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# Disability in a Human Rights Context

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**Abstract:** The Convention on the Rights of Persons with Disabilities (CRPD) is a modern human rights treaty with innovative components. It impacts on disability studies as well as human rights law. Two innovations are scrutinized in this article: the model of disability and the equality and discrimination concepts of the CRPD. It is argued that the CRPD manifests a shift from the medical model to the human rights model of disability. Six propositions are offered why and how the human rights model differs from the social model of disability. It is further maintained that the CRPD introduces a new definition of discrimination into international public law. The underlying equality concept can be categorized as transformative equality with both individual and group oriented components. The applied methodology of this research is legal doctrinal analysis and disability studies model analysis. The main finding is that the human rights model of disability improves the social model of disability. Three different models of disability can be attributed to different concepts of equality. The medical model corresponds with formal equality, while the social model with substantive equality and the human rights model can be linked with transformative equality.

**Keywords:** disability law; human rights; models of disability; discrimination; reasonable accommodation; accessibility; models of equality; human rights model of disability; substantive equality; transformative equality

## 1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) [1] of 2006 has had profound impact on disability law and human rights law globally. With 162 State Parties the Convention has reached more than 80% universal ratification for its 10th anniversary. Most State Parties have reviewed and revised domestic disability law and have established National Monitoring Mechanisms as prescribed by the Convention. The CRPD seeks to bring about a paradigm shift in disability policy that is based on a new understanding of disabled persons as right holders and human rights subjects. The theoretical background for this change is a modern model of disability as developed in disability studies and recent group oriented approaches in modern human rights law. According to Article 1 the purpose of the CRPD "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." It is the first human rights instrument which acknowledges that all disabled persons are right holders and that impairment may not be used as a justification for denial or restrictions of human rights. Such an approach recognizes that disability is a social construct which is created when impairment interacts with societal barriers. It is based on a new thinking about disability which is usually described as a paradigm shift from the medical to the social model of disability. The theoretical background is disability studies, a multidisciplinary research school that has emerged from disability rights movements in the UK and USA some 30 years ago. The debate about medical versus social model of disability has been the central focus during the first two decades and several scholars have emphasized that disability studies have moved on to new, less dichotomist models such as the political/relational approach of Alison Kafer ([2], p. 7). While it is true that the dichotomy between medical and social model of disability is an outdated subject for disability studies discourse, it has gained new attention within legal discourse. During the negotiations of the CRPD the medical and social model played a pivotal role. During the first decade of its existence the CRPD has been the catalyst for many law and policy reforms, which relate to the shift from, medical to the social model of disability. It is important to understand the new model of disability, which is supposed to be the foundation of modern disability law. Hence it is necessary to address the issue of disability model again. During the negotiations, reference was usually made to the social model of disability, which should replace the medical model of disability. While the latter reduces disability to a medical phenomenon of impairment, the first takes a social-contextual approach to disability. Persons with disabilities are described as "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."([1], art. 1). Disability as a social construct is the main feature of the social model of disability. However, it is opined that the CRPD is based on the human rights model of disability, which moves beyond the social model.

The CRPD also significantly impacts on international human rights law and its system. The CRPD Committee, established in 2009, consists of 18 independent experts of whom all but one, are disabled persons. No other treaty body has had such a high number of experts with impairments. As a consequence accessibility of UN buildings and information and communication systems became an issue. A Secretariat-Wide Inter-Departmental Task Force on Accessibility has been established and several resolutions on making the United Nations more accessible and inclusive for persons with disabilities have been adopted [3]. The CRPD is a modern human rights treaty with many innovative provisions. For example, State Parties have to establish a national human rights mechanism, the Convention allowed the EU to become a member as a regional integration organization, it has two standalone development provisions, but most significantly it modernizes international equality law ([1], art. 11, 32, 33, 42). As Andrea Broderick has analyzed recently: "From a theoretical and comparative perspective, it can be said with certainty that the CRPD goes further in its approach to equality than previous international human rights instruments" ([4], p. 149).

The purpose of this article is twofold. First, my goal is to show that the CRPD is based on the human rights model of disability which builds on the social model but develops it further. Secondly, I wish to demonstrate that the Convention introduces a new equality concept into international human rights law, which can be categorized as transformative equality.

## 2. The Disability Model of the CRPD[1]

Since the 1960s, there have been many different models of disability in scientific literature. The medical (bio)-model, the social model, the economic model, the minority group model, the universalist model, the Nordic relational model, the capabilities model and others. All these models attempt to understand and occasionally explain or define disability.[2]

The most important models of disability in the English-speaking world have been the medical and the social model of disability. Both models were developed by scholars of disability studies during the 1970s and 1980s in the UK and the USA. With the adoption of the United Nations Convention on the Rights of Persons with Disability (CRPD), a new model emerged which is the human rights model of disability.

The medical model of disability, which the CRPD tries to overcome, regards disability as an impairment that needs to be treated, cured, fixed or at least rehabilitated. Disability is seen as a

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[1] Part 2 and 3 of this article are an updated version of an earlier publication, see [5]. I thank Maria Bergh, Michele Friedner, Piers Gooding, Susan Schweik, Tom Shakespeare and Gerard Quinn for helpful comments on this earlier version.

[2] For an overview of these and other models see ([6], pp. 61–181; [7]; [8], pp. 15–28).

deviation from the normal health status. Exclusion of disabled persons from society is regarded as an individual problem and the reasons for exclusion are seen in the impairment. Disability according to the medical model remains the exclusive realm of helping and medical disciplines: doctors, nurses, special education teachers, and rehabilitation experts. Michael Oliver, one of the founding fathers of the social model of disability, has called this the ideological construction of disability through individualism and medicalization, the politics of disablement [9]. Another feature of the medical model of disability is that it is based on two assumptions that have a dangerous impact on human rights: (1) disabled persons need to have shelter and welfare; and (2) impairment can foreclose legal capacity. The first assumption legitimizes segregated facilities for disabled persons, such as special schools, living institutions or, sheltered workshops. The second assumption has led to the creation of mental health and guardianship laws that take an incapacity approach to disability [10,11]. During the negotiations of the CRPD, the medical model served as a determent. While there was often no consensus among stakeholders which way to go in terms of drafting the text of the convention, there was overall agreement that the medical model of disability definitely was not the right path [12,13]. Rather the social model of disability was supposed to be the philosophical basis for the treaty. The paradigm shift from the medical to the social model has often been stated as the main achievement of the CRPD. However, while it is true that the social model of disability has been the prevalent reference paradigm during the negotiation process, my understanding of the CRPD is that it goes beyond the social model of disability and codifies the human rights model of disability.

The social model of disability explains disability as a social construct through discrimination and oppression. Its focus is on society rather than on the individual. Disability is regarded as a mere difference within the continuum of human variations. The social model differentiates between impairment and disability. While the first relates to a condition of the body or the mind, the second is the result of the way environment and society respond to that impairment. Exclusion of disabled persons from society is politically analyzed as the result of barriers and discrimination.

## 3. The Difference between the Social and the Human Rights Model

While I do not claim ownership of the terminology, the human rights model of disability appeared in an article on international and comparative disability law reform that I wrote together with Gerard Quinn 1999/2000 and in the background study to the CRPD that we edited in 2001. In a chapter called "Moral Authority for Change", we wrote:

> Human dignity is the anchor norm of human rights. Each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful but because of their inherent self-worth...The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual center stage in all decisions affecting him/her and, most importantly, locates the main "problem" outside the person and in society [14].

