principle and the *equal* right to family life runs parallel to each other, and informs each other. Therefore, the best interest of the child to live within their family should be supported by referring to the child's equal right to family life – measured against the interests of other children. Accordingly, the best interest of the child is to live within a family and any separation of a child negates this right. The legal analysis in chapter four further establish that the only justification for separation according to article 23(4) is when a child is facing imminent harm in terms of abuse. Accordingly, all separations of children from their families are not prohibited. However, any decision to separate the child from her or his family must carefully address both the severity of the harm and the risk of such harm. Importantly, as established under chapter five, a (risk of) harm could arguably have been prevented by providing adequate assistance (see section 8.2 below).

The interpretation of what the best interest of the child principle entails in practise is key to ensure children's equal right to family life. If interpreted in line with the understanding of disability and age under the CRPD, the principle have the potential to ensure an extensive protection of the right to live within a family. As discussed in chapter three, the principle of the best interest of the child is modelled upon the same principle established in the CRC,<sup>246</sup> which is founded on a welfare approach to childhood<sup>247</sup> and criticised for relying on a medical model of disability.<sup>248</sup> Interpreting the best interest of the child in line with the understanding of disability and age under the CRPD (i.e. qualified autonomy) arguably reduces the paternalistic legacy of the best interest principle and instead introduce a human rights based interpretation.<sup>249</sup> As have been illustrated throughout the analysis, the interdependence between the child and his or her family in order to enjoy the equal right to family life permeates the entire article 23,<sup>250</sup> which further emphasise children's right to live in a family as the point of departure for what the best interest of the child is.

In addition to this material condition – that any separation decision has to be in accordance with the best interest of the child – the separation decision also includes requirements of procedure and lawfulness. It can be concluded that the requirement of lawfulness are specifically important in relation to article 23(4) since the material right is largely about the process to separate the child from their parents. In addition, children with disabilities possess a multi-vulnerability due to their impairment and age. Addressing the lawfulness of a decision through the procedural leg of article 23(4) would be evaluated together with a material analysis and require a detailed assessment of each individual case. Generally however, the question of the leeway of discretion in the national legislation and what kind of process that can be considered

<sup>246</sup> Article 3(1), CRC.

<sup>247</sup> Broderick, article 7, 2017, p. 207.

<sup>248</sup> *Ibid*, p. 197.

<sup>249</sup> See for instance article 7(3) and preamble (h), CRPD; Bruce, 2014, pp. 332-333.

<sup>250</sup> Bruce, 2014, pp. 334-335.

adequate is key to evaluate the effective realisation of the equal right to family life for children with disabilities.

It must be emphasised that separations of a children from their families without the agreement of the parents can never be based on the disability of the child (directly or indirectly). Justifying a separation on the basis of disability is both discrimination and a violation of article 23(4).<sup>251</sup>

*The obligation not to segregate irrespective of the parents' agreement*

In contrast to chapters four and five, the legal analysis in chapter six is based on a situation where a child is separated from their parents with the (reluctant) agreement of the parents. It is concluded through the legal analysis that even though it might be possible to argue that the state interfered with the parents' "will" in other ways than forcibly separating the child, article 23(4) in its entirety specifically addresses circumstances where the authorities have taken a decision against the parents' explicit contestation. Therefore, the core legal response to a situation where children is separated from their parents with the agreement of the parents is the *equal* right of a child with disabilities to live within a family and the right to support to this end according to 23(3). As concluded above, the equal right to family life runs parallel to the principle of the best interest of the child. What is essential for a situation where children is segregated from their parents with the agreement of the parents is that the equal right to family life is legally connected to the provision of adequate assistance in order for families to care for their child in their home and thereby exercise their right to family life in practise. Recalling the conclusion that the best interest of *all* children is to live within a family, this right is – for children with disabilities – dependent on the state obligation to provide adequate support to the family.

## **8.2 The connection between the state obligation to provide assistance and the right to family life**

In chapter five, the legal analysis is based on the provisions in article 23(3) – providing that states shall provide services and support to children with disabilities and their families – and 19(b) obliging states to ensure that persons with disabilities have access to support services and specifically providing for the right to personal assistance.

