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# WORKING PAPERS

AEL 2016/01  
Academy of European Law

Human Rights of Persons with Disabilities in  
International and EU Law

Dorothy Estrada-Tanck (ed.)



European University Institute  
**Academy of European Law**

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EU Law**

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EUI Working Paper **AEL** 2016/01

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ISSN 1831-4066

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Printed in Italy  
European University Institute  
Badia Fiesolana  
I – 50014 San Domenico di Fiesole (FI)  
Italy  
[www.eui.eu](http://www.eui.eu)  
[cadmus.eui.eu](http://cadmus.eui.eu)

## **Abstract**

The present Working Paper derives from the ‘Workshop on Human Rights of Persons with Disabilities in International and EU Law’ organised by the Human Rights Working Group of the European University Institute (EUI) and the Academy of European Law (AEL), and held at the EUI in Florence, Italy, on 27 April 2012. The workshop brought together a diverse group of leading academics, practitioners, and civil society members, in the field of human rights of persons with disabilities. The five individual papers of participants in the workshop assembled within the present Working Paper reflect a rich plurality of visions that analyse the 2006 United Nations Convention on the Rights of Persons with Disabilities, the significance of this ground-breaking instrument for international law and particularly human rights law, as well as its relationship with and its impact on EU Law. Ultimately, the examined key legal issues are evaluated in terms of their potentials and limitations for persons with disabilities themselves and the States and societies they live in.

## **Keywords**

Human rights, persons with disabilities, UN Convention on the Rights of Persons with Disabilities, non-discrimination, reasonable accommodation, international human rights law, EU law



## **Acknowledgments**

This text originates from the ‘Workshop on Human Rights of Persons with Disabilities in International and EU Law’ organised by the Human Rights Working Group of the European University Institute (EUI) and the Academy of European Law (AEL), and held at the EUI in Florence, Italy, on 27 April 2012. Gratitude is owed to all the participants in the workshop for the exchange of insightful ideas that feed into this publication.

The present AEL Working Paper is the result of the participation of the workshop members who were willing and able to prepare their written contributions, update them and patiently await the edition procedure (during which a new job, two pregnancies and a couple of babies came by!). I especially thank the five authors for their commitment, dedication and understanding during this process.

Thank you also to the generous donors that made the workshop possible and thus, who facilitated the path for this working paper: the AEL itself and its then Co-Directors, Professors Marise Cremona, Francesco Francioni and Loic Azoulay; Professors Martin Scheinin, Ruth Rubio-Marín and Claire Kilpatrick from the Law Department; former EUI President Josep Borrell; and the EUI Human Rights Working Group.

A particular word of thank you goes to Anny Bremner, Coordinator of the AEL, and Joyce Davies, Administrative Assistant of the AEL, for their help in coordinating the workshop and the assembling of this text.



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## Introduction

**Dorothy Estrada-Tanck\***

The idea of this Working Paper was first conceived in the ‘Workshop on Human Rights of Persons with Disabilities in International and EU Law’ organised by the Human Rights Working Group of the European University Institute (EUI) and the Academy of European Law (AEL), and held at the EUI in Florence, Italy, in April 2012.

The workshop brought together a diverse group of leading experts who exchanged ideas with the EUI research and faculty community on the standards, aspirations and implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Speakers ranging from academics and diplomats to members of civil society, intergovernmental and international organisations, explored the role of the CRPD within domestic legislations and jurisdictions, from developed to developing countries, as well as the challenges it poses for different actors under international law and EU law, and ultimately, its relevance and potentials for the persons with disabilities throughout the world. This opened a space for timely and innovative discussions to which the EUI wished to contribute constructively.