In this background study to the CRPD, we did not discuss whether there is a difference between the social and the human rights model of disability. I think there is and I have six propositions in this regard.

### *3.1. Proposition 1: Disability Is a Social Construct but Human Rights Do Not Require a Certain Health or Body Status*

First, whereas the social model merely explains disability, the human rights model encompasses the values for disability policy that acknowledges the human dignity of disabled persons. Only the human rights model can explain why human rights do not require absence of impairment.

The social model of disability was created as one explanation[3] of exclusion of disabled people from society. It has been developed as a powerful tool to analyze discriminatory and oppressive structures of society. To use Michael Oliver's words:

> Hence, disability according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure to discrimination institutionalised throughout society [16].

This sociological explanation of disability may lay the foundation for a social theory of disability. However, the social model does not seek to provide moral principles or values as a foundation of disability policy. The CRPD, however, seeks exactly that. According to article 1 CRPD the purpose of the treaty 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." In order to achieve this purpose, eight guiding principles of the treaty are laid down in article 3 CRPD and the following articles tailor the existing human rights catalogue of the International Bill of Human Rights[4] to the context of disability. Human rights are fundamental rights. They cannot be gained or taken away from an individual or a group. They are acquired qua birth and are universal, i.e., every human being is a human rights subject. Neither social status, nor identity category, nor national origin or any other status can prevent a person from being a human rights subject. Therefore, human rights can be called unconditional rights. It does not mean that they cannot be restricted but it means that they do not require a certain health status or a condition of functioning. Thus, human rights do not require the absence of impairment. The CRPD reflects this message in its preamble and in the language of its articles. For example, when the universality of all human rights for all disabled persons is reaffirmed ([1], preamble para. c), or when it is recognized that the human rights of all disabled persons, including those with more intensive supports needs, have to be protected ([1], preamble para. j). The article on the rights to equal recognition as a person before the law with equal legal capacity ([1], art. 12, para. 1 and para. 2) is of course another example of this assumption.

Thus, the human rights model of disability defies the presumption that impairment may hinder human rights capacity. The social model of disability also acknowledges the importance of rights ([16], p. 63) and has often been associated with the rights based approach to disability as opposed to needs based or welfare approach to disability policy [17–20]. However, non-legal scholars of disability studies have emphasized that the social model of disability is foremost not a rights-based approach to disability but extends beyond rights to social relations in society, to the system of inequality ([21]; [22], p. 23). They do, however, concede that social model advocates have supported struggles for civil rights and anti-discrimination legislation ([16], pp. 152–56; [22], p. 23).

### *3.2. Proposition 2: Human Rights Are More Than Anti-Discrimination*

Secondly, while the social model supports anti-discrimination policy civil rights reforms, the human rights model of disability is more comprehensive in that it encompasses both sets of human rights, civil and political as well as economic, social and cultural rights.

The social model of disability served as a stepping-stone in struggles for civil rights reform and anti-discrimination laws in many countries ([18], p. 6; [23], pp. 10–13; [24]). Meanwhile, the social model of disability has become officially recognized by the European Union as the basis for its disability

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[3] Other models are e.g., the normalization principle, the minority model, or the Nordic relational model [15].

[4] Consisting of three human rights instruments: Universal Declaration of Human Rights, International Covenant on Civil and Political Rights and International Covenant on Economic, Social and Cultural Rights.

policy [25]. Within disability studies, this rights based approach in disability was characterized as a tool for stipulating citizenship and equality [16]. To demand anti-discrimination legislation was a logical consequence of analyzing disability as the product of inequality and discrimination. In the US, where the social model of disability was conceptualized as the minority group model [26], the fight for civil rights was similarly seen as a way to disclose the true situation of disabled persons as members of an oppressed minority. The focus on rights was perceived as an alternative to needs based social policy that portrayed disabled persons as dependent welfare recipients. The ideology of dependency was coined by Michael Oliver as an essential tool of social construction of disability ([16], p. 83). Thus, anti-discrimination legislation was seen as a remedy to a welfare approach to disability. Disabled persons could thus be described as citizens with equal rights. Architectural barriers could be defined as a form of discrimination. Segregated schools could be described as apartheid. The shift from welfare legislation to civil rights legislation in disability policy became the focus of disability movements in many countries [18,20,27]. "We want rights not charity" was and still is a slogan to be heard around the world from disability rights activists.

However, anti-discrimination law can only be seen as a partial solution to the problem. Even in a society without barriers and other forms of discrimination, people need social, economic and cultural rights. People need shelter, education, employment or cultural participation. This is true for all human beings, and thus for disabled persons. However, because impairment often leads to needs for assistance, it is especially true that disabled persons need more than civil and political rights. While welfare policies and laws in the past have failed to acknowledge and empower disabled persons as citizens [28], laws on personal assistance services or personal budgets proofed that even classical social laws can give choice and control to disabled persons ([29], pp. 15–20; [30,31]). It is thus illustrative that the global independent living movement has always phrased their demands in terms of broader human rights, rather than in terms of pure anti-discrimination rights. The human rights model of disability includes both sets of human rights: political, and civil and economic, and cultural rights. These two baskets of human rights, which have been adopted as distinct categories of human rights during the cold war area for political reasons,[5] are fully incorporated in the CRPD as they are in the Universal Declaration of Human Rights (UDHR) of 1948 [33]. The legal hierarchy of civil and political rights over economic, social and cultural rights is slowly but steadily decreasing through international jurisprudence and the strengthening of monitoring and implementation of the International Covenant on Economic, Social and Cultural Rights (ICESCR) [34].

A major milestone was the coming into force of an individual complaints procedure for economic, social and cultural rights in 2012 enabling the United Nations "to come full circle on the normative architecture envisaged by the Universal Declaration of Human Rights."[6] The universality, indivisibility and interdependence of all human rights were firmly established as a principle of international human rights law on the World Conference of Human Rights two decades earlier in Vienna [36]. The CRPD is a good example of the indivisibility and interdependence of both sets of human rights. It not only contains both sets of human rights, the text itself is evidence of the interdependence and interrelatedness of these rights. Some provisions on rights cannot be clearly allocated to one category only. For instance, the right to be regarded as a person before the law ([1], art. 12) is a right commonly regarded as a civil right ([33], art. 6; [37], art. 16). However, article 12 (3) CRPD speaks of support measures disabled persons might need to exercise their legal capacity. Are these support measures realized by social services which fall into the economic, social and cultural rights sphere? Another example would be the right to independent living ([1], art. 19). It is one of the few rights of the CRPD which has no clear equivalent in binding pre-treaty law. The right to independent living and being included in the community is an answer to human rights violations against disabled persons

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[5] For an illustrative account of the political history of human rights, see [32].

