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The right to live in the community as the right to have rights

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Foreword

I would like to thank my supervisor, Associate Professor Per Sundman, for his encouragement, valuable advice and all the replies to my questions that he has provided throughout our consultations.

Abstract

The present thesis explores Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, which recognizes the right of all persons with disabilities to live in the community, with choices equal to others. The relationship between Article 19 and the other articles of the Convention are explored, in order to discuss the role of Article 19 in the Convention. The thesis examines whether the right to live in the community, set out in Article 19, can be considered as the most central right of the Convention. The thesis applies the legal analytical method, and it is based on the Convention on the Rights of Persons with Disabilities; the communications of the Committee on the Rights of Persons with Disabilities; official reports of the United Nations as well as international non-governmental organizations; and scientific articles from books and journals. By using Arendt's idea of "the right to have rights" as a theory, this thesis argues that the right to live in the community, contained in Article 19, constitutes the right to have rights for persons with disabilities and therefore it can be considered as the most central right of the Convention.

Keywords: Article 19, CRPD, the right to live in the community, community living, central right, human rights

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1 Introduction

Besides a number of national laws¹ and international conventions on human rights², a separate international convention aims to guarantee the rights of persons with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD or the Convention)³ interprets both civil and political rights as well as economic, social and cultural rights, based on its target group. It has been emphasised many times⁴ that the CRPD does not intend to create any new rights, rather it aims to set out the obligations of its States Parties to ensure that persons with disabilities can enjoy their existing human rights.

Despite the existence of various documents guaranteeing rights for all people, persons with disabilities are often discriminated against and their rights are often violated. Statistics show that the living conditions of persons with disabilities are remarkably lower than that of the general population, all over the world, even in developed countries.⁵ As an example, we can highlight Sweden, a high-income country, where persons with disabilities still have a significantly lower living standard compared to other groups in society.⁶ According to the latest report on the development of disability policy, prepared by the Swedish Agency for

1 In Sweden, for example, there is an act concerning support and service for persons with certain functional impairments (Lag (1993:387) om Stöd och Service till Vissa Funktionshindrade) which provides for the right to personal assistance since the nineties. A more recent example is that the lack of accessibility became a new form of discrimination in 2015, and thereby the prohibition of discrimination based on disability got a stronger legal protection in Sweden (Diskrimineringslag (2008:567)).

2 Article 1 of the Universal Declaration of Human Rights (UDHR), proclaimed by the United Nations (1948), contains the principle of equal human rights: "All human beings are born free and equal in dignity and rights.". Human rights are clarified in various conventions, such as the International Covenant on Civil and Political Rights (ICCPR, 1966) and the International Covenant on Economic, Social and Cultural Rights (ICESC, 1966). Persons with and without disabilities are entitled to all of the human rights listed in these Covenants.

3 United Nations, *Convention on the Rights of Persons with Disabilities*, 13 December 2006

4 United Nations. *Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities*, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/frequently-asked-questions-regarding-the-convention-on-the-rights-of-persons-with-disabilities.html#iq6> Accessed 05 February 2017; Trömel, Stefan. A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities. In: *European Yearbook of Disability Law, Volume 1*, Gerard Quinn and Lisa Waddington (eds.), 115-137. Antwerp: Intersentia, 2009, 118.

5 United Nations Office of the High Commissioner. *The 2016 Social Forum*, <http://www.ohchr.org/EN/Issues/Poverty/SForum/Pages/SForum2016.aspx> Accessed 18 May 2017

6 Swedish Agency for Participation. Evaluation and analysis of disability policy from 2011 to 2016. 2016. <http://www.mfd.se/globalassets/dokument/publikationer/2016/utvardering-och-analys-av-funktionshinderspolitiken-2011-20161.pdf> Accessed 09 February 2017

Participation⁷, the levels of education are lower for persons with disabilities when compared to the general population. There are still big differences in labour market participation between persons without disabilities and persons with disabilities, who additionally continue to feel discriminated against on the labour market. Furthermore, there is lower participation in cultural life and in politics for persons with disabilities, compared to the rest of the population.⁸ These inequalities can be observed in other countries as well, to a similar or a much greater extent, than in Sweden. In many countries, a considerable number of persons with disabilities continue to live in institutional settings due to the lack of available living arrangement alternatives.⁹ Human rights abuses are widespread in such institutions, including physical and sexual abuse by the staff and other residents, inadequate clothing and food.¹⁰ Many persons with disabilities who live together with their families, instead of institutions, are usually also excluded from the life of the community in such countries because of the absence of the necessary support services.¹¹

When the goal is to resolve the abovementioned inequalities, the right to community living stands out from the catalogue of rights. Article 19 of the CRPD highlights the problem of exclusion and recognizes “the equal right of all persons with disabilities to live in the community, with choices equal to others”.

1.1 Problem Statement, Purpose and Research Questions

It has often been stated that Article 19 demonstrates a core article of the CRPD. From a disability perspective, Article 19 is declared as a central article, on the basis that it reflects the “essence of the convention”¹², namely the rights-based approach. The CRPD indicates a paradigm shift in approaches to disability, that is, persons with disabilities are no longer seen

7 A Swedish governmental expert authority within the field of disability policy.

8 Swedish Agency for Participation. *Evaluation and analysis of disability policy from 2011 to 2016*, 27, 59, 120, 140, 142

9 A/HRC/28/37, United Nations High Commissioner for Human Rights, *Thematic study on the right of persons with disabilities to live independently and be included in the community*, 12 December 2014, 7.

10 ECCL European Coalition for Community Living. Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities (ECCL Focus Report). 2009. <http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009-final-WEB.pdf> Accessed 15 April 2017, 5.

11 Ibid, 3

12 A/HRC/28/37, 4.

as “objects” of charity and welfare but as “subjects” of rights.¹³ Emphasizing that persons with disabilities have to be seen as the holder of rights, Article 19 gives a unique illustration of the abovementioned paradigm shift. The problem involves how to show that a different understanding of Article 19’s central role can complement the current ideas on the justification of this central role. The conduction of the present study is aimed at showing that it is possible to offer such an important complementing explanation. Within the framework of this, it will be examined whether the concept of “the right to have rights” can offer a reasonable explanation of the central role of Article 19 in the CRPD.

Accordingly, the main research question is formulated as:

- 1. Can we consider the right to live in the community, set out in Article 19, as the most central right of the CRPD, and if so, why?**

The following sub-questions need to be answered first, in order to reach an answer for the main research question:

- 1. What distinguishes the right to live in the community from the other rights guaranteed under the CRPD?**
- 2. What characterizes the relationship between Article 19 and the other articles of the CRPD?**

The logical order of responding to the research questions requires that the thesis first provides answers to the sub-questions and then closes the discussion by answering the main research question.

13 United Nations Office of the High Commissioner. *The Convention on the Rights of Persons with Disabilities Training Guide Professional Training Series No. 19*, 2014
http://www.ohchr.org/Documents/Publications/CRPD_TrainingGuide_PTS19_EN%20Accessible.pdf
Accessed 16 April 2017

1.2 Theory: What makes an article central in a convention?

The question above defines the essence of my theory. In order to be able to establish a reasonable system of criteria, based on which, a central role can be granted to a convention article, the first task is to clarify the meaning of “a central role”. To establish the ordinary meaning of the word “central”, I turned to the Oxford English Dictionary which provides us with the following definition: “that is at the core or heart of something; of, relating to, or constituting *the most important* or significant part or aspect of something”¹⁴ (highlighted by the author). There are a number of ways to approach what makes certain article(s) the most important part(s) of a particular convention. In other words, the phrase “most important” can mean many things. Regarding convention articles, we can differentiate between the articles in terms of their normative strength and choose the “most important” one accordingly. For example, the right not to be subjected to torture, guaranteed under Article 15 of the CRPD, can be considered a stronger right than the right to work, guaranteed under Article 27 of the CRPD, – given that the prohibition against torture is exceptionally strong. The right not to be subjected to torture is often considered as an absolute right under international human rights law, meanwhile the normative strength of the right to work would not be considered as strong since there might be no work to get. Thereby, I defined the meaning of importance in this case in terms of normative strength. One right having more normative strength than other rights, however, is not a relation of being more or less central. Normative strength does not tell us much about the relationship between different rights. For example, the prohibition of torture has no influence on the right to work and vice versa. Accordingly, the present thesis does not define centrality of an article based on its normative strength.

In the case of the CRPD, a possible way of granting a central role to Article 19, is based on a disability perspective, according to which, the CRPD indicates a paradigm shift in approaches to disability. Hereinafter I will refer to this approach as the paradigm shift perspective. From the paradigm shift perspective, a central role is given to Article 19 because it reflects the paradigm shift.¹⁵ Centrality is thereby attached to the new meaning. Let me

¹⁴ Oxford English Dictionary. <http://www.oed.com> Accessed 10 February 2017

¹⁵ Worth mentioning here is that civil society, particularly representative organisations of persons with disabilities, were actively involved in the drafting process of the convention text, based on the principle of the slogan “nothing about us, without us”, which also had a significant impact on the development of the

explain how I understand this new meaning. Prior to the creation of the CRPD, persons with disabilities were granted the same human rights as today, though implicitly. The CRPD nevertheless gives an explicit formulation of the rights of persons with disabilities, thereby bringing about a paradigm shift, creating new meaning.