Along these lines, speakers at the workshop were invited to submit papers reflecting their presentations and the exchange held at the workshop. The collected five individual papers presented here express a plurality of visions regarding key legal issues at stake in the interpretation, understanding and implementation of the UN CRPD, both in international and EU law, and ultimately, the significance of the Convention for persons with disabilities and the societies they live in. The papers have been updated to reflect the state of affairs as of the time specified in each one of them. As a shared conclusion that can be derived from all of the papers, one can emphasise the need for innovative mechanisms to be enacted by the international community, the EU, States, academia and civil society, including the human

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rights world, for upholding and fulfilling the rights of persons with disabilities in terms of equality and non-discrimination, as enshrined in the holistic and ground-breaking instrument of the UN CRPD.

Indeed, the CRPD, in force since 2008, is novel in many ways. It adopts a new model considering persons with disabilities as full subjects of the law with clearly defined human rights, thus substituting the previous medical paradigm, as well as the social development model and the model based solely on non-discrimination principles. It incorporates elements of such understandings yet moves beyond them in the creation of a more comprehensive and integral framework. Because the treaty views disability as a result of the interaction between an inaccessible environment and a person, rather than an inherent attribute of an individual, it considers persons with disabilities as right holders capable of exercising such rights in an independent manner on the basis of equal citizenship. As one may derive from Article 1 of the Convention, more than the existence of persons with disabilities, there are disabling social structures, rules and practices.

Also, the UNCRPD is, so far, the first and only of the nine core international human rights treaties to which the European Union (EU) is a party, and the first human rights treaty which the European Community, as it then was, was involved in negotiating and signing,<sup>1</sup> alongside its Member States. From its very conception and negotiation, it adopted an “experimentalist character”,<sup>2</sup> prioritizing actors such as Non-Governmental Organizations and National Human Right Institutions, and also envisioning them as necessary and helpful partners in the implementation of the Convention.

**Theresa Degener**, in her paper ‘Challenges and Compliance of the UN CRPD’, applies her academic knowledge and her valuable experience as member of the UN Committee on the Rights of Persons with Disabilities -the monitoring body of the Convention-, to walk us

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<sup>1</sup> The European Community signed the UNCRPD on March 7, 2007 declaring that “the United Nations Convention on the Rights of Persons with Disabilities shall apply, with regard to the competence of the European Community, to the territories in which the Treaty establishing the European Community is applied and under the conditions laid down in that Treaty, in particular Article 299 thereof”. The EU presented its instrument of formal confirmation on December 23, 2010, and the Convention entered into force for the EU on 22 January 2011.

<sup>2</sup> See eg, De Búrca, Grainne, ‘The European Union in the negotiation of the UN Disability Convention’, 35 *European Law Review* (2010), at 174–196.

through the legal and practical tests unique to the implementation of this instrument. At the same time, she highlights the transcendental value of the human rights model embodied by the CRPD as compared to previous models. Through a detailed comparative analysis, she examines how the medical model regards disability as impairment which needs to be treated, cured, fixed or rehabilitated, and how the social model is merely explanatory of disability, while the human rights model seeks to provide moral principles as a foundation of disability policy on the basis of the human dignity of disabled persons. Indeed, to her, only this last model can explain why human rights do not require absence of impairment as a paradigm which conceives human dignity as the cornerstone of its development.

**Stefan Tromel** in his piece on ‘The CRPD and the Role of Organizations of Persons with Disabilities’, highlights the vital contribution that representative organizations of persons with disabilities (Disabled Peoples’ Organizations, DPOs) made during the negotiation process of the UN CRPD and how this active role has evolved in the phase after the adoption and entry into force of the CRPD. The author reveals that despite the theoretical inclusion of persons with disabilities in the human rights normative system, the practical reality evidenced that the human rights machinery had paid little attention to persons with disabilities. Against this background, Tromel relates how from the start of the drafting process of the CRPD, persons with disabilities, while not necessarily experts on human rights treaties, were definitely the best experts on the human rights violations they faced. He narrates how this powerful message and request was soon to become a slogan that was used again and again by the DPO representatives: “Nothing about us without us”.