[6] Statement by Mr. Ivan Simonovic, Assistant Secretary-General, see [35].

through institutionalization and other methods of exclusion, such as hiding in the home or colonizing at distant places. The concepts of independent living and community living do not root in mainstream human rights philosophy, which is why the terms cannot be found in the International Bill of Human Rights but in international soft law related to disability that preceded the CRPD. The concept derives from the disability rights movement and other social movements such as the deinstitutionalization movement[7], which came into being in the 1960s and 1970s in the United States, Scandinavia, Italy and many other countries [38–40]. The common catalogue of human rights of the UDHR does not contain a right to independent or community living. If at all, the right to independent living can be traced back to the freedom to choose one's residence, which in other treaties is usually linked to the freedom of movement and designed as a pure civil right.[8] However, independent living requires—among others—personal assistance services, which are measures to realize social rights. Thus, the CESCR Committee has interpreted the right to an adequate standard of living ([34], art. 11) to include a right to independent living for disabled persons. However, it has also linked the issue to anti-discrimination measures. Its General Comment No.5 interprets article 11 ICESCR as a right to "accessible housing" and to "support services including assistive devices" which enable disabled persons "to increase their level of independence in their daily living and to exercise their rights." ([44], para. 33). During the last 15 years, there has been an influx of publications on deinstitutionalization, the right to independent and community living and the member state obligations under article 19 CRPD [31,39,40,45,46]. Most legal publications characterized this article as a social right with strong freedom and autonomy components. In the words of the Council of Europe Commissioner of Human Rights, Thomas Hammarberg who has published an issue paper on article 19:

> The core of the right...is about neutralising the devastating isolation and loss of control over one's life, brought on people with disabilities because of their need for support against the background of an inaccessible society. "Neutralising" is understood as both removing the barriers to community access in housing and other domains, and providing access to individualized disability-related supports on which enjoyment of the right depends for many individuals ([47], p. 11).

The CRPD Committee has not qualified the right to independent living yet as either civil or social human right. While the CRPD contains the progressive realization clause usually applied to state responsibility regarding social, economic and cultural rights, it also includes a reminder that even economic, social and cultural rights are immediately applicable under some circumstances in public international law.[9] The upcoming General Comment on article 19 CRPD will probably address this issue.

### *3.3. Proposition 3: Impairment Is to Be Recognized as Human Variation*

As a third argument, I would state: Whereas the social model of disability neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life and early death due to impairment, and dependency, the human rights model of disability acknowledges these life circumstances and demands them to be considered when social justice theories are developed.

The social model of disability has been criticized for neglecting the experience of impairment and pain for disabled people and how it affects their knowledge and their identity. Both the dichotomy of impairment and disability as well as the materialist focus of the social model have been criticized,

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[7] Which in some countries was part of the disability rights movement, in other countries it was not.

[8] Art. 13(1) UDHR: "Everyone has the right to freedom of movement and residence within the border of each State." [41]. See also Art. 12(1) ICCPR, Art. 5(d), (i) CERD, Art. 15(4) CEDAW [37,42,43].

[9] Art. 4(2) CRPD reads: "With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law." [1].

especially by feminist disabled writers such as Jenny Morris. In her famous book *Pride against Prejudice*, she claims:

> However, there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are *entirely* socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability—and do indeed disable us—to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. A feminist perspective can help to redress this, and in so doing give voice to the experience of both disabled men and disabled women ([48], p. 10).

In a later publication, she writes:

> If we clearly separate out disability and impairment, then we campaign against the disabling barriers and attitudes which so influence our lives and the opportunities which we have. This does not justify, however, ignoring the experience of our bodies, even though the pressures to do this are considerable because of the way that our bodies have been considered as abnormal, as pitiful, as the cause of our lives not being worth living...In the face of this prejudice it is very important to assert that autonomy is not destiny and that it is instead the disabling barriers "out there" which determine the quality of lives. However, in doing this, we have sometimes colluded with the idea that the "typical" disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment ([49], p. 9).

Other writers followed this path of criticism. Marian Corker and Sally French who brought discourse analysis to disability studies added that besides neglecting the importance of impairment, the social model fails to "conceptualize a mutually constitutive relationship between impairment and disability which is both materially and discursively (socially) produced."([50], p. 6). Many other disability studies scholars have shared this critique. Bill Hughes and Kevin Paterson proposed to develop a sociology of impairment based on post-structuralism and phenomenology as a response to this dilemma of impairment/disability dichotomy [51]. Tom Shakespeare has challenged the dichotomy on the basis that both are socially constructed and inextricable interconnected ([52], pp. 72–91). The founders and advocates of the social model have emphasized that the social model of disability was never meant to ignore impairment. Michael Oliver states: "This denial of the pain of impairment has not, in reality, been a denial at all. Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than professional and medical treatment." ([16], p. 38).

However, he also contends that the social model is not a social theory of disability which when developed should contain a theory of impairment ([16], p. 42).

The human rights model of disability has not been brought into this debate yet. The CRPD does not make any statement regarding impairment as a potential negative impact on the quality of life of disabled persons because the drafters were very determined not to make any negative judgment on impairment. However, persons with higher support needs are mentioned in the preamble ([1], preamble para. (j)) as a reminder that they must not be left behind and that the CRPD is meant to protect all disabled persons not only those who are "fit" for mainstreaming. Impairment as an important life factor is also recognized in two of the principles of the treaty, though both principles do not mention impairment explicitly. Article 3 (a) introduces "respect for the inherent dignity...of persons" and paragraph (d) refers to "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity." Respect for human dignity is one of the cornerstones of international human rights and domestic constitutional law today. It was introduced in many human rights catalogues after World War II as a response to the atrocities of the Nazi Regime and today is recognized as a core value of the United Nations [53]. However, it needs to be recognized that the CRPD relates to the concept of human dignity more often than other human rights treaties. Respect for the human dignity of disabled persons is the purpose and one of the eight guiding principles of the treaty ([1], art. (1), (3)(a)). In addition, it is referred to five times in such various contexts such as discrimination ([1], Preamble para. h)), awareness raising ([1], art. 8(1)(a)), recovery from violence ([1], art. 16(4)), inclusive education ([1], art. 24(1)(a)) and care delivery by health professionals ([1], art. 25(d)). Further, recognition of the "inherent dignity and worth and the equal and inalienable rights of all members of the human family" are regarded as the "foundation of freedom, justice and peace in the world." ([1], preamble para. (a)).

The diversity principle of article 3 CRPD is a valuable contribution to human rights theory in that it clarifies that impairment is not to be regarded as a deficit or as a factor that can be detrimental to human dignity. Thus, the CRPD is not only build on the premise that disability is a social construct, but it also values impairment as part of human diversity and human dignity. At this point, I think the human rights model goes beyond the social model of disability. This recognition is important as a fundamental premise for answering ethical questions that are triggered by the way society treats impairment, such as euthanasia, prenatal diagnosis, or medical normalization treatment. As we have stated in our background study:

> The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centre stage in all decisions affecting him/her and, most importantly, locates the main "problem" outside the person and in society. The "problem" of disability under this model stems from a lack of responsiveness by the State and civil society to the difference that disability represents. It follows that the State has a responsibility to tackle socially created obstacles in order to ensure full respect for the dignity and equal rights of all persons ([14], p. 14).

Another important aspect of the principle of human dignity is that it reaffirms that all human beings are right-bearers. As Lee Ann Basser has pointed out, this is particularly important for disabled people who have long been denied this status. She refers to Dworkin's conceptualization of rights as special entitlements as "trumps" [54], and says if rights are trumps "then dignity is the key that turns the lock and allows entry into society and require that each person be treated with equal concern and respect in that society." ([55], p. 21). The international disability rights movement has fought for the CRPD for more than two decades. I think the long time struggle for a human rights treaty was not only a fight of DPOs for political change but also an individual struggle of disabled people for recognition and respect in the sense of Axel Honneth's recognition theory [56]. According to Honneth, political struggles of social movements always have a collective and an individual dimension. The individual dimension relates to the struggle as a process of identity formation, which needs to be facilitated by self-respect, self-confidence and self-esteem. The struggle for human rights of disabled persons is thus a struggle for the global collective of disabled people but also a fight for respect and recognition of the disabled individual by society. The human rights model of disability clarifies that impairment does not derogate human dignity nor does it encroach upon the disabled person's status as rights-bearer. Therefore, I think, the human rights model of disability is more appropriate than the social model to encompass the experience of impairment, which might not always be bad but certainly can be. It also allows us to analyze politics of disablement as the denial of social and cultural recognition, which is an aspect of the critique of the social model of disability [57,58]. The human rights model of disability demands that impairment is recognized in theories of justice. Whether these are social contract theories, take a capability approach or take an ethics of care as their basis is another matter.[10]

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[10] For a combination of capabilities and other approaches see [59].