However, I have chosen to use an alternative way of defining what makes an article central in a convention. I will use Hannah Arendt's idea of "the right to have rights" as a theory that provides help in developing an understanding of why Article 19 can be regarded as a central article of the CRPD.

Arendt has focused on examining the situation and treatment of refugees and other stateless people of the twentieth century. As she put it, "the Rights of Man, supposedly inalienable, proved to be unenforceable... whenever people appeared who were not citizens of any sovereign state"¹⁶. Through her famous expression of "the right to have rights", Arendt formulated what refugees and stateless people need: "a right to belong to some kind of organized community"¹⁷. She pointed out the lack of such a right, as human rights declarations considered it self-evident that human beings are already members of a community, and she drew attention to the fact that belonging to a community is not self-evident. Just as it has not been self-evident throughout history that persons with disabilities are full members of the society.¹⁸ It is not self-evident even today and it is not a reality for everyone, since the CRPD specifies the right to live in the community.

I aim to apply Arendt's theory to persons with disabilities – the focus group of this thesis – bearing in mind today's reality of that people with the same kind of disabilities have very different possibilities regarding how they live their lives. While one person with a certain kind of disability has a job and maintains a household, in one country, another person with the same kind of disability lives in an institution and vegetating for most of the time, in another country. In many cases, persons belonging to the latter group lack the right to make

content and the structure of the CRPD. In: Schulze, Marianne. *A Handbook on the Human Rights of Persons with Disabilities. Understanding the UN Convention on the Rights of Persons with Disabilities*. 2010. https://iddcconsortium.net/sites/default/files/resources-tools/files/hi_crpdp_manual_sept2009_final.pdf Accessed 3 April 2017, 14.

¹⁶ Arendt, Hannah. *The Origins of Totalitarianism*. New York: Harcourt Brace Jovanovich, 1973. p. 293

¹⁷ Ibid, 297

¹⁸ Kanter, Arlene S. The Globalization of Disability Rights Law. *Syracuse Journal of International Law and Commerce*, vol. 30 (2003), 245.

decisions concerning their own lives and they are not recognised as equal before the law.¹⁹ During the drafting of the CRPD, the then Secretary General of the United Nations, Kofi Annan stated that “persons with disabilities make up the world’s largest minority group. They are disproportionately poor, are more likely to be unemployed, and have higher rates of mortality than the general population. All too often, they do not enjoy the full spectrum of civil, political, social, cultural and economic rights. For many years, the rights of persons with disabilities were overlooked.”²⁰ I am convinced that the exclusion of persons with disabilities is comparable to the exclusion experienced by refugees during the first half of the twentieth century, as described by Arendt. People, belonging to marginal social groups, were/are not seen as rights subjects and they did/do not enjoy full rights as citizens. Therefore, the theory of “the right to have rights” has a significance in case of both types of exclusion.

Meanwhile Arendt focused on the problematic that people without citizenship remain without rights, I focus on the problematic that certain citizens can find themselves in a position without rights in comparison to other citizens, when they are excluded from the life of the community and are forced to live their lives as “secondary citizens”.

What is "the right to have rights" that was missing from the existing human rights conventions, as formulated by Arendt? This phrase has been interpreted in different ways by a number of thinkers of which I would like to highlight the work of Seyla Benhabib. According to Benhabib, Arendt uses the term “right” in this phrase in two different meanings. The first word “right” of the famous formula invokes a “moral claim to membership”²¹, meanwhile the second appearance of the term “right” refers to enforceable civil and political rights that enjoy protection, usually by the state.²² Accordingly, the first term “right” refers to a moral right to membership that every human should have.²³ Arendt formulates that “the right of every individual to belong to humanity, should be guaranteed by humanity itself”²⁴,

19 A/HRC/28/37, p. 6.

20 Schulze. *A Handbook on the Human Rights of Persons with Disabilities. Understanding the UN Convention on the Rights of Persons with Disabilities*, 14.

21 Benhabib, Seyla. *The Rights of Others: Aliens, Residents, and Citizens*. Cambridge: Cambridge University Press, 2004, 56.

22 Ibid, 57

23 Ibid, 56

24 Arendt. *The Origins of Totalitarianism*, 298.

then she adds, “it is by no means certain whether this is possible.”²⁵ Benhabib draws attention to the difference between the first and the second appearance of the term “right” in the phrase, in terms of who has the duty to recognize others as “rights-bearing persons”²⁶. In case of the first term “right” in the phrase, humanity should guarantee this right to have rights, and not the fellow-citizens or a state. Thereby, as Benhabib concludes it, to recognise each other “as equal rights-bearing persons”²⁷, imposed on humanity, is a “moral duty”²⁸. The moral duty on everyone to recognise each other “as equal rights-bearing persons”²⁹ can however be considered as a challenge which often leads to hardships during the practical implementation. Which is certain that this so-called moral right (to have rights) was not part of the catalogue of rights. It is not quite clear to me whether the supplement of human rights documents with a new right to membership would meet the requirements of Arendt’s theory, or in fact the fulfilment of such new right would make people be entitled to civil and political rights. Let me explain how do I understand it. Arendt’s text describes the phrase “human rights” as “the evidence of hopeless idealism”³⁰. At the same time, it insists that one specific right is missing from the catalogue of rights: when discussing the problem of the stateless people and refugees, it is argued that people need a “the right to have rights”. I referred to this tension that appears in Arendt’s text, when I stated that it is not quite clear to me whether complementing human rights documents with an additional right to membership would meet the requirements of her theory, or in fact the fulfilment of such new right. Since adding another right, that supposed to establish that rights in general will be respected, might be just another “evidence of hopeless idealism” if it is not respected. Therefore, we can suggest that the concept of “the right to have rights” is not about the mere introduction and declaration of a new right. My theory is based on Arendt’s “discussion” of “the right to have rights” in her famous ninth chapter in the book of “The origins of Totalitarianism”, but I find it important to emphasize that the “right to have rights” is not merely a guarantee of one right in my understanding, but one right the enjoyment of which can provide the possession of other basic

25 Ibid, 298

26 Benhabib. *The Rights of Others: Aliens, Residents, and Citizens*, 57.

27 Ibid, 60

28 Ibid, 58

29 Ibid, 60

30 Arendt. *The Origins of Totalitarianism*, 269.

human rights. In practice, the bigger challenge for the duty-bearers³¹ is of course ensuring the enjoyment and promotion of the rights. The first step is to recognize the need to guarantee such a right by legislation, however the law will not solve the problems in practice by itself.

Based on the above, the idea of “the right to have rights” refers to the suggestion that the enjoyment of one right can make the exercise of other rights possible. In the perspective of this thesis, centrality is therefore not a question of new meaning, rather a question of construction.

The criteria for granting a central role to a convention article, includes the following, in the present thesis:

- it guarantees a right, the enforcement of which constitutes a prerequisite of the realisation and implementation of all the other rights in the given convention
- without the enjoyment and promotion of such right, the enforcement of other rights, ensured by the convention, becomes impossible

Using the term “central” in a structural sense is what distinguishes my approach from the paradigm shift perspective. It shall be noted that the rights, guaranteed under the CRPD, are indivisible, interdependent and interrelated³², however, based on Arendt's theory, a right can be highlighted as central. The hypothesis is that Article 19 – and the right to live in the community, contained therein – constitutes the right to have rights for persons with disabilities and therefore it can be considered as the most central right of the CRPD, from the perspective of the present thesis.

31 The duty-bearers of human rights obligations are the States Parties of the human rights treaties. Nevertheless, the CRPD is open for accession also by any regional integration organisation and the European Union has already signed it, and accordingly became a Party to this international human rights treaty. Source: Joseph, Sarah and Fletcher, Adam. Scope of Application. In: *International Human Rights Law*, Daniel Moeckli, Sangeeta Shah and Sandesh Sivakumaran (eds.), 119-139. Oxford: Oxford University Press, 2014, 120.

32 Indivisibility of human rights was established not least under the Vienna Declaration and Programme of Action, adopted by the World Conference on Human Rights in Vienna on 25 June 1993.

1.3 Material and Method

Since the general approach of this thesis is to reveal the content of the CRPD articles and the relationship between them, the method that can be considered appropriate, is the legal analytical method (*rättsanalytisk metod*)³³. Determining the law in force can constitute a part of the legal analytical work, however a more important task is to analyse the current law. The analysis can be based on a variety of materials, including soft law, recommendations of international bodies, statistics, etc.³⁴ Accordingly, this thesis will use the general comments³⁵ and recommendations³⁶, adopted by the Committee on the Rights of Persons with Disabilities (the CRPD Committee)³⁷. The general comments and recommendations are not legally binding and neither primary sources of law³⁸, rather they are to guide the States Parties when implementing the convention provisions. I will use them as an authentic interpretative instrument to the convention text, in line with the legal analytical method. A critical approach can also be part of the chosen method³⁹, and I find it important to apply such an approach when analysing the CRPD. The chosen theory will provide critical questions that will help me to analyse the CRPD.