One aspect of the human rights model of disability enshrined in the CRPD is that it includes both first and second-generation human rights. According to Degener, some of the articles in the CRPD cannot be said to belong solely to either civil and political or economic social and cultural rights.<sup>252</sup> In addition, the CRPD illustrates the indivisibility and interdependence of both sets of

<sup>251</sup> CRPD General Comment No. 6, 2018, para 61.

<sup>252</sup> Degener, 2016, p. 37.

rights.<sup>253</sup> This is also true for article 23 which both ensures the equal right to family life for children with disabilities (which would be described as a civil and political right) but also requires service and support to realise this right (which would instead be categorised as a social and economic right). As have been illustrated through the legal analysis, the right to family life is dependent and intrinsically linked to the obligation to provide adequate service and support.

This legal link between a separation decision by the authorities (when there is no agreement from the parents) or a segregation decision by the parents themselves (resulting in a denial of the right to family life) and the preceding denial of assistance needs to be established in order to be contrary to article 23(3) and article 19(b). In other words, it must be shown that a separation / segregation was a result of the state's failure to provide adequate assistance in order for it to constitute a violation of article 23(3) and article 19(b). The causality between a potential denial of assistance and the separation / segregation must be shown to successfully advance this argumentation.

#### *The obligation to facilitate family reunification*

The legal analysis reveals that the link to the provision of adequate assistance remains part of the state obligation to facilitate family reunification. Irrespective of whether or not the separation was legitimate in the first place, the obligation to facilitate family reunification is relevant after a separation has been conducted. In this respect, the moment a separation decision is taken, the work to facilitate family reunification (including through the provision of adequate assistance) must commence in order to be in conformity with the CRPD.

#### *The obligation not to separate without the agreement of the parents*

Even though a separation might have been implemented in accordance with article 23(4) in line with the best interest of the child to prevent abuse and neglect – it could not be considered to be conducted as a last resort measure if less intrusive means at an earlier stage was applicable, such as adequate assistance. Any such separation that could have been avoided by providing adequate assistance in order to prevent neglect and abuse is also contrary to article 16(1-2) of the CRPD. In such situation, the obligation to provide adequate assistance would erase the only legitimate ground under 23(4) (according to the best interest principle) for separation. Accordingly, the denial of adequate assistance would constitute a violation the right to family life, given that that adequate assistance serves as a prerequisite for the enjoyment of that right.

#### *The obligation not to segregate irrespective of the parents' agreement*

It is important to emphasise that the legal link between the denial of assistance and the segregation in 23(3) is of particular importance in a situation where the parents have agreed to the segregation in order to establish a violation. Hence, in such situation it is harder to pursue as a violation of article 23(4) as

<sup>253</sup> Degener, 2016, p. 35.



a measure being against the “will” of the parents. With the provision of adequate assistance, children’s equal right to family life can be ensured. Without such assistance, there is no equal right to family life. Further, the best interest of the child is to live within a family with the assistance they require in order for families to care for their children and for children to exercise their right to family life. A denial of assistance needed in order for families to care for their child in a common home would by extension result in a denial of exercising the *equal* right to family life in practise, as well as violate the principle of the best interest of the child. Accordingly, the state obligation to ensure the best interest of the child and the equal right to family life cannot be fulfilled without the provision of adequate assistance. Arguably, a segregation due to the lack of adequate assistance violates article 23(3) since it is against the best interest of the child (as protected in article 7 on “Children with disabilities”) as well as the equal right to family life (as protected by articles 23(3) and 7), even though conducted with the reluctant agreement of the parents. Conclusively, a segregation of a child from their family in the best interest of the child can only be conducted as a last resort after all other means – including adequately providing for the family – have been exhausted.

### **8.3 The options for states in providing alternative care and acceptable living arrangements for children**

Chapter seven examined the provisions in article 23(5) – obliging the state to provide alternative care within the wider family or within in a family setting, and 19(a) obliging states to ensure that individuals can choose their place of residence and not be obliged to live in particular living arrangements.