## 4. Proposition 4: Multiple Discrimination and Layers of Identity Are to Be Acknowledged

Fourthly, the social model of disability neglects identity politics as a valuable component of disability policy whereas the human rights model offers room for minority and cultural identification.

The social model also has been criticized for neglecting identity politics as a valuable component of emancipation. Identity politics can be defined as politics which values and cares for differences among human beings and allows persons to identify positively with features that are disrespected in society. Gay pride, black pride, feminism, or disability culture are manifestations of these identity politics. The social model of disability does not provide much room for these issues because its focus is not on personal emancipation but on social power relations. Identity politics in the context of disability can have several meanings. The term might relate to impairment categories or impairment causes. Deaf people have created their own culture and deaf studies have become an important strand of disability studies in which deaf identity plays an important role [60,61]. Like deaf or hard of hearing persons, blind and deafblind people were among the first groups who created their own organizations who are still operative today [62,63] and so are many other impairment-related organizations.

Another identity factor in the context of disability might be the difference between acquired and congenital impairment. To be born blind or deaf or physically or intellectually impaired is very different from becoming disabled through illness, accident, violence or poverty. Further, some impairments or "disorders" may come along with unique experiences of exclusion and identity. For example, Peter Beresford, who identifies as a mental health user, argued for a social model of madness, way before the CRPD came into being [64]. Finally, identity may be shaped by more than impairment, but also by gender, "race", sexual orientation and identity, age or religion. Disabled women were among the first to criticize the disability rights movement (and the women's movement) for neglecting other identity features [48,65–67]. Disabled people of color followed [68] and authors like Ayesha Vernon raised the issue of intersectional discrimination and multi-dimensional oppression [69].

Impairment related identity policy has been seen with suspicion by social model proponents because these organizations were either seen as apolitical self-help groups or as another example of the medicalization of disability. Anita Silvers found identity politics unsuitable for disabled persons because of the heterogeneous constituency of the disability community or because other identity constructs such as women's roles as caretakers or child-bearers are commonly denied to disabled individuals [70]. Tom Shakespeare has offered a helpful summary of further criticism against identity politics and the harm it might do to disability politics ([52], pp. 92–110).

Other systems of oppression such as sexism and racism have been acknowledged as an important factor in constructing identity and social status from the beginning of the social model of disability ([16], pp. 70–78), but it has been admitted that the social model of disability was not intended to cover all different experiences of oppression ([16], p. 39).

Human rights instruments are at least partly the political response to collective experiences of injustice. The history of human rights law as it developed after World War II shows that identity based social movements were strong players in the making of international law [71,72]. The current core human rights treaties are a manifestation of this process. The International Convention on the Elimination of All Forms of Racial Discrimination (CERD) of 1965 as well as the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (CRMW) of 1990 are responses to colonization and racism, the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) of 1979 is the response to sexism, the Convention on the Rights of the Child (CRC) of 1989 is the answer to adultism and the CRPD is the answer to ableism. The development of these thematic human rights treaties have been called the personification [73] and the pluralization ([74], p. 77) of human rights. These treaties were adopted because human rights politics and theory as developed on the basis of the International Bill of Human Rights were based predominantly on the experiences of western, white, male, nondisabled adults and ignored the experiences of other individuals. This ignorance was and is a reflection of different systems of subordination that run alongside axes of inequality such as "race", gender, sexuality, body and mind functioning. The emergence of social movements that opposed these systems of subordination brought with it the birth of critical studies such as gender studies, critical race studies and disability studies. Human rights law as moral law and as ideology is not only a reflection of political conflict among states or a reflection of global and domestic power relations, it is also a tool for social transformation. Whether successfully or not, may be debated, but it is important to acknowledge these different functions of human rights law. The current human rights treaties may be the outcome of World War II and cold war conflicts, but they also reflect emancipation and democratic gains of social movements. Feminism for example did have a major impact on international public law in theory and practice during the last decades. The artificial distinction between private and public spheres of life and the assumption that states only hold responsibility for violations in the public sphere were successfully challenged by feminist international lawyers. The public/private distinction in international law is the result of the hegemony of male experiences of human rights violations. Human rights violence taking place in the private sphere, such as domestic violence, where ignored within the first four decades of international human rights law. Feminist legal scholars such as Hilary Charlesworth, Christine Chinkin [75] and Catherine MacKinnon [76] have successfully argued that this artificial distinction not only ignores women's experiences but that it also serves to hide state complicity with the perpetrators and that this legal doctrine stabilizes patriarchal subordination. Feminist critical race lawyers such as Mari Matsuda [77] and Angela Harris [78] have taken feminist legal theory a step further by introducing anti-essentialist approaches to civil rights law. Thus, I would argue that current human rights law is rather the result of human rights law becoming truly universal than seeing these group specific human rights instruments as testimony "that there is something specific about these groups...which...*cannot* be taken adequately into account by human rights instruments that have the ambition to covering the whole human genre."([79], p. 497, emphasis in the original).

The human rights model of disability as based on the existing canon of core human rights treaties gives consideration to different layers of identity. It acknowledges that disabled persons may be male or female, non-whites, disabled, children or migrants. It is clear that there are more layers of identity to be considered in international human rights law and that the issue of intersectionality of discrimination has yet to be solved [80,81].

In addition to human rights law in general, the CRPD also acknowledges different layers of identity within the context of disability and human rights. For instance, disabled children and disabled women have their own stand-alone articles. ([1], art. 6 and art. 7) The women's article even acknowledges "that women and girls with disabilities are subject to multiple discrimination" which is the first binding intersectionality clause in a human rights treaty. Further recognition of gender and age can be found throughout the treaty.[11] Other grounds, such as "race", color, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, or birth and age are, however, only recognized in the preamble ([1], preamble para. (p)). For these and other layers of identity—such as age or sexual orientation—lobbying was not strong enough during the negotiations.

A few impairment-related groups are recognized though. These are deaf, blind and deafblind persons. Article 30 CRPD on cultural participation demands that states recognize and support their "specific culture and cultural identity, including sign languages and deaf culture." ([1], art. 30(4)). The other context in which deaf, blind and deafblind persons are specifically mentioned is the right to education. Article 24 CRPD demands that persons who belong to these impairment groups are provided with the tools to education that are adequate to their identity, such as Braille and sign language ([1], art. 24(3)(a) and (b)), that they are provided with role models and qualified teachers and the most disputed paragraph reads:

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[11] Women and girls with disabilities are mentions in the following provisions: Preamble para. (p), (q), (r ), (s); Art. 3(g), (h); Art. 4(3); Art. 8(2)(b); Art. 13; Art. 16(2), (3), (5); Art. 18; Art. 23(1)(b), (c), (3), (5); Art. 25 (b), Art. 28; Art. 29; Art. 34 CRPD [1].

> (1)...States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:
> ...
>
> > (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
> > ...