In addition to the CRPD and its sources of interpretation such as the general comments and recommendations, I will use the Vienna Convention on the Law of Treaties (the Vienna Convention)⁴⁰ as an aid to interpret the articles of the CRPD. The Vienna Convention regulates how international treaties shall be interpreted. It is a tool primarily for national and international tribunals and judges, however, it can be relevant for scholars as

33 Sandgren, Clas. *Rättsvetenskap för uppsatsförfattare: Ämne, material, metod och argumentation*, 3d ed., Stockholm: Norstedts Juridik, 2015, 44-47.

34 Ibid, 46

35 The UN treaty bodies, including the CRPD Committee, publish their interpretation of the provisions of its respective human rights treaty in the form of "general comments" or "general recommendations". (Source: United Nations Office of the High Commissioner. *Human Rights Treaty Bodies – General Comments*, <http://www.ohchr.org/EN/HRBodies/Pages/TBGeneralComments.aspx> Accessed 16 April 2017)

36 The States Parties are obliged to submit regular reports to the CRPD Committee on how the rights are being implemented. Following the examination of these reports, the Committee shall make general recommendations on the reports and shall forward these to the State Party concerned. (Source: United Nations Office of the High Commissioner. *Committee on the Rights of Persons with Disabilities*, <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> Accessed 16 April 2017)

37 The CRPD Committee was established by the CRPD.

38 In accordance with Article 38 of the Statute of the International Court of Justice.

39 Sandgren. *Rättsvetenskap för uppsatsförfattare: Ämne, material, metod och argumentation*, 46.

40 United Nations, *Vienna Convention on the Law of Treaties*, 22 May 1969

well. Accordingly, I will apply its relevant articles when interpreting the CRPD. The CRPD articles will be interpreted in good faith, in the light of the Convention's preamble, purpose, general principles, and its *travaux préparatoires*.⁴¹

The primary materials for the analysis comprise of the Convention on the Rights of Persons with Disabilities and the CRPD Committee's general comments and recommendations. Official reports, prepared under the auspices of the United Nations; reports of NGOs, such as the European Disability Forum, and scientific articles from books and journals, focusing on Article 19 and/or analysing the CRPD, will be used as secondary materials.

1.4 Delimitations

It must be noted that the scope of the study requires some limitations to be recognized. During the critical legal analysis, the focus will be on the CRPD articles containing either substantial rights or general provisions (Articles 1–30). The rest of the articles regulating, inter alia, the implementation and monitoring (Articles 31–40) will not be discussed.

Although the CRPD is closely connected to its Optional Protocol, the provisions of the latter one will be mentioned, but not analysed further.

1.5 Previous Research

Previous research, relevant for the present thesis, includes research papers, examining which articles can be considered as central in the CRPD. A number of papers, focusing on this subject, were identified. Earlier conducted research by, inter alia, Alex L Pearl and Amita Dhanda, has been an inspiration for the present thesis. Research papers by these authors argue for the central role of Article 12 (equal recognition before the law), based on its recognition that all persons with disabilities possess legal capacity and have the right to exercise it. In the article "*Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?*", Dhanda finds the fundamental role of legal capacity, guaranteed

⁴¹ Ibid, Articles 31-32

under Article 12, in that it makes it possible to obtain all other rights, guaranteed under the Convention⁴². The article “*Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward*”, written by Pearl, argues similarly and describes what makes the protection of legal capacity in Article 12 fundamental. If persons with disabilities are deprived of their legal capacity presumed necessary to make decisions about one’s life, they become deprived of their rights to family life (Article 23), to education (Article 24), to participate in political and cultural life (Articles 29–30). Without legal capacity, people cannot make healthcare decisions (Article 25), they may receive treatment against their will (Articles 14–15) and they may be denied access to justice (Article 13).⁴³ Thereby, both authors state that the enjoyment of legal capacity represents the prerequisite for the enjoyment of all the other rights in the CRPD. However, they also emphasize that the provisions of Article 12 can be interpreted differently by the States Parties, which entails the risk of being interpreted in a way that legitimizes substitute decision-making regimes.⁴⁴ Therefore, Article 12 has to be interpreted in line with the aims of the CRPD in order to be the biggest driving force for the full inclusion of all persons with disabilities, providing real improvements in their lives.⁴⁵ These studies can be considered an interesting point of departure for the present thesis that partly aims to build on them.

1.6 Outline

Chapter two will provide an illustration of the brief history of the CRPD. To be able to establish well-founded answers to the research questions, I consider such a background essential – explaining why it was necessary to draft a convention on the rights of persons

42 Dhanda, Amita. Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?. *Syracuse Journal of International Law and Commerce*, vol. 34, Issue 2 (2007), 456.

43 Dhanda. *Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?*, 461.; Pearl, Alex L. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward. *Leeds Journal of Law and Criminology*, vol. 1 nr. 1. (2013), 10-12.

44 Pearl. *Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward*, 6.

45 Dhanda. *Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?*, 462.; Pearl. *Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward*, 30.

with disabilities. Chapters three and four will focus on the right to live in the community, and a critical legal analysis will be performed on the CRPD in Chapter five, considering that this convention recognizes this right. In Chapter six, there will be a discussion why can we consider the right to live in the community, set out in Article 19, as a central right of the Convention. Finally, in Chapter seven, the conclusions will be drawn, based on the analysis performed.

2 Background: An international human rights convention on the rights of persons with disabilities

The articulation of the rights of persons with disabilities in a separate international human rights convention needs to be explained first. My intention here is not to provide a detailed disclosure of the drafting history of the CRPD, rather to establish an understanding as to why this convention was drafted. Therefore, the focus will be on three main aspects: the problems facing human rights treaties, prior to the creation of the CRPD; the development of a paradigm shift in perspectives on disability; and the outline of the adopted disability specific convention.

In this part of the thesis, content analysis will be performed on primary sources, mainly UN documents, and secondary sources from books and journals, in order to conclude which facts necessitated the creation of the CRPD.

2.1 The problem with human rights treaties

Prior to the creation of the CRPD, persons with disabilities shared the same human rights with others, in theory, meanwhile they were denied many of them, in practice.⁴⁶ The basic

46 United Nations Office of the High Commissioner for Human Rights. *From Exclusion to Equality: Realizing the rights of persons with disabilities*, 2007, <http://www.refworld.org/docid/49fab8192.html> Accessed 2 May 2017, p. 4.

human rights and fundamental freedoms were “either not applied or applied differently”⁴⁷ to persons with disabilities. Denial of the basic rights is not surprising in the light of the human history, characterized by exclusion, making persons with disabilities „invisible citizens”⁴⁸. This invisibility led to an unequal distribution of the rights between persons with- and without disabilities. For example, when persons with disabilities are forced to live in institutions, restrictions are placed on their family and privacy rights (civil rights), when persons with disabilities are denied the right to vote, they cannot participate in political debate on equal terms with others (political rights), when persons with disabilities are excluded from the ordinary education system, they find themselves in a disadvantageous situation in the fields of education and work (social rights).⁴⁹

The abovementioned „invisibility” provided one of the arguments for a disability specific convention.⁵⁰ Meanwhile then in force international human rights instruments⁵¹ and their norms applied to persons with disabilities as well, they did not contain special equality provisions for persons with disabilities, however they did in case of other groups, such as minorities or women. Furthermore, other groups than persons with disabilities who were also disadvantaged throughout history, were already protected by thematic conventions and international bodies, monitoring respect for their human rights.⁵² Persons with disabilities stayed beyond the scope of the different international treaty monitoring bodies and the disability dimension could not be present in all human rights issues. According to the „visibility argument”, a thematic convention for persons with disabilities was needed for „mainstreaming disability in the existing treaty monitoring machinery”⁵³ but also for indicating to the world that persons with disabilities have the same rights than anyone else.

In 2001, the UN General Assembly adopted a resolution on a „Comprehensive and integral international convention to promote and protect the rights and dignity of persons

47 Quinn, Gerard and Degener, Theresia. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*. New York and Geneva: United Nations, 2002, 23.

48 Ibid, 23

49 Ibid, 25

50 Ibid, 294

51 Such as the ICCPR and the UDHR.

52 Quinn and Degener. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, 293.

53 Ibid, 295

with disabilities”⁵⁴. An Ad Hoc Committee has been established with a task to draft the text of such a convention. Organisations representing persons with disabilities were key participants in the negotiations of the CRPD.⁵⁵

Before providing further description on the CRPD, let me explain the paradigm shift – already mentioned in the introductory part of this thesis –, which has been in thoroughly discussed by the participants of the negotiations and which appears in the Convention.