**Delia Ferri** in her paper ‘The UN Convention on the Rights of Persons with Disabilities as an “Integral Part” of EU Law’, analyses the status and the effects of the UN CRPD on the EU legal order, considering that it is a human rights treaty but also a mixed agreement. She examines the effects of the UN CRPD provisions within the EU legal order, in light of relevant case law of the Court of Justice of the European Union. In reviewing the status of the CRPD under EU law, the author also reminds us of the need of considering the matter in light of pressing legal questions such as the prospect of future EU accession to the European Convention on Human Rights. Still, she stresses that one should give due weight to the interpretation of human rights by the European Court of Human Rights (independently of possible EU accession to the ECHR), or via the EU Charter of Fundamental Rights, to

evaluate whether the Convention might provide for a binding term of reference for fundamental rights in the EU.

**Philippe Reyniers**, in his paper ‘A Note on the Experimentalist Nature of the Rights of Persons with Disabilities’, emphasises that the rights of persons with disabilities relate to the legal pragmatic framework of experimentalism: these rights are entwined with ideas of *problem-solving process* and *experiment*. Legal pragmatism claims that contemporary social problems cannot be remedied by rules and binary criteria of permissibility, and proposes to engage people into experimentation and deliberative processes. In this respect, he considers that the CRPD can be seen as an experimentalist instrument. As its drafting-process was open to non-governmental organizations, the Convention differs from traditional instruments of public international law, which are the result of diplomatic negotiations. As Reyniers stresses, the Convention mandates the inclusion of persons with disabilities in the mechanisms of review, expressing thereby an ongoing willingness to engage with civil societies.

This perspective highlighted by Reyniers connects with the following paper by **Masa Anisic**, who underlines how the guiding principle of inclusive participation of the CRPD places a broader mandate, not only to the state but also to society, to allow persons with disabilities to fully become members of their community and society at large.

**Masa Anisic**, in her piece ‘The UN Convention on the Rights of Persons with Disabilities as a Tool for Stronger Social Rights Realisation’, accentuates how the CRPD explicitly clarifies the consideration of persons with disabilities as rights holders, detaching them from the perception of welfare recipients. Her analysis of the right and principle of full participation also allows for breaking down classical binaries of civil and political rights (traditionally thought of as negative rights)/economic, social and cultural rights (typically deemed as rights to be progressively fulfilled). Indeed, as she examines, the Convention’s definition of discrimination, which encompasses the denial of reasonable accommodation, has a dual effect: one of creating an immediate obligation (versus only a progressive one), and one which requires implementation of civil and political rights through positive measures in order to address ongoing systemic discrimination against persons with disabilities. This also allow for the justiciability of *all* human rights of persons with disabilities, thus blurring the traditional division of human rights.

I would like to spare some words to highlight the character of the UN CRPD as a comprehensive and integral international convention that seeks, among other aims, to redress “the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries”.

Indeed, within the context of globalization and the great social and economic inequality existing at the global level, human rights can function as ends in themselves in their character of materialization of certain ethical values such as social justice, and at the same time as tools to rearrange asymmetries in power and wealth. Along these lines, one cannot but call attention to the fact that the majority of persons with disabilities live in under-developed or developing countries. Almost 15% of the world’s population is formed by persons with disabilities (over 650 million people), of whom approximately 80% live in developing countries,<sup>3</sup> and about 80 million people living in the EU have a mild to severe disability.<sup>4</sup> Millions and millions of persons with a disability have to face harsh socio-economic conditions and, in some cases, severe poverty, deprivation and marginalisation. In this sense, the protection of human rights may be seen as well part of the realisation of the values of equality and non-discrimination as central features both of international and EU law.