The legal analysis of article 23(5) suggests that the only acceptable living arrangement for children with disabilities is within a family, and anything else is to be considered a violation of article 23(5). Therefore, any particular living arrangements should automatically be considered contrary to the CRPD, since they are not a family. This is also heavily emphasised by the CRPD Committee concerning article 19. Consequently, a placement of a child with disabilities in a particular living arrangement would undermine the child’s right to family life and be a violation of the right to family life contrary to both article 23(5) and 19(a). This also corresponds to the main purpose of adding the provision in article 23(5), which was to prevent “any form of institutionalisation of children with disabilities”.<sup>254</sup>

One of the main arguments brought forward by states to justify the placement in particular living arrangements and explain the lack of community based service and support is (the lack of) financial resources. Interestingly though, research show that the cost of providing adequate assistance to a child to “remain in their family is significantly lower than the cost of placing a child

<sup>254</sup> Della Fina, article 23, 2017, p. 436.

in residential care”.<sup>255</sup> Therefore, it cannot be emphasised too much that state parties to the CRPD have extensive obligations with regard to the provision of adequate assistance long before any segregation, separation or placement in particular living arrangement may be in question. Accordingly, while a placement of a child within the wider family or within a family setting is in compliance with article 23(5), such placement conducted on the basis of a preceding denial of assistance would still constitute a violation of article 23(3) and possibly also 23(4), as discussed above. Consequently, a placement of a child in a particular living arrangements due to a preceding denial of assistance would arguably constitute a double violation, contrary to both the right to family life under 23(3) and 23(4) as well as 23(5) and 19 since it constitutes an unacceptable living arrangement.

The question of how far the state parties obligations reach if the national authorities have done everything they can in terms of providing assistance to prevent a potential segregation, separation or placement however remains. It is likely that such situation would open up for the possibility of placing a child in a particular living arrangement. States’ intentions behind the placement in particular living arrangements are usually “good” in the sense that they provide care and services to children with disabilities and their families.<sup>256</sup> However, the assumption that persons with disabilities needs “shelter and welfare” is based on a medical model of disability (as described in chapter three above).<sup>257</sup> This kind of mindset approves a placement of a child with disabilities in a particular living arrangement, whether it be a large institution or a small group home, but becomes problematic from a human rights perspective, in particular the disability- and age perspective enshrined in the CRPD. As a representative of the CRPD Committee, Degener argues that many state parties to the CRPD possess an understanding of disability which follows this medical model of disability.<sup>258</sup> One could therefore assume that laws and policies regarding the separation and placement of children with disabilities may be shaped by the medical understanding of disability, and not by the rights-based understanding of disability and age adopted through the CRPD.

In order to be in compliance with the understanding of disability and age under the CRPD – corresponding with the human rights model of disability - the only option for alternative placement of a child is within a family setting - i.e. foster care or adoption – rather than in a particular living arrangement. Conclusively, in order to comply with its obligations under the CRPD, state parties to the Convention must refrain from placing children in any other living arrangements than within a family, irrespective of whether or not the parents agreed to the separation / segregation.<sup>259</sup>

<sup>255</sup> Mulheir, 2012, p. 133.

<sup>256</sup> *Ibid*, p. 117.

<sup>257</sup> Degener, 2016, p. 33.

<sup>258</sup> *Ibid*, p. 32.

<sup>259</sup> This conclusion mirrors the High Commissioner for Human Rights on Mental Health, interpreting article 23(5) as if no other options then a placement within another family is permissible, see OHCHR, 2017, para 58.

## 8.4 Summary of conclusions

This final section summarise the main findings of each research question regarding the scope and strength of article 23, including the protection it gives, the situations it covers, and the strength it possess.

Research question 1(a) reads as follow: “What is the significance of parents’ agreement to separation and / or segregation for state obligations according to the CRPD?”. The significance of parents’ agreement to separation and / or segregation for state obligations lies within the applicability of either the provision in 23(3) or the provision in 23(4). If a separation is conducted without the agreement of the parents, the only potential limitation is if the separation is conducted in accordance with the best interest of the child principle. Further, the best interest of the child is – as a rule – to live within their family. The only justification for separation according to article 23(4) is when a child is facing imminent harm in terms of abuse. If a segregation is conducted with the agreement of the parents, the core legal argument against segregation is the *equal* right of a child with disabilities to live within a family like other children do in accordance with article 23(3). The *equal* right to family life runs parallel with the best interest principle which is – as a rule – to live within a family, irrespective of whether or not the parents agreed to the segregation.

