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## **A human rights model of disability**

The CRPD has been a success from the start: Its negotiation history among UN human rights treaties is the fastest<sup>1</sup>; its ratification record is splendid<sup>2</sup>. It was opened for signature in March 2007 and came into force on 3 May 2008 after the twentieth state had ratified the Convention. Only six years later, 151 states<sup>3</sup> of the United Nations have become states parties. There are several reasons why it can be called a “first of” convention: the first human rights treaty adopted in the 21<sup>st</sup> century and after the 1993 Vienna Conference of human rights, the first to be acceded by a regional integration organization<sup>4</sup>, the first group focused treaty with a national monitoring mechanism<sup>5</sup>. Unlike its eight sister treaties it has a stand-alone article on international cooperation.<sup>6</sup>

### **Challenges for the implementation of the Convention on the Rights of Persons with Disabilities**

As a member of the CRPD Committee<sup>7</sup>, I am involved in reviewing states parties reports<sup>8</sup>, individual complaints<sup>9</sup> and other inquiries<sup>10</sup>, and general comments. As of 3 October 2014, we have reviewed nineteen state reports, we have decided on eight individual communications and we have adopted two general comments.<sup>11</sup>

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<sup>4</sup> The EU acceded to it on 23 December 2010.

<sup>5</sup> Art. 33 CRPD.

<sup>6</sup> Art. 32 CRPD.

<sup>7</sup> 2011–2018.

<sup>8</sup> Art. 35 CRPD.

<sup>9</sup> Against States Parties that have ratified the Optional Protocol to the CRPD, Art. 1 OP to CRPD.

<sup>10</sup> Art. 6 OP to CRPD.

<sup>11</sup> GC No 1 on legal capacity (Art. 12 CRPD) and GC No 2 on accessibility (Art. 9 CRPD). All documents can be found at: <http://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx> (last visited 5 October 2014).

Based on the status of the work of the CRPD Committee, I would argue that there are many challenges for implementing this new human rights treaty. Like any other human rights treaty, the CRPD is a visionary law designed to transform society into a more just society. But visions cannot be achieved over night. Human rights implementation is a process with several agents and many hurdles to overcome. However, there are some challenges that are unique to the CRPD. Obviously, one is to establish a national monitoring mechanism that is independent from government, complies with the Paris Principles (PP) and works in collaboration with civil society organizations, notably disabled persons' organizations (DPO). National Human Rights Institutions which comply with the PP seem to be the best qualified entities to be designated as independent monitoring mechanism in accordance with article 33 (3) CRPD. However, they often need to develop good working relations with DPOs and learn to become true "agents of change"<sup>12</sup>. Further, the Convention enshrines a number of substantive provisions that bring new challenges to conventional human rights theory and jurisprudence. The most challenging being the right to be recognized as an equal person before the law (article 12) closely followed by the right to independent and community living (article 19). However, states parties obligations relating to accessibility (article 9) and reasonable accommodation (articles 2 and 5) are equally revolutionary, not to speak of the right to inclusive education (article 24). Some of the dialogues with states parties in the course of reviewing their reports showed that there is a deep misunderstanding relating to the scope and content of state obligations under these and other provisions of the CRPD. Often – so it seems – states parties do not understand the profound change in disability policy and law that is embedded in the CRPD. The often-cited paradigm change relating to the model of disability is hard to grasp.

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<sup>12</sup> Quinn, 'Resisting the "Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?', in O. M. Arnadóttir and G. Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities. European and Scandinavian Perspectives* (2009).

Disability studies provide the theoretical background for what we call the shift from the medical to the social model of disability. The social model of disability views disability as a social construct and locates the problem of disability outside the individual in discrimination policies. However, within disability studies the social model of disability has been almost as strongly criticized as the medical model of disability. Michael Oliver, one of the founding fathers of the social model of disability, has recently called for a halt to this criticism, unless someone can come up with an alternative.<sup>13</sup> My understanding of the CRPD is that this convention offers such an alternative: the human rights model of disability. It is by no means the only alternative to the social model of disability. Many models of disability have been developed inside and outside disability studies, among them more recently, the capability approach model<sup>14</sup> and the cultural model<sup>15</sup> of disability. My thesis is that the human rights model is an improvement of the social model of disability and that it is a tool to implement the CRPD. However, most states parties to the CRPD are far from comprehending this new model of disability and are still stuck with the medical model of disability.