2.2 The paradigm shift in perspective on disability

Disability issues can be approached in various ways. From different models, the medical- and the social model of disability were in the centre of discussions, during the negotiations of the CRPD.⁵⁶ These models were developed in disability studies during the 1970s and 1980s, and they have different explanation of disabilities. In the medical model, “disability” is seen as an impairment, „a deviation from the normal health status” that needs to be treated.⁵⁷ Thereby, the focus lies on the impairments, and the „problem of disability”⁵⁸ is located within the person who becomes regarded as an object of social protection, care and medical treatment.⁵⁹ The exclusion of persons with disabilities becomes an individual problem, reaching beyond the scope of society.⁶⁰ In contrast, the social model regards “disability” as a social construct and the focus lies on the barriers in the society, instead of the individual impairments.⁶¹ The exclusion of persons with disabilities is not considered as an individual problem anymore.

It was out of question, during the negotiations of the CRPD, that the medical model of disability cannot serve as a philosophical basis for the Convention. The Convention is

54 A/RES/56/168 United Nations General Assembly, *Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities*, 19 December 2001

55 Schulze. *A Handbook on the Human Rights of Persons with Disabilities. Understanding the UN Convention on the Rights of Persons with Disabilities*, 13-14.

56 Degener, Theresia. Disability in a Human Rights Context. *Laws*. vol. 5 no. 3 (2016) doi:10.3390/laws5030035. p. 2.

57 Degener. *Disability in a Human Rights Context*, 2-3.

58 Quinn and Degener. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, 14.

59 A/HRC/28/37, p. 3.

60 Degener. *Disability in a Human Rights Context*, 2-3.

61 McCallum. *The United Nations Convention on the Rights of Persons with Disabilities: Some Reflections*, 3.; Degener. *Disability in a Human Rights Context*, 2.

often stated to be based on the social model of disability⁶² that regards disability as generated from an interaction between the individual impairments of persons and the barriers in the society. This social model is reflected by Paragraph E of the Preamble⁶³, as well as by Article 1 of the CRPD⁶⁴. Even though the social model of disability has been considered as the philosophical basis for the CRPD, during its negotiations, a number of authors⁶⁵ argue that the drafters codified the human rights model of disability, which „builds on the social model but develops it further”.⁶⁶ The human rights model, similarly to the social model, asserts that disability is a social construct. However, the human rights model can mediate that human rights do not require certain body status. Meanwhile the social model requires non-discrimination rights for persons with disabilities, the human rights model encompasses both sets of human rights. The human rights model considers impairments as a condition which can have a negative impact on the quality of life but which belongs to the human diversity and have to be valued as such.⁶⁷ According to this approach, persons with disabilities are regarded as subjects of human rights on an equal basis with others, who are capable of making decisions regarding their own lives.⁶⁸ Society is responsible for ensuring that persons with disabilities can be an integral part of it. In the development of such paradigm shift in perspectives on disability, the creation of the CRPD is regarded as an „important milestone”⁶⁹ by the United Nations High Commissioner for Human Rights. The paradigm shift which appears in the Convention, therefore refers to a shift from a medical- to a human rights-based approach.⁷⁰ This statement is supported and confirmed by the CRPD Committee which used the term „human rights model of disability” in its concluding observations⁷¹.

⁶² Degener. *Disability in a Human Rights Context*, 2-3.

⁶³ „Disability is an evolving concept and... disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”

⁶⁴ „Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

⁶⁵ Theresia Degener, Gerard Quinn

⁶⁶ Degener. *Disability in a Human Rights Context*, 2-3.

⁶⁷ Ibid, 19

⁶⁸ Ibid, 1

⁶⁹ A/HRC/28/37, 3

⁷⁰ Ibid, 3

⁷¹ CRPD/C/ARG/CO/1 Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Argentina as approved by the Committee at its eighth session (17–28 September 2012)*, 8 October 2012

2.3 A disability specific human rights convention

The CRPD was adopted on 13 December 2006 by the General Assembly of the United Nations⁷² and it entered into force on 8 May 2008⁷³ as a legally binding international human rights treaty. It guarantees both civil and political, as well as economic, social and cultural rights to persons with disabilities.

The purpose of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”⁷⁴ Eight principles seek to guide the achievement of this purpose. All the principles are of particular importance, however, I would like to highlight three of them from the point of view of this thesis: “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; non-discrimination; and full and effective participation and inclusion in society”⁷⁵.

When defining the range of rights in the CRPD, special attention was paid to the experiences of persons with disabilities.⁷⁶ The Convention identifies those public and private areas where persons with disabilities could not exercise their existing human rights due to barriers and discrimination in the society.⁷⁷ The States Parties are required to take effective measures with respect to these areas.⁷⁸ An Optional Protocol, which was adopted simultaneously with the Convention,⁷⁹ enables individuals and groups to complain to the CRPD Committee if they believe to be a victim of human rights violation – provided that the state under whose jurisdiction they belong have signed the Protocol.

72 A/RES/61/106 United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, 13 December 2006

73 United Nations, *Entry into Force*, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.htm> Accessed 18 April 2017

74 Article 1, CRPD

75 Article 3, (a-c), CRPD

76 McCallum. *The United Nations Convention on the Rights of Persons with Disabilities: Some Reflections*, 5.

77 United Nations Office of the High Commissioner for Human Rights, *From Exclusion to Equality: Realizing the rights of persons with disabilities*, p. 5.; McCallum. *The United Nations Convention on the Rights of Persons with Disabilities: Some Reflections*, 5.

78 When the States Parties are fulfilling their specific obligations provided for in the substantive provisions, they have to take into account the general obligations as well, set forth in Article 4.

79 A/RES/61/106

The CRPD has a significant impact on international human rights law.⁸⁰ It shows in a clear way how taking measures in different areas is necessary to enable persons with disabilities to exercise the rights and freedoms. As of May 2017, 173 countries had ratified and 14 countries had signed it.⁸¹ It means that countries all over the world have reviewed their laws – or the review is in process – in order to ensure their compliance with the Convention. The impact of the CRPD is also reflected in the judgments of international courts, such as the European Court of Human Rights.⁸² Despite the undeniable power of the CRPD, it should be mentioned that the strengths of its provisions are weakened by the optional nature of the aforementioned Protocol and the possibility that the States Parties may make reservations when ratifying the Convention.

Hereafter, I will show what the right to live in the community means under Article 19 and why the CRPD specifies such a right. Thereafter, it will be examined what distinguishes the right to live in the community from the other rights guaranteed under the Convention. The thesis will then move on to analyse the relationship between Article 19 and the other articles of the CRPD. Against this background, a discussion will be performed concerning Article 19's central role.

3 The right to live in the community

In order to establish an understanding of what this right is about, let me first introduce the normative content of Article 19 and its core concepts: deinstitutionalization, community living, personal assistance and independent living.

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take

⁸⁰ Degener. *Disability in a Human Rights Context*, 2.

⁸¹ United Nations Office of the High Commissioner for Human Rights. *Ratification of 18 International Human Rights Treaties*, <http://indicators.ohchr.org/> Accessed 21 April 2017

⁸² European Court of Human Rights, *Case of Stanev v. Bulgaria* (Application no. 36760/06), Judgement 17 January 2012; *Case of Glor v. Switzerland* (application no. 13444/04), Judgement 30 April 2009; *Case of Guberina v. Croatia* (Application no. 23682/13), Judgement 22 March 2016

effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) 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;*
- (b) 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;*
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*⁸³

In its introductory sentence, Article 19 recognizes the right of all persons with disabilities to live in the community, with choices equal to others. Thereby the States Parties undertake the obligation to take all appropriate measures to facilitate the full enjoyment of this right by persons with disabilities. It should be noted that the CRPD aims to guarantee the right to live in the community for every person with all kinds of disabilities, regardless of the degree to which they require support from the society.

Article 19 (a) aims to ensure that persons with disabilities have choice and control over their living arrangements that constitute a decisive segment of people's life, fulfilling a basic function in it. In this context, Article 19 (a) prohibits the forced placement of people in particular living arrangements, on the ground of having a disability.⁸⁴ Article 19 (a) read together with the introductory sentence recalls the concepts of deinstitutionalization and independent living, of which the latter will be discussed later on. “Particular living arrangements” refer to the forced institutionalization of people, even though the text of Article 19 does not contain a clear reference to institutions because the drafters found that it would not have been clear for everyone what is meant under the term “institution”.⁸⁵

83 Article 19, CRPD

84 A/HRC/28/37, p. 7.

85 Schulze. *A Handbook on the Human Rights of Persons with Disabilities. Understanding the UN Convention on the Rights of Persons with Disabilities*, 79.