In particular, article 23(4) protects from undue state involvement in situations where a separation is enforced by the authorities. It covers a range of circumstances where the separation is conducted without the agreement of the parents, however not situations where a child is facing imminent harm in terms of abuse. The requirements of procedural safeguards and lawfulness adds an important layer of protection, given the intrusiveness of a separation and the multi-vulnerability children with disabilities possess. The strength of the provision in article 23(4) arguably lies within the interpretation of the best interest of the child. If interpreted in line with the understanding of disability and age under the CRPD it has the potential to truly ensure children’s equal right to live within a family. Children’s *equal* right to family life as protected under article 23(3) cover an even broader range of situations, in particular situations where the segregation is conducted with the agreement of the parents, or even at their own initiative.

Research question 1(b) reads as follow: “What is the connection between the obligation to provide assistance and the right to family life according to the CRPD?”. The right to family life is legally connected with the obligation to provide assistance both within article 23 itself and through a contextual interpretation of article 23 and 19. This legal link – the causality between a potential denial of assistance and a separation / segregation – must be demonstrated to successfully argue for a violation of article 23(3) and article 19(b). Any separation conducted without the agreement of the parents that could have been avoided by providing adequate assistance in order to prevent any potential abuse is contrary to article 16(1-2). Further, the *equal* right to family life is legally connected to the provision of adequate assistance in order

for families to care for their child. Any segregation conducted due to a denial of assistance would by extension result in a denial of exercising the *equal* right to family life in practise, contrary to article 23(3) and 7.

The strength of article 23(3) lies within the legal link between the equal right to family life and the obligation to provide assistance to ensure this right. In this way, article 23(3) covers situations where a potential segregation is conducted with the agreement of the parents, however due to the state's failure to provide adequate assistance to the family to care for their child in their common home. The article also cover situations where a separation or segregation has already been conducted, since the state obligation to provide assistance is part of the obligation to facilitate family reunification. Thus, the equal right to family life in article 23(3) remains relevant even in situations where the child is no longer with their parents. Clearly, the state obligation to ensure the equal right to family life and the best interest of the child cannot be fulfilled without the provision of adequate assistance.

Research question 1(c) reads as follow: "What are the options for states in providing alternative care and what is considered as an acceptable living arrangement for children according to the CRPD?". The only acceptable living arrangement for children with disabilities is within a family. Any other particular living arrangements is automatically considered contrary to the CRPD, since they are not a family. A placement of a child with disabilities in a particular living arrangement therefore undermine the child's right to family life and is contrary to both article 23(5) and 19. The only option for alternative placement of a child is within a family setting.

Finally, article 23(5) and 19 protects against placement in any other setting than a family – from small group homes to large institutions. It also ensures the provision of alternative care understood as within a family setting, i.e. foster family or adoption. It covers situations where a child is already placed in a particular living arrangement. It also covers situations where the authorities have taken a decision about a placement in a particular living arrangement where the child is about to be placed. The strength of article 23(5) lies within the prevention of a placement in any form of particular living arrangement, irrespective of whether or not the parents agreed to the segregation / separation and irrespective of whether or not the segregation / separation was legitimate in the first place. Thus, article 23(5) protects against the mere placement of a child in a non-family setting.

Conclusively, article 23 has the potential to protect a wide scope of situations where segregation, separation or placement of children with disabilities might occur. The analysis of the article also reveals a number of strengths, both in itself and through a contextual analysis. Essentially, article 23 of the Convention provide a strong protection of children's right to live within a family and creates far-reaching obligations on states to promote, protect and ensure the enjoyment of this right in practise.