### **Understanding the human rights model of disability**

Apparently, most states parties have a problem to understand the model of disability which has been adopted with the CRPD. Several states parties reports reveal an understanding of disability which follows the traditional medical model of disability. As it has often been stated, this model regards disability as an impairment that needs to be treated, cured, fixed or at least rehabilitated. Disability is seen as a deviation from the normal health status. Exclusion of disabled persons from society is regarded as an individual problem and the reasons for

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<sup>13</sup> Oliver, *The social model of disability: thirty years on*, 28 *Disability & Society* (2013), at 1026.

<sup>14</sup> Mitra, *The Capability Approach and Disability*, 16 *Journal of Disability Policy Studies* (2006).

<sup>15</sup> Waldschmidt, *Brauchen die Disability Studies ein "kulturelles Modell" von Behinderung?*, in G. Hermes and E. Rohrman (eds), *Nichts über uns - ohne uns! Disability Studies als neuer Ansatz emanzipatorischer und interdisziplinärer Forschung über Behinderung* (2006).

exclusion are seen in the impairment. For example: Because a person is deaf and blind, it is assumed that she or he cannot participate in political or cultural life. Disability according to the medical model remains the exclusive realm of helping and medical disciplines: doctors, nurses, special education teachers, 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.<sup>16</sup> 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.<sup>17</sup> During the negotiations of the CRPD, the medical model served as a deterrent. 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.<sup>18</sup> 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

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<sup>16</sup> M. Oliver, *The politics of disablement* (1990).

<sup>17</sup> Dhanda, *Legal capacity in the disability rights convention*, 34 *Syracuse Journal Of International Law and Commerce* (2007).

<sup>18</sup> Kayess and French, *'Out of Darkness into Light?'*, 1 *Human Rights Law Review* (2008); Trömel, *'A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities'*, in G. Quinn and L. Waddington (eds), *European Yearbook of Disability Law* (2009).

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 analysed as the result of barriers and discrimination. For example: Because voting material is not produced in Braille or information on candidates is not provided in sign language or through alternative communication, a person who is deaf blind is excluded from political participation. Because deaf blind persons are denied the right to interpreters outside employment in theatre plays, cinemas and other places of cultural life, they are excluded from cultural participation in society. Because deaf blind persons are never accepted as actors or actresses in television, theatre or the film industry, they are invisible in cultural life.

Insofar, the social model of disability is the heuristic venture of a rights based approach to disability that focuses on anti-discrimination law rather than on welfare programmes. The scientific context and theoretical framework of this model is disability studies – an interdisciplinary school of thought that breaks away from the traditional disciplines of the disability industry such as special education or rehabilitation science.

Now, what is the difference between the social and the human rights model of disability and why is the CRPD a manifestation of the latter?

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 in 1999/2000<sup>19</sup> and in the background study to the CRPD that we undertook 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

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<sup>19</sup> Degener and Quinn, ‘A Survey of International, Comparative and Regional Disability Law Reform’, in M. L. Breslin and S. Yee (eds), *Disability Rights Law and Policy* (2002), at 13.

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 centre stage in all decisions affecting him/her and, most importantly, locates the main 'problem' outside the person and in society.<sup>20</sup>

However, in that study we did not expressly distinguish the human rights model from the social model. I do so now and provide six arguments to substantiate.

## **The difference between the social and the human rights model**

### ***1. Impairment does not hinder human rights capacity***

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<sup>21</sup> of exclusion of disabled people from society. It has been developed as a powerful tool to analyse 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

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<sup>20</sup> G. Quinn and T. Degener, *'Human rights and disability'* (2002), at 14.