Institutions are characterized by rigidity of routine and a paternalistic approach in providing services. According to a guideline, conducted by the European Expert Group in 2012, residents of the institutions are isolated from the broader community, their personal preferences are not given priority, they lack privacy and control over their lives and the decisions affecting them⁸⁶, for example what food to eat or when to receive visitors. Living in an institution leads to segregation from the rest of the society. Since the mere existence of institutions is contrary to the CRPD, a number of concluding observations, adopted by the CRPD Committee, require the States Parties, in which institutions still exist, to adopt adequate strategies in order to realise deinstitutionalization.⁸⁷ The term “deinstitutionalization” refers to a process in which a shift occurs from institutional care to community-based services, allowing persons with disabilities to live within their communities and to make decisions about their own lives.⁸⁸ Article 19 (a) focuses on guaranteeing persons with disabilities to make choices regarding their own lives, including their living arrangements that has several dimensions: to make decisions about the place of residence but also the daily routines of everyday life.

Based on the core human rights principle that “all human beings are born free and equal in dignity and rights”⁸⁹, persons with disabilities and their representative organisations argued, before and during the drafting of the CRPD, that all persons are capable to make choices, regarding their own needs, which must be acknowledged. The development of the elements of Article 19 was influenced by the exploration of such misconceptions that persons with disabilities are not able to make reasonable decisions regarding their own lives.⁹⁰ The practices which made it impossible for persons with disabilities to have control over their

86 European Expert Group on the Transition from Institutional to Community-based Care. Common European Guidelines on the Transition from Institutional to Community-based Care. 2012. <http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf> Accessed 08 May 2017, 10.

87 CRPD/C/HUN/CO/1 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17-28 September 2012)*, 22 October 2012; CRPD/C/AUT/CO/1 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013)*, 13 September 2013

88 A/HRC/28/37, 8.

89 Article 1, UDHR

90 A/HRC/28/37, 3-5.

lives, including their living arrangements, are recognized and to be changed according to Article 19.

Article 19 (b) refers to the requirement that persons with disabilities have to be supported by personalized community-based services in order to be able to live in the community. “Community living” means that persons with disabilities can live in their local communities and participate in its everyday life, including growing up in their families, living in their own homes, going to the neighbourhood school, etc.⁹¹ Personal assistance is specified by the CRPD as an example of the personalized community-based services. It refers to a type of providing support which is essential for many persons with disabilities “to meet practical needs of everyday life”⁹², inter alia, eating, dressing or communicating with others. If the provided practical assistance is based on the will of persons with disabilities, it can ensure them having the same choices and control over their lives as other citizens, and thereby they can lead an independent life.⁹³ Personal assistance is ensured by legislation in some countries⁹⁴, however it is waiting for introduction in most countries.⁹⁵

In addition, Article 19 (c) aims to ensure that persons with disabilities have the opportunity to access the mainstream community services, such as mainstream education-, transportation- or healthcare services.

To be able to live as equal citizens in the community, persons with disabilities are in need of community-based services, including personalized, disability-specific as well as mainstream services offered to all members of the community. Article 19 (b) and (c) constitute a prerequisite of Article 19 (a), inasmuch in the lack of community-based alternatives, persons with disabilities do not have real options to choose from. In the lack of personalized community-based support or mainstream community services, persons with certain types of disabilities are either forced to live their lives in institutions and/or they become dependent on support from their families. By contrast, community-based support services can enable people to live independently. “Independent living” means that persons

91 ECCL Focus Report, 6.

92 A/HRC/28/37, 11.

93 ECCL Focus Report, 6.

94 For example, in Sweden, the Act concerning Support and Service for Persons with Certain Functional Impairments provides for the right to personal assistance.

95 Schulze. *A Handbook on the Human Rights of Persons with Disabilities. Understanding the UN Convention on the Rights of Persons with Disabilities*, 79.

with disabilities are enabled to have the same control over their lives as persons without disabilities. Based on this concept, persons with disabilities have the opportunity to choose their place of residence, school, or marital status, just like anyone else.⁹⁶ Living independently does not entail living without support, rather it refers to having the same options as persons without disabilities and exercising the same freedom of choice as others regarding decisions over one's life.⁹⁷

After having clarified the normative content of Article 19 and the main concepts contained therein, I aim to draw the conclusions so far. Article 19 includes the guarantee of two rights: the right to live independently and the right to be included in the community. However, Article 19 refers to these rights as one right. Living independently is connected to the individual exercise of choice and control over one's life, meanwhile community living is tightly bound to social life and inclusion. Thereby, independent living and community living – in other words, the concepts of autonomy and inclusion – are to mutually reinforce each other and to jointly avoid segregation.⁹⁸ Therefore, when I write about the right to live in the community, I consider it self-explanatory that this right is inseparably attached to the right to live independently. Thus, referring to the right to community living becomes identical with referring to Article 19 in the present thesis.

4 A right that stands out

It shall be noted that there was a consensus during the drafting process that the CRPD should not create any special human rights for persons with disabilities that previously did not exist in other human rights treaties. The formulation “on an equal basis with others” which appears in every substantive article of the Convention is to reflect that neither new nor disability specific rights were introduced by the convention.⁹⁹ Instead of creating new rights, the CRPD is aimed at formulating existing human rights in a way that is “relevant to the impairments

⁹⁶ Ibid, 78

⁹⁷ A/HRC/28/37, 5.

⁹⁸ Ibid, 5

⁹⁹ Degener. *Disability in a Human Rights Context*, 15.

and experiences of people with disabilities and takes into account the barriers imposed by society”¹⁰⁰ – in order to promote the realization of these rights.

The right to live in the community has its roots in previously established core catalogues of human rights. Previously existing human rights conventions contain such civil- as well as social rights that form part of the right to community living.¹⁰¹ For instance, the International Covenant on Civil and Political Rights guarantees the right to liberty of movement and freedom to choose his residence for everyone¹⁰². The Convention on the Rights of the Child¹⁰³ recognizes the right of children with disabilities to actively participate in the community¹⁰⁴. In any case, this multi-component right to community living was not declared explicitly until the creation of Article 19 of the CRPD. Neither the Universal Declaration of Human Rights, nor different conventions that clarify and list all human rights based on the Universal Declaration, contain a right to community living. The CRPD is the first legally binding international human rights treaty that explicitly recognizes the right to live in the community for all persons with disabilities.¹⁰⁵ Thereby, the right to live in the community stands out from the other rights contained in the Convention.

It is to be mentioned that according to some opinions¹⁰⁶, the main justification behind drafting Article 19 was that the rights included in it are relevant only for persons with disabilities. I do not dispute the relevance of this article for persons with disabilities, however I would question if it was solely relevant to this group of the society, in the context of the theory that was previously discussed and accepted by the present thesis. Can we consider this right to be the right that was previously missing from human rights treaties and turned human rights into “hopeless idealism” for certain groups of the society? To develop an answer, let us go and see how the different rights, guaranteed under the CRPD, are related to each other.

100 McCallum. *The United Nations Convention on the Rights of Persons with Disabilities: Some Reflections*, 5.

101 Degener. *Disability in a Human Rights Context*, 6.

102 Article 12, ICCPR

103 United Nations, *Convention on the Rights of the Child*, 20 November 1989

104 Article 23, CRC

105 ECCL Focus Report, 21.

106 Trömel. *A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities*, 119.

5 Relationship between Article 19 and the other articles of the CRPD

In the following, the relationship between Article 19 and the other articles, setting out the substantial rights of the Convention, will be analysed. In line with the CRPD Committee's position, the present thesis adopts that Articles 5–30 contain the rights provisions of the Convention.¹⁰⁷ Besides examining the relation between Article 19 and the other articles, the discussion will additionally focus on which rights are guaranteed under the respective articles, and what preconditions can be identified regarding the enforcement of these rights – in the light of their *travaux préparatoires*, providing an insight into why these rights were articulated in the Convention.

As it was mentioned, the right to live in the community is a complex right, which includes civil as well as social rights. Given that the CRPD contains additional rights not belonging clearly either to civil or social rights¹⁰⁸, the rights provisions will not be discussed solely according to a classification based on whether they belong to civil or social rights. Instead, this thesis identifies different sets of rights, according to what function they serve, in the context of disability¹⁰⁹, bearing in mind that all human rights are indivisible and interdependent.

The following sets of rights are identified:

1. Equality and non-discrimination
2. Accessibility
3. Rights that protect the integrity of persons
4. Liberty rights
5. Rights that restore choice and independence

¹⁰⁷ This view appears in every Concluding observations, adopted by the CRPD Committee.

¹⁰⁸ Degener. *Disability in a Human Rights Context*, 5.

¹⁰⁹ Quinn and Degener. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, 19.

5.1 Article 19 and the equality and non-discrimination provision

Article 19 is closely linked to the equality and non-discrimination provision of the CRPD, enshrined in Article 5. The prohibition of discrimination appears also as one of the general principles¹¹⁰ and of the general obligations¹¹¹. Even though Article 19 does not explicitly prescribe the prohibition of discrimination when guaranteeing the right to choose where to live and to have access to community services, it is included implicitly in the article, by using the formula of “on an equal basis with others”. Non-discrimination is a civil right and as such, is subject to immediate realization by the States Parties. However, it imposes negative as well as positive obligations on the states.