I remember very well the long nights we fought over the wording of this paragraph in the Ad Hoc Committee. The World Blind Union, the World Federation of the Deaf and the World Federation of the Deafblind were all represented with superb experts. We had long debates about whether or not there should be a human right to special education or at least a right to choose between mainstream and special education. The opinions oscillated between "segregation is always and inherently unequal" and "mainstream education means assimilation which means for many bad education." These debates were loaded with identity issues and it showed us that it was important to make room for it.

The final text is a true compromise and in my opinion a masterpiece. The credit for it goes to a large extent to Rosemary Kayess, an eminent international lawyer and disability rights activist from Australia, who acted as a facilitator to the article on the right to education.

### *4.1. Proposition 5: Prevention Policy Can Be Human Rights Sensitive*

My fifth argument is that while the social model of disability is critical of prevention policy, the human rights model offers a basis for assessment when prevention policy can be claimed as human rights protection for disabled persons.

Prevention of impairment is an element of public health policy which has long been criticized by disability rights activists as being stigmatizing or discriminatory. The object of critique can be the mode of implementation of public health policy or the goals. While prevention of traffic accidents or polio is not seen as problematic, the ways these policies are proclaimed can be stigmatizing towards disabled persons. For instance, if advertisement for safe driving is accompanied by a poster of a quadriplegic person titled: "Being crippled for the rest of your life is worse than death", disabled persons are abused as determent. Another example are vaccination campaigns against polio which utilize slogans such as "Oral vaccination is sweet, polio is cruel!" Public health campaigns like these led to fierce protest from the disability rights movement in the 1970s and 1980s in several countries. The goals of medical prevention programs can be the target of protest if it has to do with life or death issues such as selective abortion or assisted suicide. The message that some see conveyed with these programs is that a life with a disability is not worth living. What is claimed as prevention of impairment policy is in fact a policy that aims at eliminating disabled persons. Michael Oliver has characterized these programs as the core of ideological construction of disability [16]. Feminist disability studies scholars have written widely on the conflicts between women's right to reproductive autonomy and disabled people's right to non-discrimination [81–84]. This particular difficult subject also came up during the negotiations of the CRPD but was dropped due to time pressure and the unlikelihood to achieve a compromise on this matter with pro-life advocates[12] and many feminists in the room.

Unlike the UN World Programme of Action Concerning Disabled Persons (WPA) of 1982 [85] and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 1993 (StRE) [86], the CRPD does not refer to impairment prevention as a matter of disability policy. These two declarations are the most important human rights instruments preceding the CRPD. At the time of their adoption, they marked a milestone in the eventual recognition of human rights of disabled persons because they added a human rights component to traditional disability policy. The latter

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[12] The Vatican is a UN member state and the delegation took a very active role in this matter.

consisted of a three-tiered approach to disability: definition, prevention and rehabilitation. The WPA and the StRE added a fourth element to disability policy: equality of opportunities. However, both instruments refer to prevention of impairment as an element of disability policy and include prenatal care as an important measure ([85], para. 13 and 52–56; [86], para. 22). Especially the WPA has been influenced not only by an upcoming international disability rights movement ([87], pp. 97–99), but also by health professionals. This is revealed by the fact that the Leeds Castle Declaration on the Prevention of Disablement of 12 November 1981 is cited almost in full length in the WPA text ([85], para. 54). This declaration which was written by a group of scientists, doctors, health administrators and politicians praises biomedical research as "revolutionary new tools which should greatly strengthen all interventions." ([85], para. 54). The WPA even includes a paragraph on the cost effectiveness of prevention programs: "It is becoming increasingly recognized that programmes to prevent impairment or to ensure that impairments do not escalate into more limiting disabilities are less costly to society in the long run than having to care later for disabled persons."[13]

The WPA has been criticized for perpetuating the medical model of disability ([88], p. 278; [89]). While the WPA and StRE are both referenced in the preamble of the CRPD ([1], preamble para. f)), prevention does not appear prominently in the text of the treaty. This was a deliberate decision taken during and before the negotiations ([13], p. 120). The purpose of the CRPD is to promote and to protect the rights of persons who have a disability. It was argued that it was incoherent to deal with prevention of disability in the same instrument. Thus, with the adoption of the CRPD, it was made clear that primary prevention of impairment might be an important aspect of the right to health ([34], art. 12) as enshrined in the ICESCR, but that it is certainly not an appropriate measure to protect the human rights of people living with a disability. This is an important message to member states who claim that they spend a lot of money for disabled persons and then submit reports which show that a large part of the budget is spent on impairment prevention policy.

However, as Tom Shakespeare has pointed out [52], not all impairment prevention policy is bad, and most disabled persons actually are in need of this kind of public health policy. In fact, the 2011 WHO World Report on Disability gives evidence that disabled persons experience poorer level of health due to a variety of factors, such as inaccessible health care services, risk of developing secondary conditions, higher risk of being exposed to violence, increased rates of health risk behavior ([90], pp. 57–60). This is also recognized in the CRPD in the context of the rights to health. There prevention is addressed not with relation to primary prevention but to secondary prevention programs to "prevent further disabilities including among children and older persons" ([1], art. 25 (b)). Article 25 CRPD is an example of framing the right of health of disabled persons in a human rights context. It demands equal access to general and specialized health care services for disabled persons. Services must be community based and sensitive to freedom rights and to the dignity of disabled persons. Discrimination through provision or denial of health care must be prohibited and prevented. As the WHO Report underlines:

> Viewing disability as a human rights issue is not incompatible with prevention of health conditions as long as prevention respects the rights and dignity of people with disabilities, for example in the use of language and imagery...Preventing disability should be regarded as a multidimensional strategy that includes prevention of disabling barriers as well as prevention and treatment of underlying health conditions [90], p. 8).

### *4.2. Proposition 6: Poverty and Disability Are Interrelated but There Is a Roadmap for Change*

As a sixth argument, I opine: Whereas the social model of disability can explain why 2/3 of the one billion disabled persons in this world live in relative poverty, the human rights model offers a roadmap for change.

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[13] WPA para. 55 (emphasis added) [85].

From early on, social model proponents and critics acknowledged the close link between poverty and disability ([16], pp. 12–13). Indeed, the interrelatedness of poverty and disability was put forward as evidence that not only disability but also impairment is a social construct ([52], pp. 34–35). There is now abundance of evidence that impairment and poverty are mutually reinforcing ([90], pp. 10–11). Impairment may increase the risk of poverty and poverty may increase the risk of impairment. Lack of resources, lack of education, dearth of access to fundamental services are among the factors to be considered when trying to understand why 2/3 of the world population of disabled people live in the developing world. The social model has helped to understand that disability is a development issue. Social model advocates and disability studies researchers have had a significant impact on empowerment policies that address these issues ([86], pp. 206–59; [91], p. 15; [92–95]). The United Nations, the World Bank and other development agents have long acknowledged that disability is a development issue [96], however, disability was not mainstreamed in development policies. Thus, disability was initially not recognized as one of the issues in the Millennium Development Goals. Only after the adoption of the CRPD did this change dramatically, and disability became a central subject of international cooperation policy.