<sup>21</sup> Other models are e.g. the normalization principle, the minority model, or the Nordic relational model, Traustadóttir, *'Disability Studies, the Social Model and Legal Developments'*, in O. M. Arnadóttir and G. Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities* (2009)

systematically upon disabled people as a group who experience this failure to discrimination institutionalised throughout society.<sup>22</sup>

This sociological explanation of disability may lay the foundation for a social theory of disability. But the social model does not seek to provide moral principles or values as a foundation of disability policy. The CRPD, however, seeks exactly that. 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’.<sup>23</sup> 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<sup>24</sup> 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. E.g., when the universality of all human rights for all disabled persons is reaffirmed,<sup>25</sup> or when it is recognized that the human rights of all disabled persons, including those with more intensive supports needs, have to be protected.<sup>26</sup> The article on the rights to equal recognition as a person before the law with equal legal capacity<sup>27</sup> is of course another example of this assumption.

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<sup>22</sup> M. Oliver, ‘*Understanding disability*’ (1996), at 33.

<sup>23</sup> Art. 1 CRPD.

<sup>24</sup> Consisting of three human rights instruments: Universal Declaration of Human Rights, Human Rights Committee, Committee on Economic, Social and Cultural Rights.

<sup>25</sup> Preamble para c) CRPD.

<sup>26</sup> Preamble para j) CRPD.

<sup>27</sup> Art. 12(1) and (2) CRPD.

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<sup>28</sup> and has often been associated with the rights based approach to disability as opposed to needs based or welfare approach to disability policy.<sup>29</sup> 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.<sup>30</sup> They do, however, concede that social model advocates have supported struggles for civil rights and anti-discrimination legislation.<sup>31</sup>

## ***2. The human rights model includes first and second generation human rights***

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.<sup>32</sup> Meanwhile, the social model of disability has become officially recognized by the European Union as the basis for its disability policy.<sup>33</sup> Within disability studies, this rights based approach in disability was characterized as a tool for stipulating citizenship and equality.<sup>34</sup> To demand anti-discrimination legislation was a logical consequence of analyzing disability as the product of inequality and

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<sup>28</sup> M. Oliver, *supra* note 22, at 63.

<sup>29</sup> L. Waddington, *'From Rome to Nice in a Wheelchair'* (2006); Degener and Quinn, *supra* note 19; A. Lawson, *'Disability and equality law in Britain. The role of reasonable adjustment'* (2008); A. Lawson and C. Gooding, *'Disability Rights in Europe. From Theory to Practice'* (2005).

<sup>30</sup> V. Finkelstein, *'The 'Social Model of Disability' and the Disability movement'* (2007), at:

[http://www.leeds.ac.uk/disability-](http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/The%20Social%20Model%20of%20Disability%20and%20the%20Disability%20Movement.pdf)

[studies/archiveuk/finkelstein/The%20Social%20Model%20of%20Disability%20and%20the%20Disability%20Movement.pdf](http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/The%20Social%20Model%20of%20Disability%20and%20the%20Disability%20Movement.pdf); Priestley, *'We're all Europeans now! The social model of disability and European social policy'*, in C. Barnes and G. Mercer (eds), *The social model of disability* (2005), at 23.

<sup>31</sup> Priestley, *supra* note 30, at 23; M. Oliver, *supra* note 22, at 152–156.

<sup>32</sup> Degener and Quinn, *supra* note 19, at 6; C. Gooding, *'Disabling laws, enabling acts'* (1994), at 10–13; C. Barnes, *'Disabled people in Britain and discrimination'* (1991).

<sup>33</sup> European Disability Strategy 2010–2020, at: [http://eur-](http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT)

[lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT](http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT) (last visited 14 March 2013).

<sup>34</sup> M. Oliver, *supra* note 22, at 112.



discrimination. In the US where the social model of disability was conceptualized as the minority model,<sup>35</sup> 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 which 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.<sup>36</sup> 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.<sup>37</sup> ‘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,<sup>38</sup> laws on personal assistance services or personal budgets proofed that even classical social laws can give choice and control to disabled persons.<sup>39</sup> It is thus illustrative that the global independent living

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<sup>35</sup> L. J. Davis, *The disability studies reader* (1997).

<sup>36</sup> M. Oliver, *supra* note 22, at 83.