Articles 6 and 7 give special attention to women and children with disabilities, given that they can be easily disadvantaged due to their age and/or gender. Several reports confirm that in institutional settings, persons with disabilities are vulnerable to violence and abuse to a higher degree and women with disabilities are especially exposed.¹¹² Article 6 specifically mentions that women and girls with disabilities “are subject to multiple discrimination”. Multiple discrimination can prevent people from enjoying their right to live in the community on equal terms with others, therefore, enabling women to enjoy their right to community living requires special attention and additional measures.

Article 7 requires that the “best interests of the child” prevails in all matters concerning them but also the will and preferences of the child have to be considered. Naturally, this requirement has an important role during the enforcement of Article 19.

When promoting equality and non-discrimination, the States Parties are required to combat prejudices relating to persons with disabilities. Raising awareness throughout society, regarding persons with disabilities and their rights can be perceived as a general duty of the States Parties¹¹³. Article 8 has an important role in overcoming prejudices and the previously

110 Article 3 (b), CRPD

111 Article 4 (e), CRPD

112 CRPD/C/GC/3 Committee on the Rights of Persons with Disabilities, *General comment No. 3 (2016) on women and girls with disabilities*, 25 November 2016, p. 16.

113 Quinn, Gerard. A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities. In: *European Yearbook of Disability Law, Volume 1*, Gerard Quinn and Lisa Waddington (eds.), 89-114. Antwerp: Intersentia, 2009, 103.

mentioned misconceptions, to be changed according to Article 19, namely that persons with disabilities are not able to make reasonable decisions regarding their own lives. Awareness raising is important when realizing deinstitutionalization process, in accordance with Article 19, in those countries where such institutions still exist. Since negative stereotypes can prevent persons with disabilities to live in the community, awareness raising is essential.

5.2 Article 19 and the accessibility provision

Accessibility is specified as one of the key principles¹¹⁴ but also as a separate provision (Article 9) that requires the States Parties to take appropriate measures to make the main areas of community living accessible to persons with disabilities, on an equal basis with others. The obligations of the states, in relation to Article 9, include taking appropriate measures to ensure access to persons with disabilities to all “facilities and services open or provided to the public”. Article 19 (c) requires the States Parties to ensure that “community services and facilities for the general population are available on an equal basis to persons with disabilities”. The abovementioned community services and facilities open or provided to the public, the requirements for which appear in both Articles 9 and 19, include physical environment, transportation as well as information and communication. Equal access makes it possible for persons with disabilities to use the same transportation system or to attend the same school as their neighbours. Accessibility represents a precondition for persons with disabilities to enjoy effectively all their human rights and fundamental freedoms.¹¹⁵

Article 21¹¹⁶ requires the States Parties to ensure that persons with disabilities can exercise the right to freedom of expression. What generally prevents persons with certain types of disabilities from exercising this right is that they either require support to express themselves or they are lack the relevant information based on which they could make a decision.¹¹⁷ Therefore, Article 21 provides for how information and communication can be made accessible and requires the states to provide “information intended for the general public” in accessible formats and to let persons with disabilities to express themselves in alternative

114 Article 3 (f), CRPD

115 CRPD/C/GC/2 Committee on the Rights of Persons with Disabilities, *General comment No. 2 (2014) on Article 9: Accessibility*, 22 May 2014, p. 4.

116 Freedom of expression and opinion, and access to information

117 Quinn. *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 107.

communication forms depending on their choice. In the context of Article 19, it is relevant that everyone can express his or her opinion when choosing a way of life. It is important for everyone to get information in an accessible form about which lifestyles to choose from or what kind of community services are available – in order to be able to make a well-founded decision and to express this decision. The right to accessibility and community based support services play a crucial role in the enjoyment of the rights provided under Article 21.

Article 29 recognizes the political rights of persons with disabilities and requires the States Parties to ensure that persons with disabilities can “effectively and fully participate in political and public life on an equal basis with others”. Article 30 aims to ensure access for persons with disabilities to cultural life, recreation, leisure and sport. Articles 29 and 30 aim to remove barriers in society in two important fields. Participating in political and cultural life makes a part of participating in the life of the community, governed by Article 19. The enjoyment of these rights requires accessible environment (Article 9), the recognition of legal capacity (Article 12) and available community based support services (Article 19).

5.3 Article 19 and the articles containing rights that protect the integrity of persons

Raising awareness to “the issue of selective abortion on the basis of disability”¹¹⁸ lies behind the articulation of the right to life in Article 10 of the CRPD. During the drafting process, disability organisations argued that in a number of cases “the life of persons with disabilities had been put in danger, because of a perceived low quality and value of life”¹¹⁹. For the matter of fact, persons with disabilities who are forced to live in institutions in the lack of community based alternatives or being segregated from the community in other ways, may actually experience a lower quality of life. Inclusion in the community, therefore, has vital importance for avoiding the development of doubts that can lead to negative judgments about the right to life. Such doubts can be that persons with disabilities cannot live a life of good quality. If it is natural for a community that persons with disabilities are a part of it, decision makers and/or society will not question their right to life as it has happened throughout human

118 Quinn. *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 104.

119 Trömel. *A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities*, 124.

history. Besides reaffirming the right to life, the CRPD stresses the obligations the states under international law, to take all necessary measures “to ensure the protection and safety of persons with disabilities in situations of risk”, including situations of humanitarian emergencies (Article 11).

The right to freedom from torture or cruel, inhuman or degrading treatment or punishment (Article 15) complements the general formulation of this right with reference to medical and scientific experimentation that no one shall be subjected to “without his or her free consent”. Thereby, this right is closely connected to the right of persons with disabilities to make decisions about their life, also covered by Articles 12 and 19. During the debate on Article 15, the drafters decided to handle “the issue of involuntary treatments” in a separate article, and that is how Article 17 was created.¹²⁰ It aims to protect the integrity of persons with disabilities by ensuring that the physical and mental integrity of persons with disabilities shall be respected on an equal basis with others. Article 16 requires the States Parties to take all appropriate measures to protect persons with disabilities from all forms of exploitation, violence and abuse, “both within and outside the home”. Articles 15 – 17 are related to Article 19 in the context of “particular living arrangements”. Persons with disabilities are particularly vulnerable when living in institutional settings. They are more likely to experience all forms of violence, they are subject to a high level of inhuman and degrading treatment¹²¹ and are exposed to abuse and exploitation¹²². Institutionalization of people, as prohibited under Article 19, is contrary to Articles 15 and 16 as well.

5.4 Article 19 and the articles containing liberty rights

Article 14 reaffirms the general right to liberty and supplements it, by adding that “the existence of a disability shall in no case justify a deprivation of liberty”. By prohibiting all forms of deprivation of liberty on the basis of disability, Article 14 is closely connected to Article 19. Article 19, read together with articles 12 and 14, prohibits the institutionalization

¹²⁰ Ibid, 130

¹²¹ CRPD/C/ARM/CO/1 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Armenia as adopted by the Committee at its seventeenth session (20 March – 12 April 2017)*, 8 May 2017

¹²² CRPD/C/UKR/CO/1 Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Ukraine, adopted by the Committee at its fourteenth session (17 August – 4 September 2015)*, 2 October 2015

and the deprivation of liberty on the grounds of disability. The lack of available community based support services (Article 19) can easily lead to the violation of Article 14, when persons with disabilities are institutionalized.¹²³

Articles 18 (liberty of movement and nationality) and 20 (personal mobility) include liberty rights¹²⁴ just like Article 14. They address disability-related obstacles in connection with the enjoyment of these classical liberty rights. The recognition that persons with disabilities often encounter difficulties when they want to move from one country to another, was one of the reasons behind the creation of Article 18.¹²⁵ Meanwhile, Article 20 requires the States Parties to ensure personal mobility “with the greatest possible independence for persons with disabilities”. Facilitating access to good quality personal mobility aids, enshrined in Article 20, is vital just like accessibility (Article 9) for persons with disabilities, to be able to live in their community independently, as facilitated in Article 19.

5.5 Article 19 and the articles containing rights that restore choice and independence

It should be mentioned that this group of articles (5.5) are close to the group of articles containing liberty rights (5.4). The reason why they will be discussed separately is that, even though both groups are about liberty, the articles discussed under Section 5.5, focus on restoring liberty.

Similarly to Article 19, Article 12 (equal recognition before the law) is concerned with the right of persons with disabilities to make decisions regarding their own lives. Article 12 affirms that persons with disabilities “enjoy legal capacity¹²⁶ on an equal basis with others

123 See the CASE OF STANEV v. BULGARIA (Application no. 36760/06). Here, the European Court of Human Rights found that the applicant had been deprived of his liberty unlawfully and arbitrarily as a result of his placement in an institution against his will. The Court held that there had been a violation of Article 5 § 1 (right to liberty and security) of the European Convention on Human Rights. It shall be noticed that the Court interpreted the European Convention on Human Rights with respect to the provisions of the CRPD (Articles 12 and 14).