The CRPD is the first human rights treaty with a standalone provision on development. Article 32 CRPD on international cooperation was one of the major controversial provisions from the beginning to the end of the negotiations ([13], p. 132). Together with article 11 CRPD on situations of risk and humanitarian emergencies, it provides a solid roadmap for disability policy in international humanitarian und development cooperation. Article 32 CRPD demands that international cooperation is inclusive and accessible to disabled people; that disability is mainstreamed in all development programs; and that DPOs are involved in the monitoring of these activities. Article 11 CRPD demands that states take adequate actions to protect disabled persons in situation of natural disaster or humanitarian emergencies. This latter article was introduced after the Tsunami of 2004 in the Indian Ocean, which led to the death of several hundred thousand human beings, among them many disabled individuals who were excluded from rescue. By the end of the negotiations, the Lebanon war had started in July 2006, which increased the already politicized nature of the article. Under these circumstances, it was amazing to reach consensus on the text of these articles.[14] Both these articles bring at least three important aspects to the development and humanitarian policy: (1) a human rights based approach to development and humanitarian aid; (2) disability mainstreaming as a leitmotif of international cooperation; and (3) the importance of DPO involvement. These aspects are not new, they have been raised before but with the CRPD, they have become binding international law.

A human rights approach in development means that people living in poverty are not objects of welfare and charity but rights-holders who have a say in the distribution of resources and needs assessment. Participation is a means, and a goal and strategies need to be empowering. Development projects need to target disadvantaged, marginalized and excluded groups. These are some of the principles that make up the UN common understanding of the human rights based approach to development cooperation which was adopted in 1997 [97]. While the new rights based approach in development is not without shortcomings [98], it is an important step into the direction of achieving social justice in times of globalization. Disability mainstreaming is an important strategy to overcome segregation structures implemented and maintained by traditional disability policies. Without active and equal participation of disabled people and their representative organizations, development strategies and programs will perpetuate and exacerbate discrimination against disabled persons. The impact of the CRPD in combating poverty can be seen in various development policies of State Parties, who have now incorporated disability inclusive development programs in their international cooperation policies. At the international level the impact can clearly be seen in the 2030 Agenda, which

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[14] Actually, because there could not be reached consensus on a reference to foreign occupation in the treaty—initially in article 11, later in the preamble—this issue was the only part of the treaty which could not be approved by consensus. For details see ([13], p. 125).

was adopted on 25 September 2015 by the UN General Assembly and include the new Sustainable Development Goals (SDG) [99]. While disabled persons were not included in the predecessor, the Millennium Development Goals which were in force until 2015, the 2030 Agenda contains eleven references to persons with disabilities.[15] This gives hope that disabled persons will not be foreclosed from development initiatives and funding streams implementing the 2030 Agenda.

### *4.3. Developing the Social Model into a Human Rights Model of Disability*

My intention is not to abandon the social model of disability, but to develop it further. The social model of disability was the most successful dictum during the negotiations of the CRPD. If there is one single phrase which summarizes the success story of the CRPD, it is that it manifests the paradigm shift from the medical to the social model of disability in international disability policy. Not everyone who used the term during the negotiation process was knowledgeable about disability studies. Indeed, I concur with Rosemary Kayess and Phillip French in their analysis that the enormous influence the social model had during the negotiations has come from a "populist conceptualization of the social model as a disability rights manifesto and its tendency towards a radical social constructionist view of disability, rather than from its contemporary expression as a critical theory of disability." ([12], p. 7). However, given that the drafting of international human rights norms is always a highly political undertaking, the reductionism in the use of the social model is comprehensible. The social model of disability had become the motto of the international disability movement and it served as a powerful tool to demand legal reform. My intention is not to denounce the social model but to carry it further. Like many other human rights projects, the CRPD once planted into this world through adoption by the General Assembly took a life of its own. The impact has been significant in many areas, such as human rights monitoring, international cooperation, accessibility and legal capacity discourse, or inclusive education to name but a few. In our background study, we found that while the disability rights movement had embraced the idea of human rights, many disability rights organizations had not become human rights organizations in terms of agents in the system, comparable to mainstream human rights organizations like Amnesty International or Human Rights Watch ([14], pp. 256–70). Today, DPOs have influential agents in the UN human rights system. Thus, it could be concluded that political activism has turned to human rights and the CRPD is a codification of the human rights model of disability. The Committee has embraced the term human rights model of disability in its concluding observations.[16]

## 5. CRPD as an Equality Treaty

The CRPD has been modeled on existing treaties, notably the International Covenant on Civil and Political Rights (ICCPR) [37], the International Covenant on Economic, Social and Cultural Rights (ICESCR) [34], the Convention on the Elimination of all Form of Racial Discrimination (CERD) ([102], p. 195), the Convention Against All Forms of Discrimination Against Women (CEDAW) [43], and the Convention on the Rights of the Child (CRC) ([103], p. 3). While first two treaties belong to what is called the International Bill of Human Rights[17] and comprise the globally recognized core catalogue of human rights, the latter are group focused and are of different legal character. CERD and CEDAW are known to be anti-discrimination instruments, CRC is recognized

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[15] Three instances in the Declaration relating to human rights (para. 19), vulnerable groups (para. 23) and education (para. 25) and seven instances in the SDG: goal 4 (education), goal 8 (employment), goal 10 (reducing inequalities), goal 11 (inclusive cities) goal 17 (means of implementation and data) and one instance in follow up and review relating to data disaggregation (para. 74, (g)) [100].

[16] Concluding Observations on the initial report of Argentina as approved by the Committee at its eighth session (17–28 September 2012), CRPD/C/ARG/CO/1, 8 October 2012, para. 7–8; concluding Observations on the initial report of China, adopted by the Committee at its eighth session (17–28 September 2012), CRPD/C/CHN/CO/1, 15 October 2012, para. 9–10, 16, 54 [101].

[17] Together with the Universal Declaration of Human Rights of 1948 [33].

as a more holistic treaty, comprising more than pure anti-discrimination rights. When the CRPD was negotiated between 2002 and 2006, there was an early consensus, that the legal character shall be a hybrid of both models. Thus, the CRPD demands State Parties to take positive measures with respect to many areas of public and private live, such as infrastructure ([1], art. 9), international cooperation and emergencies ([1], art. 32 and 11), inclusive education and employment ([1], art. 24 and 27), living ([1], art. 19), mobility ([1], art. 20), and decision-making in daily life ([1], art. 12). However, there is no doubt that equality and anti-discrimination is at the heart of the Convention. Every single substantive article includes an equality or anti-discrimination reference, the most typical being "on an equal basis with others". In addition there are two articles specifically dealing with the right to equality and non-discrimination. ([1], art. 5 and 6). Furthermore, equality and discrimination appear in the preamble ([1], preamble, para. (a), (c), (e), (h) (f), (k), (p), (r) and (y)), in the general principles of the Convention ([1], art. 3(b), (e), and (g)) and in the definition article ([1], art. 2). There are at least two reasons for the strong emphasis of equality and non-discrimination in the Convention. There was consensus that the CRPD should not create new human rights or special rights for disabled persons and thus, the goal was to provide human rights for disabled persons on an equal basis with the general population in each member state. Secondly, the shift to non-discrimination and equality reflects the supersession of the medical model with the social model. Recognizing disability as a social construct turns the focus on the elements in our world, which contribute to the social construction of disability. Discrimination is certainly one of the main factors in this regard. However, the CRPD did not stop short at embracing the non-discrimination and equality principles and contextualizing them to disability. It went further, in that it introduced new equality and non-discrimination concepts into international human rights law and a new definition of discrimination.