The UN CRPD itself emphasizes in its Preamble “the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries”. Looking at the EU’s action within a broader framework of international cooperation may also be enriching and open the door for broader dialogue regarding best legal practices with other regions and jurisdictions. In more general terms, one can conclude that the CRPD “now acts as a prism through which a disability rights approach can be streamlined across all activities of the EU”.<sup>5</sup>

In this context, a final reflection is in place given the time of publication of this Working Paper. In the face of the biggest migration and refugee ‘crisis’ the EU and other parts of the world are confronting, it is certainly a moment to recall and reinforce human rights. Let us bear in mind that among the thousands of persons fleeing from war, violence and human

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<sup>3</sup> See official UN power point presentation, Convention in Brief, slide no. 5, at <http://www.un.org/disabilities/>

<sup>4</sup> See European Commission information at [http://ec.europa.eu/news/justice/101115\\_en.htm](http://ec.europa.eu/news/justice/101115_en.htm)

<sup>5</sup> Waddington, Lisa, Gerard Quinn and Eilionóir Flynn (eds.), *European Yearbook of Disability Law*, Vol. 4, Intersentia, Cambridge, Antwerp, Portland (2013), at 2.

insecurity, there are persons with disabilities who experience added vulnerabilities.<sup>6</sup> Indeed, the ‘crisis’ is such not only for the receiving States in the sense of new and unexpected challenges, but first and foremost it is a true crisis for the refugees themselves, many of them such as persons with disabilities enduring heightened conditions of systemic risk and discrimination. Under this perspective, the need to underline the ethical and political exigence of the EU -and its legal obligation-, to protect and guarantee human rights, particularly of those in conditions of vulnerability, becomes evident.

One can only hope that the international community as a whole and the EU in particular, can reimagine creative ways of protecting human dignity effectively in the contemporary world where millions of persons with disabilities still await the promise of justice and equality of human rights law to be delivered.

May 2016

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<sup>6</sup> Human Rights Watch, *Europe’s Refugee Crisis: An Agenda for Action* (2015), at 3, 13 and 17.

## Challenges and Compliance of the UN CRPD

Theresia Degener\*

### 1. From the Social Model to the Human Rights Model of Disability

When the final vote on the draft text of the CRPD within the Ad Hoc Committee took place on 25 August 2006 in New York, I thought, ‘This treaty should have been adopted twenty years earlier.’ Two attempts in this respect were defeated in the General Assembly in the 1980s because the time wasn’t ripe. The Standard Rules on the Equalization of Opportunities<sup>1</sup> of 1993 were adopted for consolation, and only as soft law. Yet, while the CRPD is a latecomer compared to its sister treaties, it has been a success from the start of its negotiations in 2002: Its negotiation history among UN human rights treaties is the fastest; its ratification record is splendid;<sup>2</sup> it gave rise to profound reforms in disability law and policy at national, regional and international level; it modernized human rights law and international cooperation to an extent none of us involved in the negotiation process had ever imagined. On the evening of the 25<sup>th</sup> August 2006, all of us who attended the celebration in the Permanent Mission of the Republic of Korea to the UN knew that the difficult battle over words was over, but a much harder fight over implementation was yet to come. However, in that moment, the atmosphere was filled with joy and the experience based knowledge that the unthinkable is possible, emphasized by the fact that the piano was played by our deafblind friend and colleague Lex Grandia that evening. Lex Grandia, who passed away on 19<sup>th</sup> April 2012, a few days before our meeting here in Florence, was one of the great leaders of the disability rights movement who have helped to give birth to the CRPD. As president of the World Federation of the Blind, he was the representative of a group mostly ignored and forgotten in national disability policy programmes, its individuals being at high risk of human rights violations. It has been pointed out by many authors that the success story of the CRPD can only be

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<sup>1</sup> UN GA RES/48/96, 4 March 1994.

<sup>2</sup> UNCRPD – status of ratification: convention 159 signatories, 154 ratifications; OP 92 signatories, 86 ratifications (2 May 2015).

explained by the active involvement of disabled persons and their organizations during the negotiation process. Credit for this goes definitely to Lex Grandia, who was a great theologian, a charismatic leader of the movement and a great friend to many of us. I wish to dedicate this paper to him.

As a member of the CRPD Committee, I am involved in reviewing state reports, individual complaints and general comments. As of 30 April 2015, we have received 80 state reports. Of the reports submitted so far, we have reviewed 27 in full, among them Tunisia, Spain, Peru, Argentina, Hungary and China).<sup>3</sup> The number of overdue reports by August of 2015 was 49, which makes a percentage of overdue reports of 60%.