<sup>37</sup> M. L. Breslin and S. Yee, *Disability Rights Law and Policy* (2002); A. Lawson and C. Gooding, *Disability Rights in Europe* (2005); L. Vanhala, *Making rights a reality?* (2011).

<sup>38</sup> Hvinden, *Redistributive and Regulatory Disability Provision: Incompatibility or Synergy?*, in G. Quinn and L. Waddington (eds), *European Yearbook of Disability Law* (2009).

<sup>39</sup> Degener, *Personal Assistance services and laws: a commentary*, in Rehabilitation International/World Institute on Disability (eds), *International Symposium on Personal Assistance models* (1991); A. Power, J. E. Lord and A. S. DeFranco, *Active citizenship and disability* (2013); R. Townsley, *The Implementation of Policies Supporting Independent Living for Disabled People in Europe* (2010).

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 era for political reasons,<sup>40</sup> are fully incorporated in the CRPD as they are in the Universal Declaration of Human Rights (UDHR) of 1948. 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).

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.'<sup>41</sup>

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.<sup>42</sup> 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<sup>43</sup> is a right commonly regarded as a civil right.<sup>44</sup> 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

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<sup>40</sup> For an illustrative account of the political history of human rights, see R. Normand and S. Zaidi, *'Human rights at the UN'* (2008).

<sup>41</sup> Statement by Mr. Ivan Simonovic, Assistant Secretary-General. Deposit of the 10<sup>th</sup> instrument of ratification of the OP-IESR New York, 5 February 2013, at: [www2.ohchr.org/english/bodies/cescr/index.htm](http://www2.ohchr.org/english/bodies/cescr/index.htm) (last visited 4 March 2013).

<sup>42</sup> Vienna Declaration and Programme of Action, A/CONF.157/23, 12 July 1993, at: <http://www.unhcr.org/refworld/docid/3ae6b39ec.html> (last visited 14 March 2013).

<sup>43</sup> Art. 12 CRPD.

<sup>44</sup> Art. 16 ICCPR, Art. 6 UDHR.

would be the right to independent living.<sup>45</sup> 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 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<sup>46</sup>, which came into being in the 1960s and 1970s in the United States, Scandinavia, Italy and many other countries.<sup>47</sup> 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.<sup>48</sup> 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<sup>49</sup> to include a right to independent living for disabled persons. But 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.'<sup>50</sup> 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

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<sup>45</sup> Art. 19 CRPD.

<sup>46</sup> Which in some countries was part of the disability rights movement, in other countries it was not.

<sup>47</sup> T. Degener and Y. Koster-Dreese, *Human rights and disabled persons: Essays and relevant human rights instruments* (1995); C. Parker, *A Community For All: Implementing Article 19* (2011); G. Quinn and S. Doyle, *Getting a Life* (2012).

<sup>48</sup> Art. 13(1) UDHR: 'Everyone has the right to freedom of movement and residence within the border of each State'. See also Art. 12(1) ICCPR, Art. 5(d), (i) CERD, Art. 15(4) CEDAW.

<sup>49</sup> Art. 11 ICESCR.

<sup>50</sup> CESCR General Comment No 5 para 33.

obligations under article 19 CRPD.<sup>51</sup> Most legal publications characterized this article as a social right with strong freedom and autonomy components.<sup>52</sup> 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, wrought 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.<sup>53</sup>

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.<sup>54</sup>

### ***3. The human rights model values impairment as part of human diversity***

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

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<sup>51</sup> For example: R. Townsley, *supra* note 39; G. Quinn and S. Doyle, *supra* note 47; C. Parker, *supra* note 47; J. Mansell *et al.*, 'Deinstitutionalization and community living' (2007); FRA European Union Agency for Fundamental Rights, 'Choice and control: the right to independent living' (2012).

<sup>52</sup> C. Parker, *supra* note 47; G. Quinn and S. Doyle, *supra* note 47.

<sup>53</sup> T. Hammarberg, 'The right of people with disabilities to live independently and be included in the community' (June 2012), at 11.

<sup>54</sup> 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.'

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, 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 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.<sup>55</sup>

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

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<sup>55</sup> J. Morris, *Pride Against Prejudice* (1991), at 10 (emphasis in the original).