## 6. Disability-Based Discrimination Transcending Concepts in International Law

Clauses of non-discrimination and recognition of the right to equality can be found in most of the core international human rights treaties.[18] The right to equality is considered one of the most fundamental human rights in public international law. The early human right treaties do not contain definitions of discrimination. ICPPR and ICESCR both prohibit discrimination and promote equality in several of their provisions ([34], art. 3, 7, 13; [37], art. 2(1), 3, 14, 23, 25, 26),[19] however, the definition of discrimination and equality was left for the treaty bodies to be elaborated in General Comments.[20] Only the more group focused treaties provided for a definition. According to CERD, racial discrimination is defined as "any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life." ([1], art. 1 (1)). Similarly, CEDAW defines discrimination against women as "any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field." ([103], p. 3, art. 1). The CRPD adopts this definition but goes beyond. Disability-based discrimination is defined as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable

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[18] For an overview see [104].

[19] Art. 2 (1), Art. 3, Art. 14, Art. 23, Art. 25, Art. 26 ICCPR; Art. 2 (2), Art. 3, Art. 7, Art. 13 ICESCR.

[20] The Human Rights Committee adopted General Comment No. 4 on equal rights between men and women in 1981 and replaced it with General Comment No. 28 in 2000. General Comment No. 18 on non-discrimination was adopted in 1989. The CESCR adopted GC No. 16 on equal rights of men and women in 2005 and GC No. 20 on non-discrimination in 2010.

accommodation." ([1], art. 2). The latter is defined as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms." ([1], art. 2). Thus, the CRPD extends the officially recognized definition of discrimination by explicitly embracing all forms of discrimination and by adding state duties to provide for adjustments and modifications in order to eliminate barriers which prevent disabled persons from equal enjoyment of human rights. Such a duty acknowledges the fact that structural, environmental, communicative or other barriers exist in society which amount to discrimination against disabled persons. In order to combat discrimination it is not sufficient to refrain from "distinction, exclusion or restriction" some active measures need to be taken in order to make society accessible. Similarly article 9 CRPD on accessibility demands that positive measures are taken to eliminate barriers in the built environment, in information and communication and with regard to transportation. In its General Comment No 2 of 2014 on accessibility the CRPD Committee has distinguished the duty to provide reasonable accommodation from the duty to provide accessibility. While the measures for creating accessibility—e.g., building a ramp—might be the same, the personal scope is different. Accessibility duties target groups of disabled persons whereas reasonable accommodation is oriented towards the individual. The duty to provide accessibility is according to the General Comment No 2 "an *ex ante* duty. States parties therefore have the duty to provide accessibility before receiving an individual request to enter or use a place or service. States parties need to set accessibility standards, which must be adopted in consultation with builders and other relevant stakeholders. Accessibility standards must be broad and standardized [105]." In contrast, "[t]he duty to provide reasonable accommodation is an *ex nunc* duty, which organizations of persons with disabilities, and they need to be specified for service-providers, means that it is enforceable from the moment an individual with an impairment needs it in a given situation (workplace, school, etc.) in order to enjoy her or his rights on an equal basis in a particular context. Here, accessibility standards can be an indicator, but may not be taken as prescriptive. Reasonable accommodation can be used as a means of ensuring accessibility for an individual with a disability in a particular situation. Reasonable accommodation seeks to achieve individual justice in the sense that non-discrimination or equality is assured, taking the dignity, autonomy and choices of the individual into account." ([1], general comment No. 2 CRPD/C/GC, 22 May 2014 para. 26). The Committee has also interpreted accessibility as part of the equality principle in that "denial of access to the physical environment, transportation, including information and communication technologies, and facilities and services open to the public should be viewed in the context of discrimination" ([1], general comment No. 2 CRPD/C/GC, 22 May 2014 para. 23). Thus, the non-discrimination and equality concept enshrined in the CRPD has a group component extending the notion of non-discrimination as purely individual. While the right to non-discrimination as enshrined in art. 5 CRPD is designed as a traditional individual right, equality is also understood as a group principle, which needs interaction with representative organizations of persons with disabilities in order to be realized. This group component can be derived from General Comment 2 but also from the text of the Convention itself. More than other human rights treaties, the CRPD gives space to civil society as agents in human rights implementation. Article 4 (3) demands that State parties closely consult with disabled persons and their representative organisations. Similarly, article 33 (3) demands that civil society can fully participate in the national monitoring process. The strong recognition of representative organizations of disabled persons—usually called DPO (disabled persons' organizations)—as instrumental in implementing and monitoring the CRPD can be attributed to the process of negotiation of the treaty. It is well known, that civil society had a particularly high influence in the making of the convention [12,13,106]. Disabled persons were actors in all stake holder groups: Delegations of state parties, non-governmental organizations—most of them being DPOs—UN organizations and National Human Rights Institutions. The majority of disabled experts were representatives of DPOs. At the end of the negotiations, more than 400 NGOs had been accredited to the Ad Hoc Committee, the body in charge of the drafting of the treaty. The "new diplomacy" obtained through negotiations such as the CRPD treaty[21] gives voice to groups who have been invisible in international human rights law because of systemic wide spread discrimination. Giving voices to these groups in international human rights instruments also means to acknowledge that discrimination effects individuals as members of social groups and hence non-discrimination measures need to target individuals and groups. The duty to provide reasonable accommodation and the accessibility obligations as well as the participation provisions relating to DPOs reflects this dual approach to non-discrimination. Both, individuals who are at risk of discrimination as well as their collective voices need to be protected and empowered by non-discrimination measures. In addition, the CRPD is the first human rights treaty to explicitly acknowledge intersectional discrimination. Art. 6 CRPD speaks of multiple discrimination of disabled women and demands that State Party take appropriate measures against it. With relation to disabled women and girls multiple and intersectional discrimination is clearly recognized. Thus, it is acknowledged that individuals experience discrimination as members of a (or several) groups but these groups are not homogenous. All group members are individuals with multiple layers of identities, statuses and life circumstances. Thus, the CRPD provides for a new concept of equality which takes into account individual and structural as well as intersectional discrimination. This new equality concept falls within a modern equality concept that has been called transformative equality ([4], p. 36; [107], p. 56). According to Sandra Fredman transformative equality requires not only the removal of barriers to inclusion but also positive measures to initiate a real change that also addresses hierarchical power relations ([107], p. 115; [108]). Andrea Broderick describes the transformatory approach to equality as seeking to “address the socially constructed barriers, stereotypes, negative customs and practices which hinder the full enjoyment of rights by marginalized groups.” ([4], p. 36). The transformative equality concept is distinguished from other concepts of equality, most notably the substantive and the formal equality concept. Formal equality seeks to combat direct discrimination by treating similarly situated persons similar and differently situated persons differently. The problem with the formal equality concept is that it only works when ignorance towards differences among human beings has equality effects. Typically it helps when it results in the eradication of harmful stereotyping. It fails, however, when differences—such as impairment—are taken as rational grounds for denial of rights. Furthermore, the formal equality concept does not recognize the “dilemma of difference” as explained by Martha Minow. According to her the “stigma of difference may be recreated both by ignoring and by focusing on it” ([109], p. 20). The substantive equality model in contrast seeks to address structural and indirect discrimination and takes into account power relations. Discrimination is seen less as an issue of differential treatment but as treatment in the context of domination and oppression. Substantive and transformative equality concepts have much in common, but as Andrea Broderick clarifies, the difference lies in the role for positive measures to change structures and systems ([4], pp. 146–47). While the substantive equality model seeks to combat discriminatory behavior, structures and systems, the transformative equality concept targets changing these structures and systems with a variety of positive measures.