With the current meeting time of three working weeks per year, our committee currently faces a backlog of seven years which is the longest backlog among all treaty bodies. This is due to the high number of ratifications and our comparably short meeting time. Thus, the UN CRPD has become a victim of its own success. This destiny is shared by other treaty bodies and it is hoped that the current treaty body strengthening process<sup>4</sup> will bring about some tangible solutions to the impending collapse of the treaty body system.

Our state reports resemble those which member states have to submit to our nine sister treaty bodies, such as the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Elimination of all Forms of Discrimination Against Women or the Committee on the Rights of the Child. In one aspect, however, state reports to the CRPD differ: The CRPD is one of the first human rights treaties which mandates the establishment of a national implementation and monitoring mechanism (article 33 CRPD). Thus, the implementation of the national monitoring mechanism is a specific challenge of the UN CRPD. We also have an optional protocol that sets out the procedure for individual or collective complaints and an inquiry mechanism.<sup>5</sup> More than 100 individual communications have reached the Committee so far, of which only a few have been registered till now and

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<sup>3</sup> For a list of the existing Concluding Observations on these countries, see: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5) (last visited 30 April 2015)

<sup>4</sup> See: <http://www2.ohchr.org/english/bodies/HRTD/index.htm>

<sup>5</sup> For status of ratification see *supra* note 2.

eight cases have been finalized.<sup>6</sup> Thus, the bulk of the cases remain confidential. The Committee has adopted two general comments, one on Article 9 (accessibility) and another on Article 12 (equal recognition before the law).<sup>7</sup> The Committee also held a Day of General Discussion on the Right to Education of Persons with Disabilities on 15 April 2015.

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 and 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 system, which is in alignment with Article 33 CRPD. It prescribes a three pillar structure of national implementation and monitoring system that is entirely new to the human rights treaty system. Member States need to designate one or more focal points within governments ‘for matters relating to the implementation’ of the treaty.<sup>8</sup> They further need to have an independent national monitoring system<sup>9</sup> and civil society needs to be meaningfully involved in the monitoring process.<sup>10</sup> All three pillars present challenges for state parties. Shall there be one or more focal points in government, for instance at different levels in a federal state? Which entity within government is best suited as focal point? Usually, disability issues are part of the mandate of the ministry for social affairs but human rights as a policy subject usually belong to the realm of the foreign or justice ministry. In order to mainstream disability in all spheres of governmental policy and planning as demanded by the CRPD,<sup>11</sup> which entity within government is best suited to fulfil this duty? In a thematic study on the implementation of the CRPD, the Office of the High Commissioner for Human Rights has recommended to designate the justice ministry as focal point in order to facilitate mainstreaming disability into human rights

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<sup>6</sup> See:

[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeCategoryID=6](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeCategoryID=6)

<sup>7</sup> See: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> (last visited 28 April 2015)

<sup>8</sup> Art. 33(1) CRPD.

<sup>9</sup> Art. 33(2) CRPD.

<sup>10</sup> Art. 33(3) CRPD.

<sup>11</sup> Art. 4(1) CRPD.

policies.<sup>12</sup> So far, most member states choose to designate the ministry with mandate in disability matters as focal point which usually is the social affairs ministry. The treaty further allows one or more entities within states to serve as focal points and to coordinate matters of implementation. Some member states have established focal points and separate coordination agencies, others have vested focal points with coordination tasks.<sup>13</sup> The independent monitoring mechanism is of course one of the greatest challenges to state members. The treaty references the Paris Principles<sup>14</sup> as the standard test for these bodies, which were adopted by the United Nations in 1993 and relate to the status and functioning of national human rights institutions (NHRI). In order to be accredited by the International Coordination Committee of NHRIs, the designated institutions need to fulfil a number of requirements, such as independence from governments and pluralist composition. Member states opt for different approaches to this requirement. The NHRI might be a commission on human rights, an equality body or an ombudsperson. Often, these mainstream bodies do not have much expertise with respect to disability as a human rights issue. This is why some member states choose organizations of people with disabilities (DPOs) as tandem partners within the independent monitoring mechanism. Other member states designate national disability councils or other umbrella DPOs as independent monitoring mechanism. The latter version raises the question if DPOs can be regarded as institutes in compliance with the Paris Principles. Participation of civil society is required by the CRPD not only in national monitoring but also in national planning and implementation.<sup>15</sup> Thus it is disputable whether and how disabled experts and/or DPOs are to be included in focal points and coordination bodies.