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.<sup>56</sup>

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.’<sup>57</sup> 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.<sup>58</sup> Tom Shakespeare has challenged the dichotomy on the basis that both are socially constructed and inextricable interconnected.<sup>59</sup> 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.’<sup>60</sup> However, he also contends that the social model is not a social theory of disability which when developed should contain a theory of impairment.<sup>61</sup>

The human rights model of disability has not been brought into this debate yet, which is why my claim is hard to defend. 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 judgement on impairment. However, persons with

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<sup>56</sup> Morris, ‘*Impairment and disability: constructing an ethics of care which promotes human rights*’, 4 *Hypatia* (2001), at 17.

<sup>57</sup> M. Corker and S. French, ‘*Disability Discourse*’ (1999), at 6.

<sup>58</sup> Hughes and Paterson, ‘*The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment*’, 3 *Disability & Society* (1997).

<sup>59</sup> T. Shakespeare, ‘*Disability rights and wrongs revisited*’ (2014), at 72–91.

<sup>60</sup> M. Oliver, *supra* note 22, at 38.

<sup>61</sup> M. Oliver, *supra* note 22, at 42.

higher support needs are mentioned in the preamble,<sup>62</sup> 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.<sup>63</sup> 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.<sup>64</sup> In addition, it is referred to five times in such various contexts such as discrimination,<sup>65</sup> awareness raising,<sup>66</sup> recovery from violence,<sup>67</sup> inclusive education<sup>68</sup> and care delivery by health professionals.<sup>69</sup> 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.’<sup>70</sup>

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

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<sup>62</sup> Preamble para j) CRPD.

<sup>63</sup> Petersen, ‘*Human Dignity, International Protection*’, in R. Wolfrum (ed), *The Max Planck encyclopaedia of public international law* (2012).

<sup>64</sup> Art. (1), (3)(a) CRPD.

<sup>65</sup> Preamble para h) CRPD.

<sup>66</sup> Art. 8(1) (a) CRPD.

<sup>67</sup> Art. 16(4) CRPD.

<sup>68</sup> Art. 24(1)(a) CRPD.

<sup>69</sup> Art. 25(d) CRPD.

<sup>70</sup> Preamble para a) CRPD.

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 which 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.<sup>71</sup>

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',<sup>72</sup> 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.'<sup>73</sup> 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.<sup>74</sup> According to Honneth, political struggles of social

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<sup>71</sup> G. Quinn and T. Degener, *supra* note 20, at 14.

<sup>72</sup> R. Dworkin, 'Taking rights seriously' (1978).

<sup>73</sup> Basser, 'Human Dignity', in M. H. Rioux, L. A. Basser and M. Jones (eds), *Critical Perspectives on Human Rights and Disability Law* (2011), at 21.

<sup>74</sup> A. Honneth, 'The struggle for recognition' (1996).



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.<sup>75</sup> 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.<sup>76</sup>

#### ***4. The human rights model acknowledges identity issues***

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 which 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

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<sup>75</sup> Watson, *The Dialectics of Disability: a social model for the 21st century?*, in C. Barnes and G. Mercer (eds), *Implementing the social model of disability* (2004), at 101–117; Danermark and Gellerstedt, *Social justice: redistribution and recognition – a non-reductionist perspective on disability*, 19 *Disability & Society* (2004).

<sup>76</sup> For a combination of capabilities and other approaches see: M. A. Stein, *Disability Human Rights*, 95 *California Law Review* (2007).

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.<sup>77</sup> 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<sup>78</sup> 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. E. g., Peter Beresford, who identifies as a mental health user, argued for a social model of madness, way before the CRPD came into being.<sup>79</sup> Finally, identity may be shaped by more than impairment, but 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.<sup>80</sup> Disabled people of colour followed<sup>81</sup> and others like Ayesha Vernon raised the issue of intersectional discrimination and multi-dimensional oppression.<sup>82</sup>

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

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<sup>77</sup> P. Ladd, *Understanding deaf culture* (2003); M. Corker, *Deaf transitions* (1996).