124 Quinn. *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 109.

125 Ibid, 109

126 Legal capacity is to be distinguished from mental capacity, which “refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.” CRPD/C/GC/1 Committee on the Rights of Persons with Disabilities, *General comment No. 1 (2014) Article 12: Equal recognition before the law*, 19 May 2014, p. 3.

in all aspects of life”.¹²⁷ It is acknowledged by Article 12 that all persons with disabilities have a capacity to decide about their lives and to have those choices respected.¹²⁸ Legal capacity has been “denied to many groups throughout history, including women and ethnic minorities. However, persons with disabilities remain the group whose legal capacity is most commonly denied in legal systems worldwide.”¹²⁹ The legal system in many countries continue to prevent persons with certain kinds of disabilities to make their own decisions. Under substitute decision-making regimes “such as guardianship, conservatorship and mental health laws that permit forced treatment”¹³⁰, persons with intellectual disabilities are wholly or partly deprived of their legal capacity. Denial of legal capacity results in that the persons concerned are not allowed to practice many of their fundamental rights. They are not allowed for instance to vote, to marry or to make decisions regarding their living arrangements.¹³¹ Thereby, they cannot make decisions about their life.

Legal capacity includes two elements that cannot be separated: to be a holder of rights and to exercise those rights.¹³² The exercise of legal capacity can concern a decision about the place of residence (Article 19), but it can concern all the other aspects of life as well, for example deciding on accepting a medical treatment (Article 25)¹³³, whether to marry (Article 23) or where to work (Article 27). From this point of view, Article 12 articulates the freedom of choice in a wider manner than Article 19. Anyhow, both Article 19 and Article 12 play a crucial role in facilitating the right to make decisions concerning one’s life. Article 12 “embodies the legal aspects of living independently, exercising autonomy and having the freedom to make one’s own choices”.¹³⁴

127 Article 12 (1) reaffirms that persons with disabilities are recognized as persons before the law. Possessing legal personality “is a prerequisite for the recognition of as person’s legal capacity”. CRPD/C/GC/1, p. 3.

128 ECCL Focus Report, 28.

129 CRPD/C/GC/1, p. 2.

130 Ibid, 2.

131 Hammarberg, Thomas. Contribution from the Commissioner for Human Rights of the Council of Europe. In: *European Yearbook of Disability Law, Volume 2*, Gerard Quinn and Lisa Waddington (eds.), 153-159. Antwerp: Intersentia, 2010, 157.; CRPD/C/GC/1, 2.

132 CRPD/C/GC/1, 3.

133 A/HRC/28/37, 6.

134 Schulze. *A Handbook on the Human Rights of Persons with Disabilities. Understanding the UN Convention on the Rights of Persons with Disabilities*, 86.

Article 12 also provides that inasmuch persons with disabilities require support to be able to exercise their legal capacity, the provided support must respect “the rights, will and preferences” of persons with disabilities and should never amount to substitute decision-making.¹³⁵ In this context, an additional point of reference between Articles 12 and 19 is that the support in line with Article 12 shall be provided through a community-based approach.¹³⁶

Article 13 (access to justice) and Article 12 share their common root in the traditional right to equality before the law.¹³⁷ The close relationship that exists between Articles 12 and 13, was acknowledged during the negotiations. Without the enjoyment of legal capacity, the right to access to justice cannot be realized, since it requires the recognition of legal personality.¹³⁸

Articles 22 and 23 contain rights that are based on the individual autonomy, and aim to restore the decision-making capacity of persons with disabilities.¹³⁹ Therefore these articles are closely linked to Article 19 and especially to one of its central concepts: independent living. Article 22 affirms the right of persons with disabilities to privacy. Realising that they were often exposed to unauthorized disclosure of confidential information¹⁴⁰ concerning them, Article 22 aims to ensure that no person “shall be subjected to arbitrary or unlawful interference with his or her privacy”, “regardless of place of residence or living arrangements”. The formulation of “regardless of place of residence or living arrangements” makes a connection between Article 22 and Article 19. The privacy of persons with disabilities should be guaranteed in institutions as well, however, it can be questioned, in the light of the previously mentioned reports, that privacy could be respected in institutional settings. It is important that persons with disabilities can decide on matters concerning them, including with whom they want to share confidential information. The

135 CRPD/C/GC/1, 4.

136 CRPD/C/GC/1, 11.

137 Flynn and Lawson. *Disability and Access to Justice in the European Union: Implications of the United Nations Convention on the Rights of Persons with Disabilities*, 26.

138 Let us suppose that persons with disabilities, living in an institution are subjected to inhuman conditions. If their legal capacity is denied and they are appointed a legal guardian instead, who is the director of the institution, and makes legal decisions on their behalf, they cannot have access to justice. In this supposed case, the legal guardian should take action and sue the institution in question. Since the perpetrator and the legal guardian are the same person, it becomes impossible to sue the institution, on behalf of these persons with disabilities living in such an institution. Source: Ibid, 26

139 Quinn. *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 107.

140 Ibid, 107

enjoyment of the right to privacy requires available community based support services (Article 19) and it presupposes respect for the person's legal capacity (Article 12).

Article 22 is closely linked to Article 23 which seeks to ensure a number of rights concerning respect for home and the family, that persons with disabilities could not enjoy due to restricting provisions from the past.¹⁴¹ The States Parties shall ensure the right to marry, to found a family and to retain fertility to persons with disabilities on an equal basis with others. Article 23 is closely linked to Article 19. The personal choice and control over one's life plays a central role in both articles. Without legal capacity (Article 12), no such choices can be made. I would also like to point out that Article 23 aims to prevent children with disabilities from being segregated and institutionalized.

Article 24 (right to education) promotes inclusive education and requires the States Parties to ensure that "persons with disabilities are not excluded from the general education system on the basis of disability". The right to education has vital importance in terms of work opportunities. Depending on the quality of education one has received, opportunities for employment can significantly vary. Article 27 (right to work and employment) promotes employment in an open, inclusive work environment. Recognizing that persons with disabilities live in much poorer living conditions than persons without disabilities¹⁴², Article 28 sets out the right to an adequate standard of living, including adequate food, clothing, housing and continuous improvement of living conditions. Inadequate standard of living increases the chances to be institutionalized¹⁴³. The right of persons with disabilities to enjoy the highest attainable standard of health is recognized under Article 25. Furthermore, the States Parties are responsible for providing habilitation and rehabilitation services and programmes (Article 26) in order to enable persons with disabilities to attain and maintain independence and full inclusion in all aspects of life. Articles 24–28 belong to the economic, social and cultural rights, which had to be reconsidered and strengthened in terms of disability, as persons with disabilities could previously exercise them in a segregated environment at most. Viewing persons with disabilities as objects in the past, society did not consider persons with disabilities as worthy "subjects of social investment"¹⁴⁴ and did not

¹⁴¹ Ibid, 107

¹⁴² Quinn. *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 111.

¹⁴³ CRPD/C/GC/3, p. 17.

¹⁴⁴ Quinn. *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, 109.

find it important to develop their skills. The exercise of these rights contributes to determining one's place in the community, furthermore enriches the individual as well as the society. In order to exercise these rights, in many cases it is imperative that community-based services, including personalized as well as mainstream services, recognized under Article 19, are available. These rights, enshrined in Articles 24–28, can be exercised in their entirety within an accessible (Article 9) community (Article 19).

6 The most central right of the CRPD

Based on the analysis performed above, we can see that Article 19 is interconnected with the other articles of the CRPD. Furthermore, we can conclude that Article 19 is a central article, based on the criteria for granting central role to a convention article, accepted by the present thesis. Practising other rights is dependent on the recognition of the right to live in the community (Article 19). Inclusive education and the right to work in an open work environment cannot be realized in segregated settings. They require the enjoyment of the right to community living and available personalized support such as personal assistance. In the lack of appropriate community support services, the right to an adequate standard of living cannot be a reality for many. Participation in political life and in cultural life cannot be enjoyed in institutional settings, in the lack of the right to live in the community. Just to mention a few examples.

However, it seems that other articles than Article 19, also play a central role in the Convention. Enjoyment of the majority of the CRPD rights is dependent on the realisation of accessibility (Article 9) and the recognition of legal capacity (Article 12).

Accessibility in general represents a precondition for living independently and being included in the community (Article 19). Accessibility plays a key role in ensuring the realisation of all the other CRPD rights as well. For example, inaccessible buildings can prevent access to justice (Article 13), or inclusive education (Article 24). Freedom of expression (Article 21) cannot prevail when the necessary information is not provided in an accessible form. Accessibility considerations have to be taken into account in all aspects of life. Not surprisingly, accessibility is also specified among the principles of the Convention.