Apart from monitoring and implementation, there are a number of challenges with relation to substantive provisions. For example, the non-discrimination provision of the CRPD differs from other human rights treaties in that its definition of discrimination is broader.

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<sup>12</sup> Office of the High Commissioner for Human Rights, 'Thematic Study by the Office of the High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities' (2009).

<sup>13</sup> Beco, 'Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities. Another Role for National Human Rights Institutions?', 1 *Netherlands Quarterly of Human Rights* (2011); *Survey of National Human Rights Institutions on Article 33.2 of the Convention on the Rights of Persons with Disabilities* (August 2011).

<sup>14</sup> UN GA A/RES/48/134, 85th plenary meeting, 20 December 1993.

<sup>15</sup> Art. 4(3) CRPD.

Discrimination is not only 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’.<sup>16</sup> Similar definitions can be found in CERD and CEDAW.<sup>17</sup> Disability based discrimination also includes ‘denial of reasonable accommodations’.<sup>18</sup> The latter are 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’.<sup>19</sup>

‘Reasonable accommodation’ is a key phrase of modern disability discrimination law, which originates in US law but has been adopted as a key legal concept elsewhere around the world.<sup>20</sup> Many state parties have adopted anti-discrimination laws that also cover discrimination based on disability. However, often these laws do not include denial of reasonable accommodation as a form of discrimination. Furthermore, state reports as well as the dialogue with delegations reveal that sometimes the term itself is not well understood. Particularly, the relationship to Article 9 and the obligation to provide accessibility seems to be unclear among member states. While the right to reasonable accommodation is an essential part of the individual right to non-discrimination, the accessibility obligation is group oriented. The latter means that standards for accessibility are more general and often functioning-related, e.g., the door width has to be compatible with standard wheelchair sizes; assistive products for orientation have to be usable for the average blind, deaf or deafblind person, easy to read information has to be practical for the average learning impaired person. Accessibility is closely related to universal design, which is defined as ‘the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design’.<sup>21</sup>

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<sup>16</sup> Art. 2 CRPD.

<sup>17</sup> See Art. 1(1) CERD; Art. 1 CEDAW.

<sup>18</sup> Art. 2 CRPD.

<sup>19</sup> Art. 2 CRPD.

<sup>20</sup> Degener, ‘Disability Discrimination Law: A Global Comparative Approach’, in A. Lawson and C. Gooding (eds), *Disability Rights in Europe* (2005) and D. Schiek; L. Waddington and M. Bell, *Cases, materials and text on national, supranational and international non-discrimination law*, (2007), at 629-756.

<sup>21</sup> Art. 2 CRPD.

Accessibility obligations can best be implemented through the adoption of general regulations which need to be negotiated with respective DPOs. These obligations are *a priori* obligations in that the obligation has to be fulfilled before an individual actually seeks access. It is an obligation relating to structures and systems. Because accessibility regulations need to be group oriented there will always be disabled persons whose needs may not be met by a given regulation. Their impairment is so unique or rare that his or her functioning is not recognized. In contrast, the right to reasonable accommodation is individual related. Thus, the individual functioning together with the preferences of that person have to be taken into consideration. Reasonable accommodation obligations have to be negotiated, meaning that when a person seeks access or accommodation, rights bearer and duty bearer have to enter into a dialogue on what is an effective and reasonable accommodation and whether demands exceed disproportionate burdens. In this negotiation, equality rights of the individual are at stake but also dignity rights. If a disabled person is uncomfortable with certain assistive technologies or if she prefers certain life styles (e.g. not wearing prostheses), those preferences should be considered. On 11 April 2014, the CRPD Committee adopted General Comment No. 2, *Article 9: Accessibility*, confirming these interpretations.<sup>22</sup>