<sup>78</sup> World Blind Union (<http://www.worldblindunion.org/English/Pages/default.aspx>), World Federation of the Deaf (<http://wfdeaf.org/>).

<sup>79</sup> Beresford, *Madness, Distress, Research and a Social Model*, in C. Barnes and G. Mercer (eds), *Implementing the social model of disability* (2004).

<sup>80</sup> Asch and Fine, *Nurturance, Sexuality, and Women with Disabilities*, in L. J. Davis (eds), *The disability studies reader* (1997); Wendell, *Toward a Feminist Theory of Disability*, in L. J. Davis (eds), *The disability studies reader* (1997); Garland Thomson, *Feminist Theory, the Body, and the Disabled Figure*, in L. J. Davis (eds), *The disability studies reader* (1997); J. Morris, *supra* note 55.

<sup>81</sup> C. M. Bell, *Blackness and Disability* (2011).

<sup>82</sup> Vernon, *Multiple Oppression and The Disabled People's Movement*, in T. Shakespeare (eds), *The Disability Reader* (1998).

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.<sup>83</sup> Tom Shakespeare has offered a helpful summary of further criticism against identity politics and the harm it might do to disability politics.<sup>84</sup> 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,<sup>85</sup> but it has been admitted that the social model of disability was not intended to cover all different experiences of oppression.<sup>86</sup>

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.<sup>87</sup> 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<sup>88</sup> and the pluralisation<sup>89</sup> of human rights. These treaties were adopted because human rights

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<sup>83</sup> Silvers, 'Triple Difference: Disability, Race, Gender and the Politics of Recognition', in L. A. B. Marks and M. Jones (eds), *Disability, Diversity and Legal Change* (1999).

<sup>84</sup> T. Shakespeare, *supra* note 59, at 92–110.

<sup>85</sup> M. Oliver, *supra* note 22, at 70–78.

<sup>86</sup> M. Oliver, *supra* note 22, at 39.

<sup>87</sup> R. Burke, 'Decolonization and the Evolution of International Human Rights' (2010); C. Bob, 'The International Struggle for New Human Rights' (2009).

<sup>88</sup> Mégret, 'The Disabilities Convention', 494 *Human rights quarterly: a comparative and international journal of the social sciences, humanities, and law* (2008), at 495.

<sup>89</sup> C. C. Gould, 'Globalizing democracy and human rights' (2004), at 77.

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, non disabled 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, were ignored within the first four decades of international human rights law. Feminist legal scholars such as Hilary Charlesworth, Christine Chinkin<sup>90</sup> and Catherine MacKinnon<sup>91</sup> 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<sup>92</sup> and Angela Harris<sup>93</sup> have taken feminist legal theory a step further by

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<sup>90</sup> C. Chinkin and H. Charlesworth, *'Feminist analysis of international law'* (1998).

<sup>91</sup> C. A. MacKinnon, *'Toward a feminist theory of the state'* (1989).

<sup>92</sup> M. J. Matsuda, *'Where is your body?'* (1996).

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.’<sup>94</sup>

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<sup>95</sup> and that the issue of intersectionality of discrimination has yet to be solved.<sup>96</sup>

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.<sup>97</sup> 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.<sup>98</sup> Other grounds, such as ‘race’, colour, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, or birth and age are, however, only recognized in the preamble.<sup>99</sup> For these and other layers of identity – such as age or sexual orientation – lobbying was not strong enough during the negotiations.

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<sup>93</sup> Harris, ‘*Race and Essentialism in Feminist Legal Theory*’, 3 *Stanford Law Review* (1990).

<sup>94</sup> Mégret, *supra* note 88, at 497 (emphasis in the original).

<sup>95</sup> Intersex or transgender people as well as gay and lesbians are yet to be included in international human rights law. See Report of the United Nations High Commissioner for Human Rights: Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity, UN Doc A/HRC/19/41, 17 November 2011.

<sup>96</sup> Degener, ‘*Intersections between disability, race and gender in discrimination law*’, in D. Schiek and A. Lawson (eds), *European Union non-discrimination law and intersectionality* (2011); Bond, ‘*International intersectionality: a theoretical and pragmatic exploration of women’s international human rights violations*’, 52 *Emory Law Journal* (2003).