# Bibliography

## International Treaties

United Nations General Assembly, Convention on the Rights of Persons with Disabilities [CRPD], A/RES/61/106, 24 January 2007

United Nations General Assembly, Optional Protocol to the Convention on the Rights of Persons with Disabilities [CRPD Optional Protocol], A/RES/61/106, Annex II, 13 December 2006

United Nations General Assembly, Convention on the Rights of the Child [CRC], Treaty Series, Vol. 1577, p. 3, United Nations, 20 November 1989.

Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms [ECHR] Rome, 4.XI., 1950

United Nations General Assembly, International Covenant on Civil and Political Rights [ICCPR], GA Resolution 2200A (XXI), United Nations, Treaty Series, Vol. 999, p. 171, 16 December 1966

United Nations General Assembly, Universal Declaration of Human Rights [UDHR], 217 A (III), 10 December 1948

United Nations, Vienna Convention on the Law of Treaties [VCLT], Treaty Series, Vol. 1155, p. 331, United Nations, 23 May 1969

## United Nations General Assembly Documents

United Nations General Assembly Resolution, Rights of the child, UN doc A/RES/74/133, 20 January 2020

United Nations General Assembly on Rights of the Child, Report of the independent expert for the United Nations study on violence against children, Paulo Sérgio Pinheiro, submitted pursuant to General Assembly resolution 60/231, UN doc A/61/299, 29 August 2006

United Nations General Assembly, Report of the United Nations High Commissioner for Human Rights on Mental Health and Human rights, UN doc. A/HRC/34/32, 31 January 2017

Working Group's draft Convention in 2004; Draft Article 14 – Respect for Privacy, the Home and the Family, A/AC.265/2004/WG/1, Annex I

# **United Nations Committee on the Rights of Persons with Disabilities**

## **General Comments**

United Nations Committee on the Rights of Persons with Disabilities, General Comment No. 6: Article 5: equality and non-discrimination [CRPD General Comment No. 6, 2018], UN doc: CRPD/C/GC/6, 9 March 2018

United Nations Committee on the Rights of Persons with Disabilities, General Comment No. 5: Article 19: on living independently and being included in the community [hereinafter CRPD General Comment No. 5, 2017], UN doc: CRPD/C/GC/5, 27 October 2017

United Nations Committee on the Rights of Persons with Disabilities, General Comment No. 1: Article 12: equal recognition before the law [CRPD General Comment No. 1, 2014], UN doc. CRPD/C/GC/1, 11 April 2014

## **Jurisprudence**

United Nations Committee on the Rights of Persons with Disabilities, H.M. v. Sweden [hereinafter H.M. v. Sweden, 2012], Communication No. 3/2011, Views adopted by the Committee at its Seventh Session, 16-27 April 2012, UN doc: CRPD/C/7/D/3/2011, 21 May 2012

## **State reporting**

United Nations Committee on the Rights of Persons with Disabilities, List of issues prior to submission of the combined 2nd and 3rd periodic report of Sweden, UN doc. CRPD/C/SWE/QPR/2-3, 12 October 2018

United Nations Committee on the Rights of Persons with Disabilities, Concluding Observations on the initial report of Slovakia, UN doc. CRPD/C/SVK/CO/1, 17 May 2016

United Nations Committee on the Rights of Persons with Disabilities, Concluding Observations: Thailand, UN doc. CRPD/C/THA/CO/1, 12 May 2016

United Nations Committee on the Rights of Persons with Disabilities, Concluding Observations: Ethiopia, UN doc. CRPD/C/ETH/CO/1, 4 November 2016

United Nations Committee on the Rights of Persons with Disabilities, Concluding Observations: Lithuania, UN doc. CRPD/C/LTU/CO/1, 11 May 2016

United Nations Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Guatemala, UN doc. CRPD/C/GTM/CO/1, 30 September 2016

United Nations Committee on the Rights of Persons with Disabilities, Concluding Observations: El Salvador, UN doc. CRPD/C/SLV/CO/1, 8 October 2013

## **United Nations Committee on the Rights of the Child**

United Nations Committee on the Rights of the Child, General comment No. 14: Article 3(1): on the right of the child to have his or her best interests taken as a primary consideration [CRC General Comment No. 14, 2013], UN doc: CRC /C/GC/14, 29 May 2013