The evolution of these equality concepts coincides with recognition of the social construction of identity markers. Once it was understood that discrimination operates as a process and within hierarchical structures rather than being triggered by immutable and natural personal traits, the shortcomings of the formal equality concept became obvious. Legal theory on discrimination and equality evolved over different eras. For the realm of international human rights law Oddny Mjöll Arnadottir has most convincingly introduced three eras of equality concepts in international human rights law and she describes the CRPD as a ”legitimate child” of these developments ([110], p. 47). The first era, which spans from 1950s to the 1970s, she calls universal sameness ([110], p. 47). In this phase, the formal equality concept prevails in which equality rights are linked to sameness and

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[21] According to Sabatello, similar processes of civil society involvement took place in relation to the Rome Statute of the International Criminal Court and the Ottawa Mine Ban Treaty ([97], pp. 239–58).

symmetrical treatment approaches. The second phase runs from the 1970s to 1990s and is called specific difference and the focus is on specific discrimination grounds, which were seen as natural or immutable. During this phase, it is acknowledged that, as an exception to the rule of formal equality, some differences need to be accommodated. CERD and CEDAW are children of this era and Arnadottir names the equality model of this second era as substantive difference model ([110], p. 50). The third era is called multidimensional disadvantage era and is linked to contemporary equality law, which started in the 1990s. Concepts of multidimensional and structural disadvantage shape the thinking about discrimination in this era. The equality concept in this phase is the substantive disadvantage model. "It is a contextual approach that focuses on the asymetrical structures of power, privilege and disadvantage that are at work in society. [...] This approach has been elaborated as a response to the weakness of the other approaches that frame questions of equality in terms of the comparative concepts of sameness and difference." ([110], p. 54). The school of thought which brought about this equality concept is framed as "social construction feminism." ([110], p. 54). In this era, the state has a more proactive role to bring about change in relation to eliminate discriminatory social and political structures. While Arnadottir uses different terminology, I think it is possible to associate these three eras with the concepts of formal, substantive and transformative equality.[22] These eras correlate to different models of disability. Most authors agree that the era of formal equality clearly correspond with the medical model of disability ([4], p. 33 with further references). Disability is seen as a personal characteristic which inhibits equality and thus disabled persons are kept outside the equality and discrimination debate. Various opinions seem to exist regarding the two other concepts of equality and their relation to different models of disability. Arnadottir clearly associates the social model of disability with the third era of equality law and hence with transformative equality or in her terms to substantive disadvantage ([110], p. 60). However, she does not reflect on any other model of disability despite medical and social model. For her the CRPD "is expressly based on the social model of disability." ([110], p. 59) Broderick in contrast sees the CRPD as endorsing several models of disability, among them "a holistic human-rights based model" of disability ([4], p. 149), the capability model as well as the universalist model of disability ([4], pp. 141–42). Both, the universalist model of disability as well as the human rights model of disability she associates with the third era of equality law, the transformative equality concept ([4], pp. 45, 146). On the basis of the three phase division regarding the evolution of equality law, I would associate the medical model of disability with the first era of formal equality, the social model of disability with the second era of substantive equality and the human rights model with transformative equality. The medical model of disability is associated with formal equality because impairment is regarded as a difference that either must to be ignored or which might legitimizes different, unfavorable treatment. The social model of disability can be linked to the substantive model of equality, since impairment is seen as a difference that needs to be accommodated in order to prevent the social construction of disability. The human rights model of disability can neatly be fitted with transformative equality in that it provides the roadmap for change. However, it would be a mistake to assume that formal or substantive equality are to be abolished. The CESCR has endorsed different concepts of equality and discrimination in its recent General Comment No. 20, among them formal and substantive equality. The General Comment emphasizes that discrimination of any kind must be eradicated, both formally and substantively ([111], para. 8). Likewise the CRPD demands that "all discrimination on the basis of disability" ([1], art. 5 (2)) is combated. Formal equality helps to target direct discrimination and it should be kept in mind that disabled persons are often at risk of direct discrimination. To refuse intellectually disabled persons entrance to a dance hall because other guests might feel uneasy, cannot be sanctioned with the duty to provide reasonable accommodation. Such discrimination must be tackled with a formal equality approach. Because discrimination is a

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[22] I think I am here in line with Andrea Broderick who argues, "that substantive disadvantage equality also takes a step into the realm of transformative equality by seeking to target structural inequalities." See ([4], p. 45).

process and takes different forms, the CRPD endorses a wide concept of discrimination, and takes collective as well as individual aspects into account. The shift to the human rights model of disability and transformative equality does not replace older models of disability or equality. However it should prevent models from legitimizing the denial or restrictions of human rights.

## 7. Conclusions

The CRPD was initially drafted as a human rights convention that replaces the medical model of disability with the social model of disability. However, the drafters went beyond the social model of disability and codified a treaty that is based on the human rights model of disability. While the medical model of disability reduces the disabled individual to her impairment, the social model dissects disability as a social construct and debunks exclusion and denial of rights on the basis of impairment as ideological constructions of disability. The human rights model builds on the social model in that it is built on the premise that disability is a social construct but it develops it further. There are six propositions for this assertion. First, the human rights model can vindicate that human rights do not require a certain health or body status, whereas the social model can merely explain that disability is a social construct. Secondly, the human rights model encompasses both sets of human rights, civil and political as well as economic, social and cultural rights and thus not only demands anti-discrimination rights for disabled persons. Thirdly, the human rights model embraces impairment as a condition which might reduce the quality of life but which belongs to humanity and thus must be valued as part of human variation. Fourthly, the human rights model values different layers of identity and acknowledges intersectional discrimination. The fifth proposition is that unlike the social model, the human rights model clarifies that impairment prevention policy can be human rights sensitive. Lastly, it is opined that the human rights model not only explains why 2/3 of the world's disabled population live in developing countries, but that it also contains a roadmap for change.

The CRPD additionally develops international equality law further. It introduces a new definition of discrimination by amending "denial of reasonable accommodation" as a form of discrimination. It further introduces a concept of discrimination that is both group and individual oriented. The duty to provide accessibility and the duty to involve representative organizations of disabled people are both group oriented obligations. They are supposed to overcome (past) barriers and discrimination and bring the voices of disabled persons to the mainstream of society and help to transform it to become more inclusive. The duty to combat discrimination, including the duty to provide reasonable accommodation, is oriented towards the individual. Accessibility standards at times might be inappropriate to meet the needs of an individual with rare impairments or a person who chooses to do things differently.

The CRPD is based on a modern equality concept which has evolved over different phases of equality law with different notions of equality. The first, formal equality seeks to combat direct discrimination but fails to take account of the "dilemma of differences." The second, substantive equality seeks to address differences among individuals and power relations among them. The third is coined transformative equality and thrives to overcome structural, institutional, as well as direct and indirect discrimination by introducing positive duties to transform society. The human rights model is based on this latter concept of transformative equality, while the medical model of disability correlates to formal equality and the social model of disability corresponds to the substantive equality concept.

While formal and substantive equality theories have their shortcomings it would be premature to drop them from anti-discrimination law and policy. The CRPD encompasses all concepts of equality and, thus implicates formal, substantive and transformative equality duties for State parties. State parties have to prohibit direct and indirect discrimination against disabled persons and they have to provide accessibility and reasonable accommodation. They also have to enable meaningful participation for organizations of disabled persons in the implementation and monitoring of the Convention. Most State Parties have not yet comprehended the scope of these obligations. After all, the CRPD was not intended to create "new rights", why then should it lead to new human rights obligations? However, this is exactly what the CRPD is about.

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