The essence and function of accessibility has been discussed during the negotiations of the Convention, and it was argued that “accessibility is not a right in itself, but a precondition that needs to occur to ensure the access to existing rights by persons with disabilities”¹⁴⁵. Placing Article 9 on accessibility in front of all the other provisions, containing substantive rights, reflects this view in the Convention. This thesis accepts this approach to accessibility and recognizes that Article 9 contains general provisions that are intended to be applied to all the other articles of the CRPD. The wording of Article 9 refers to that accessibility is a general precondition for the enjoyment of the CRPD rights. People cannot have a right to access on its own. Therefore, I consider accessibility as a central precondition for enjoying all the rights, enshrined in the CRPD. Human rights presuppose access.

Let us move on to examine the central role played by Article 12 in the CRPD (see previous research). The question arises, whether Articles 12 or Article 19 can be appointed as being more central?

As we have seen in the previous chapter, having legal capacity (Article 12) is a prerequisite for many other rights. The question of legal capacity has relevance today primarily for persons with intellectual disabilities. Mostly, the same narrower group of persons with disabilities are affected by the problematics of institutionalization and the worst forms of segregations (Article 19). According to Article 1, “persons with disabilities include those who have long-term physical, *mental, intellectual* or sensory *impairments* which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (highlighted by the author). Therefore, I will continue to use the term “persons with disabilities”, without specifying with what kind of impairments individuals are most likely to experience a given situation. Particularly in the view of that persons with disabilities, regardless of the type of disabilities, share a common history of isolation, stigmatization and mistreatment¹⁴⁶, which greatly affects their right to live in the community.

Persons with disabilities often simultaneously experience being deprived of legal capacity and being placed in an institution, segregated from the community.¹⁴⁷ However,

145 Trömel. *A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities*, 118.

146 Kanter. *The Globalization of Disability Rights Law*, 245.

147 CRPD/C/GC/1, p. 12.

being institutionalized can concern persons having legal capacity as well, when state support covers solely institutional support services.¹⁴⁸ Recognizing legal capacity (Article 12), and thereby ensuring persons with disabilities to make decisions, that are legally recognized, is required in order to be able to choose living arrangements (Article 19). However, respect for the choices of a person will not guarantee inclusion in the community, since there might be no community based services available. Another example, when someone wants to exercise his or her right to marry. Is it possible to do so in institutional settings, where privacy cannot be ensured? These rights are becoming meaningless, when the practitioner of these rights is separated from the community. Let me introduce the example of a more familiar person, Adolf Ratzka¹⁴⁹, whose name is intertwined with the introduction of personal assistance in Sweden. Before moving to a country where he could live an independent life in the community, he had to live in institutions in his home country for many years, where his daily life was directed by others.¹⁵⁰ In the absence of community based alternatives, someone can hold legal capacity but still be living in institutional settings, where human rights abuses are likely to happen. For example, human rights violations can result from the lack of privacy¹⁵¹, by receiving a degrading treatment¹⁵², but violations can also be present in the form of abuse by the staff and other residents¹⁵³.

“It is imperative that persons with disabilities have opportunities to develop and express their will and preferences, in order to exercise their legal capacity on an equal basis with others.”¹⁵⁴ Persons with disabilities, thereby, need to live within the community in order to be able to realize their rights enshrined in Article 12.

I do not deny that Article 12 is a prerequisite for the exercise of all other CRPD rights (see previous research), however, in order to be able to exercise their rights, people first have

148 Keys, Mary. Legal Capacity Law Reform in Europe: An Urgent Challenge. In: *European Yearbook of Disability Law, Volume 1*, Gerard Quinn and Lisa Waddington (eds.), 59-88. Antwerp: Intersentia, 2009, 62.

149 Adolf Ratzka is the founder of STIL, the short for The Founders of Independent Living in Sweden. STIL was the first organisation in Sweden to offer personal assistance for persons with disabilities.

150 Assistanskoll. Trettio år sedan personlig assistans kom till Sverige. 2017.

<https://assistanskoll.se/20170129-Trettio-ar-sedan-assistans-kom-till-Sverige.html> Accessed 4 May 2017

151 Mental Disability Advocacy Center and the Association for Social Affirmation of People with Mental Disabilities. Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia. 2011. http://www.mdac.info/sites/mdac.info/files/croatiareport2011_en.pdf Accessed 19 May 2017 p. 25.

152 Ibid, 64

153 ECCL Focus Report, p. 5.

154 CRPD/C/GC/2, p. 11.

to become an integral part of society. Membership is a precondition for participation, through which people can enjoy their rights. Therefore, this thesis argues that Article 19 represents a prerequisite for Article 12, which represents a precondition for the exercise of all the rights and freedoms enshrined in the CRPD. When all persons with disabilities became members of the community, then the key lies in Article 12 and in accessibility as a general precondition, towards the full inclusion of people.

In this context, it should be noted that the right to equality before the law (Article 12) belongs to the civil and political rights, and as such, is subjected to immediate realization by the states. The rights provided for in Article 12 “apply at the moment of ratification and are subject to immediate realization”.¹⁵⁵ In contrast, Article 19 contains elements that are civil and political (such as non-discrimination), as well as elements that are social (such as personal assistance) in nature. The latter elements are subject to progressive realization in accordance with Article 4, that “acknowledges the constraints due to the limited available resources”¹⁵⁶ and provides for that regarding social, economic and cultural rights, each State Party shall take measures “to the maximum of its available resources... with a view to achieving progressively the full realization of these rights”. The question arises how is it possible to implement the rights under Article 12 in practice, in the absence of community based support and services? The implementation of Article 12, which is subject to immediate realization, depends on the country’s economy, whether it can ensure the right to live in the community. In order to ensure persons with disabilities all of their civil and political rights, positive measures must be taken, which can be costly.¹⁵⁷ It shows that the separation of rights into civil and political right, requiring immediate implementation, on the one hand, and economic, social and cultural rights, requiring progressive realization, on the other hand, can lead to an unjust situation.¹⁵⁸ In the absence of one social right, another civil right cannot prevail.

155 CRPD/C/GC/1, p. 8.

156 Eide, Asbjørn. Adequate Standard of Living. In: *International Human Rights Law*, Daniel Moeckli, Sangeeta Shah and Sandesh Sivakumaran (eds.), 195-216. Oxford: Oxford University Press, 2014, 213.

157 Koch, Ida Elisabeth. From Invisibility to Indivisibility: The International Convention on the Rights of Persons with Disabilities. In: *The UN Convention on the Rights of Persons with Disabilities*, Oddný Mjöll Arnardóttir and Gerard Quinn (eds.), 67-80. Martinus Nijhoff Publishers, 2009, 70.

158 A number of authors have already drawn attention to the difficulty in upholding the traditional classification of the two sets of rights. Source: Koch. *From Invisibility to Indivisibility: The International Convention on the Rights of Persons with Disabilities*, 72.

7 Conclusions

As the analysis shows, the result of the present thesis is based on earlier research and develops it further, by arguing that Article 19 can be regarded as the prerequisite of the enjoyment of Article 12.

As discussed, the United Nations High Commissioner for Human Rights considers Article 19 an article which “reflects the essence of the Convention, in which persons with disabilities are regarded as subjects of rights”¹⁵⁹, referring to the paradigm shift that has occurred in relation to disability. However, this thesis argues that Article 19 represents more than an article that reflects the paradigm shift: Article 19 offers the right to have rights that persons with disabilities did not have properly before. All human rights and fundamental freedoms can be enjoyed fully when someone has the opportunity to live within the community. When someone does not have the right to live in the community, all the other fundamental human rights guaranteed by the CRPD cannot be practiced properly. Thereby, Article 19 is a precondition for the enjoyment of all rights enshrined in the CRPD.

When profiling the contribution of this thesis in relation to the paradigm shift perspective, the perspective of this thesis does not differ completely from the paradigm shift perspective, rather it makes the paradigm shift perspective clearer. Since, the right to live in the community is necessary for being a right holder, persons with disabilities are given rights explicitly through Article 19. Article 19 provides a right to membership (the right to live in the community), and thereby complements the list of human rights with an additional right that was not explicitly provided by the previous human rights documents. Article 19 is a response to the widespread human rights violations against persons with disabilities through institutionalization and other forms of exclusion. We could see, where the lack of this right lead in the past: to segregation, with all its negative implications on human rights. Naturally, the mere declaration of the right to live in the community does not matter much in itself. It has little relevance for those who continue to live their lives in institutions or together with their relatives, being excluded from community life due to the lack of community based support and services. In those countries where the Convention is ratified and persons with

159 A/HRC/28/37, p. 4.

disabilities are guaranteed the right to live in the community but still continue living their lives in institutions, often for life, this exceptional right cannot be enjoyed in practice. In such an exposed position, it is not possible to invoke the basic human rights and freedoms. Accordingly, the final conclusion of this thesis is that the right to live in the community, contained in Article 19, constitutes the right to have rights for persons with disabilities and therefore it can be considered as the most central right of the CRPD.

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