United Nations Committee on the Rights of the Child, General comment No. 9: The rights of children with disabilities [CRC General Comment No. 9, 2006], UN doc: CRC/C/GC/9, 27 February 2007

## **United Nations Human Rights Committee**

United Nations Human Rights Committee, CCPR General Comment No. 16: Article 17, The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation, 8 April 1988

## **European Court of Human Rights**

*Sunday Times v. the United Kingdom*, App no 6538/74 (ECHR 26 April 1979)

*R.Sz. v. Hungary*, App no 41838/11 (ECHR 2 July 2013)

*Saviny v. Ukraine*, App no 39948/06 (ECHR 23 December 2008)

*W. v. UK*, App no. 9749/82 (ECHR 8 July 1987)

*Airey v. Ireland*, Series App no. 32 (ECHR 9 October 1979)

*Dragojevic v Croatia*, App no. 68955/11 (ECHR 15 January 2015)

*Big Brother Watch and others v. the UK*, App. nos. 58170/13, 62322/14 and 24960/15 (ECHR 13 September 2018)

*Wallová and Walla v. the Czech Republic*, App. No. 23848/04 (ECHR, 26 October 2006)

*Hokkanen v Finland*, App. No 19823/92 (ECHR, 23 September 1994)

*K and T v Finland*, App. No 25702/94 (ECHR 12 July 2001)

## **Academic Literature**

### **Books**

Dolan P and Frost N (Eds.) *The Routledge Handbook of Global Child Welfare* (Routledge 1st Edition 2017)

Blanck P and Flynn E (Eds.) *Routledge Handbook of Disability Law and Human Rights* (Routledge 2016)

Bruce, A 'Which Entitlements and for Whom?: The Convention on the Rights of Persons with Disabilities and Its Ideological Antecedents' (Lund University, 2014)

Oliver M 'The Social Model of Disability: Thirty Years On, Disability and Society *Disability & Society*' (2013 28:7)

Della Fina V, Cera R and Palmisano G (Eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, (2017 Springer International Publishing AG)

Bantekas I, Stein A and Michael Anastasiou D (Eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (2018 Oxford University Press)

Gerards J 'General Principles of the European Convention on Human Rights' (2019 Cambridge University Press)

Brems E and Gerards J (Eds.) *Shaping Rights in the ECHR: the role of the European Court of Human Rights in determining the scope of human rights* (2013 Cambridge University Press)

### **Articles**

Rosenthal E, 'The right of all children to grow up in a family under international law: implications for placement in orphanages, residential care and group homes' (2018-2019) 25 *Buffalo Human Rights Law Review*

Mulheir G, 'Deinstitutionalisation: A Human Rights Priority for Children with Disabilities' (2012) 9 *The Equal Rights Review*

Kayess R. and French P, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review*



Crenshaw K. 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Politics and Antiracist Politics' (1989) University of Chicago Legal Forum

Smith B, 'Intersectional Discrimination and Substantive Equality: A Comparative and Theoretical Perspective' (2016) 16 The Equal Rights Review

Broderick A, 'The United Nations Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights: A Tale of Two Halves Or a Potentially Unified Vision of Human Rights' (2018) 7:2 Cambridge International Law Journal

Favalli S, 'The United Nations Convention on the Rights of Persons with Disabilities in the Case Law of the European Court of Human Rights and in the Council of Europe Disability Strategy 2017–2023: 'from Zero to Hero'' (2018) 18:3 Human Rights Law Review

## **Publications by organisations**

Human Rights Watch Publication, Abandoned by the State: Violence, Neglect, and Isolation for Children with Disabilities in Russian Orphanages, ISBN: 978-1-62313-1579, 15 September 2014

Disability Rights International publication, Recommendations to the UN General Assembly on Behalf of Children Without Parental Care, September 12, 2019

United Nations Children's Fund (UNICEF) Publication, The state of the world's children 2013: Children with disabilities

Rosenthal, Eric, Position paper on "The right to live and grow up in a family for all children", on behalf of Disability Right International, European Network for Independent Living, Validity, TASH, 14 December 2018