<sup>97</sup> Art. 6 and Art. 7 CRPD.

<sup>98</sup> 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.

<sup>99</sup> Preamble para p) CRPD.

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.’<sup>100</sup> 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,<sup>101</sup> that they are provided with role models and qualified teachers and the most disputed paragraph reads:

(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.

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<sup>100</sup> Art. 30(4) CRPD.

<sup>101</sup> Art. 24(3)(a) and (b).

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.

##### ***5. The human rights model allows for assessment of prevention policy***

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 deterrent. 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 programmes 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 programmes 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 programmes as the core of ideological construction of disability.<sup>102</sup> Feminist disability studies scholars have written widely on the conflicts between

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<sup>102</sup> M. Oliver, *supra* note 22, at 54–59.

women's right to reproductive autonomy and disabled people's right to non-discrimination.<sup>103</sup>

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<sup>104</sup> and many feminists in the room.

Unlike the UN World Programme of Action Concerning Disabled Persons (WPA) of 1982<sup>105</sup> and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 1993 (StRE), 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 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.<sup>106</sup> Especially the WPA has been influenced not only by an upcoming international disability rights movement,<sup>107</sup> 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.<sup>108</sup> 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.'<sup>109</sup> The WPA even includes a paragraph on the cost effectiveness of prevention programmes: 'It is becoming

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<sup>103</sup> T. Degener and S. Köbsell, '„Hauptsache es ist gesund?“' (1992); E. Parens and A. Asch, 'Prenatal testing and disability rights' (2000); A. Silvers, D. T. Wasserman and M. B. Mahowald, 'Disability, difference, discrimination' (1998); Saxton, 'Why members of the disability community oppose prenatal diagnosis and selective abortion', in E. Parens and A. Asch (eds), *Prenatal testing and disability rights* (2000); J. Morris, *supra* note 55.

<sup>104</sup> The Vatican is a UN member state and the delegation took a very active role in this matter.

<sup>105</sup> WPA A/37/351/Add.1 and Add.1/Corr.1, annex .

<sup>106</sup> WPA para 13 and 52–56; StRE para 22.

<sup>107</sup> D. Driedger, 'The Last Civil Rights Movement' (1989), at 97–99.

<sup>108</sup> WPA para 54.

<sup>109</sup> WPA para 54.



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.**<sup>110</sup>

The WPA has been criticized for perpetuating the medical model of disability.<sup>111</sup> While the WPA and StRE are both referenced in the preamble of the CRPD,<sup>112</sup> prevention does not appear prominently in the text of the treaty. This was a deliberate decision taken during and before the negotiations.<sup>113</sup> 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<sup>114</sup> 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,<sup>115</sup> 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 behaviour.<sup>116</sup> 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 programmes to ‘prevent further disabilities including among

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<sup>110</sup> WPA para 55 (emphasis added).

<sup>111</sup> Degener, ‘*Disabled Women and International Human Rights*’, in K. D. Askin and D. M. Koenig (eds), *Women and International Human Rights Law* (2001), at 278; O. Nagase, ‘*Difference, Equality and Disabled People*’ (1995).

<sup>112</sup> Preamble para f) CRPD.

<sup>113</sup> Trömel, *supra* note 18, at 120.

<sup>114</sup> Art. 12 ICESCR.

<sup>115</sup> T. Shakespeare, *supra* note 59.

<sup>116</sup> World Health Organisation/World Bank, ‘*World Report on Disability*’ (2011), at 57–60.

children and older persons'.<sup>117</sup> 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.<sup>118</sup>

### ***6. The human rights model strives for social justice***

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.

From early on, social model proponents and critics acknowledged the close link between poverty and disability.<sup>119</sup> Indeed, the interrelatedness of poverty and disability was put forward as evidence that not only disability but also impairment is a social construct.<sup>120</sup> There is now abundance of evidence that impairment and poverty are mutually reinforcing.<sup>121</sup>

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

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<sup>117</sup> Art. 25(b) CRPD.

<sup>118</sup> World Health Organisation/World Bank, *supra* note 116, at 8.