Finally, Article 12 needs to be mentioned as a specific challenge in the implementation of the CRPD. Gerard Quinn has rightly characterized the issue of legal capacity reform as ‘the most important issue facing the international legal community at the moment’.<sup>23</sup> Article 12 is probably the article, which most clearly manifests the paradigm shift the CRPD seeks to bring about. It demands that state parties abolish traditional guardianship laws and substituted decision making systems for adults. It presumes that all persons with impairments, regardless of their functioning, can exercise legal capacity. It further demands that comprehensive services for supported decision making be made available to disabled persons who need support. Many member states do not accept that all disabled persons have legal capacity and have made reservations and declarations relating to Article 12.<sup>24</sup> Even those who signed the

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<sup>22</sup> CRPD Committee, *General Comment No. 2, Article 9: Accessibility*, CRPD/C/GC/2, 22 May 2014, paras. 25 and 26.

<sup>23</sup> G. Quinn, ‘Concept Paper: Personhood and Legal Capacity – Perspectives on the Paradigm Shift of Art. 12 CRPD’, Harvard Law School (20 February 2010), at 3.

<sup>24</sup> For declaration by Australia see: [http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&lang=en#EndDec](http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec); for reservations and declaration by UK see: [http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&lang=en#EndDec](http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec) (both last visited 14 March 2013)

Convention without caveats submit reports that clearly show that Article 12 is not properly interpreted. The Committee has taken a very strong stance against legal systems of substitute decision making.<sup>25</sup>

After discussion in this area with relevant stakeholders, the Committee adopted also on 11 April 2014 its General Comment No. 1, *Article 12: Equal recognition before the law*. In this General Comment, the Committee reaffirms the right of persons with disabilities to be recognized as persons before the law, including the guarantee that every human being is respected as a person possessing legal personality, which is a prerequisite for the recognition of a person's legal capacity. It stresses that such capacity includes the capacity to be both a holder of rights and an actor under the law.<sup>26</sup> The Committee clarifies as well that 'legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors', and concluded that 'Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity'.<sup>27</sup>

Regarding the debated issue of decision-making processes inherent to legal capacity, the Committee recognises that the state must provide persons with disabilities access to the support necessary to enable them to make decisions that have legal effect. However, it emphasizes that 'Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making'.<sup>28</sup> The Committee goes on to exemplify acceptable forms of support in different situations. It also acknowledges that the type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities,

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<sup>25</sup> See e.g. CRPD/C/CHN/CO/1, 15 October 2012, para. 22, at: <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G12/465/82/PDF/G1246582.pdf?OpenElement> (last visited 29 April 2015).

<sup>26</sup> CRPD Committee, *General Comment No. 1, Article 12: Equal recognition before the law*, CRPD/C/GC/1, 19 May 2014, paras. 11 and 12.

<sup>27</sup> *Ibid.*, para. 13.

<sup>28</sup> *Ibid.*, paras. 16 and 17.

but underlines that ‘At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected’.<sup>29</sup>

Regarding the safeguards against abuse and manipulation, the Committee specifies that ‘The “will and preferences” paradigm must replace the “best interests” paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others’. It determines that ‘Safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes’.<sup>30</sup>

Following this line of thought, the Committee thus concludes that ‘States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives’. It clarifies that ‘A supported decision-making regime comprises various support options which give primacy to a person’s will and preferences and respect human rights norms’, and proceeds to enlist and explain the key provisions that different forms of supported decision-making regimes should include as a minimum in order to ensure compliance with Article 12 of the CRPD.<sup>31</sup>

There are of course many more challenges we encounter in the international monitoring of the CRPD. One could mention Article 19 CRPD on the right to independent living but also all other articles containing human rights or state obligations. However, I would argue that there is one test for state parties which could be called the base challenge underlying all others and that is to understand the human rights model of disability.