<sup>119</sup> M. Oliver, *supra* note 22, at 12–13.

<sup>120</sup> T. Shakespeare, *supra* note 59, at 34–35.

<sup>121</sup> World Health Organisation/World Bank, *supra* note 116, at 10–11.

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.<sup>122</sup> The United Nations, the World Bank and other development agents have long acknowledged that disability is a development issue,<sup>123</sup> 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.<sup>124</sup> Together with article 11 CRPD on situations of risk and humanitarian emergencies, it provides a solid roadmap for disability policy in international humanitarian and development cooperation. Article 32 CRPD demands that international cooperation is inclusive and accessible to disabled people, that disability is mainstreamed in all development programmes 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 time of the end of the negotiations, the Lebanon war had started in July 2006, which increased the already politicized nature of the article. Under these

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<sup>122</sup> C. Barnes and G. Mercer, *The social model of disability* (2005), at 15; D. Driedger, *supra* note 107; B. Watermeyer, *Disability and social change* (2006), at 206–259; M. Priestley, *Disability and the life course* (2001); E. Stone, *Disability and development* (1999); B. Albert, *In or out of the mainstream? Lessons from research on disability and development cooperation.* (2006).

<sup>123</sup> J. Braithwaite and D. Mont, *Disability and Poverty: A Survey of World Bank Poverty Assessments and Implications* (February 2008).

<sup>124</sup> Trömel, *supra* note 18, at 132.

circumstances, it was amazing to reach consensus on the text of these articles.<sup>125</sup> 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 2003.<sup>126</sup> While the new rights based approach in development is not without shortcomings,<sup>127</sup> 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 programmes will perpetuate and exacerbate discrimination against disabled persons.<sup>128</sup>

### **Developing the social model into a human rights model of disability**

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<sup>125</sup> 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 Trömel, *supra* note 18, at 125.

<sup>126</sup> UN Common Understanding on Human Rights-Based Approaches to development cooperation and programming, at: [http://www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf) (visited 5 March 2013).

<sup>127</sup> Cornwall and Nyamy-Musembi, 'Putting the 'rights-based' approach to development into perspective', 8 *Third World Quarterly* (2004).

<sup>128</sup> *Global Thematic Consultation on the Post-2015 Development Agenda* (February 2013).

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.'<sup>129</sup> But 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. As Rannveig Traustadóttir, Mark Priestley and Tom Shakespeare<sup>130</sup> have illustrated, there is a variety of different social theories and models of disability in disability studies and other science fields. The British social model has been distinguished from the US minority group approach and from the Nordic relational approach.<sup>131</sup> In addition to social, cultural<sup>132</sup> and individual models of disability, theories of disability have been divided into materialist and idealist typologies.<sup>133</sup> 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 enormous so far in many areas, such as human rights

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<sup>129</sup> Kayess and French, *supra* note 18, at 7.

<sup>130</sup> T. Shakespeare, *supra* note 59, at 9–92.

<sup>131</sup> Traustadóttir, 'Disability Studies, the Social Model and Legal Developments', in O. M. Arnadóttir and G. Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities* (2009).

<sup>132</sup> Waldschmidt, 'Disability Studies: Individuelles, soziales und/oder kulturelles Modell von Behinderung?', 1 *Psychologie und Gesellschaftskritik* (2005).

<sup>133</sup> Priestley, 'Constructions and Creations: Idealism, materialism and disability theory', 1 *Disability & Society* (1998).

monitoring, international cooperation, accessibility and legal capacity discourse, or inclusive education to name but a few. In the context of the background study, we found that the disability rights movement had embraced the idea of human rights but 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.<sup>134</sup> Nevertheless, DPOs have quickly learned and some of the organizations such as the International Disability Alliance have become some of the most 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 more recent concluding observations.<sup>135</sup> Most of the state party reports, however, do not reflect a clear understanding of the human rights model of disability. While it has become unfashionable to rely on the medical model of disability, the paradigm shift to the human rights model has yet to be reflected in implementation.

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<sup>134</sup> G. Quinn and T. Degener, *supra* note 20, at 256–270.

<sup>135</sup> 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.