## **2. Understanding the Human Rights Model of Disability**

Apparently, most state parties have a problem to understand the model of disability which has been adopted with the UN CRPD. Several state party reports reveal an understanding of disability which follows the traditional medical model of disability. As it has often been

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<sup>29</sup> *Ibid.*, paras. 17 and 18.

<sup>30</sup> *Ibid.*, paras. 21 and 22.

<sup>31</sup> *Ibid.*, paras. 28 and 29.

stated, this model regards disability as impairment which 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 exclusion are seen in the impairment. Lex Grandia would have given the following 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>32</sup> Another feature of the medical model of disability is that it is based on two assumptions which have a huge 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 which take an incapacity approach to disability.<sup>33</sup> During the negotiations of the UN CRPD, the medical model served as a deterrent. While there was often no consensus among stake holders 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>34</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 achievements of the UN CRPD. While it is true that the social model of disability was often mentioned during the negotiation process, my understanding of the UN 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

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<sup>32</sup> M. Oliver, *The politics of disablement* (1990).

<sup>33</sup> Dhanda, 'Legal capacity in the disability rights convention', 34 *Syracuse Journal of International Law and Commerce* (2007).

<sup>34</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).

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. Lex Grandia might have given the following examples: 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.

The social model of disability is the heuristic venture of a rights based approach to disability which focuses on anti-discrimination law rather than on welfare programmes.

Disability studies is the scientific context and theoretical framework of the social model of disability. It is an interdisciplinary school of thought which 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 UN 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 which I wrote together with Gerard Quinn in 1999/2000<sup>35</sup> and in the background study to the CRPD which 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 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>36</sup>

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<sup>35</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.

<sup>36</sup> G. Quinn and T. Degener, *Human rights and disability* (2002), at 14.

However, in that study we didn't expressly distinguish the human rights model from the social model. I do so now and my arguments are the following:

### ***A. 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>37</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 systematically upon disabled people as a group who experience this failure to discrimination institutionalised throughout society.<sup>38</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>39</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

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<sup>37</sup> Other models are e. g. the normalization principle, the minority model, or the Nordic relational model, see *infra* note 147.

<sup>38</sup> M. Oliver, *Understanding disability*(1996), at 33.

<sup>39</sup> Art. 1 CRPD

catalogue of the International Bill of Human Rights<sup>40</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>41</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>42</sup> The article on the rights to equal recognition as a person before the law with equal legal capacity<sup>43</sup> 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<sup>44</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>45</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>46</sup> They do, however, concede that social model advocates have supported struggles for civil rights and anti-discrimination legislation.<sup>47</sup>

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<sup>40</sup> 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.

<sup>41</sup> Preamble, para c) CRPD.

<sup>42</sup> Preamble, para j) CRPD.

<sup>43</sup> Art. 12(1) and (2) CRPD.

<sup>44</sup> M. Oliver, *supra* note 39, at 63.

<sup>45</sup> L. Waddington, *From Rome to Nice in a Wheelchair* (2006); Degener and Quinn, *supra* note 36.

<sup>46</sup> V. Finkelstein, *The 'Social Model of Disability' and the Disability movement* (2007), at: <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>47</sup> Priestley, *ibid.*, at 23; M. Oliver, *supra* note 39, at 152-156.

### **B. The Human Rights Models 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>48</sup> Meanwhile, the social model of disability has become officially recognized by the European Union as the basis for its disability policy.<sup>49</sup> Within disability studies, this rights based approach in disability was characterized as a tool for stipulating citizenship and equality.<sup>50</sup> To demand anti-discrimination legislation was a logical consequence of analysing disability as the product of inequality and discrimination. In the US where the social model of disability was conceptualized as the minority model,<sup>51</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>52</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>53</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

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<sup>48</sup> Degener and Quinn, *supra* note 36, at 6; C. Gooding, *Disabling laws, enabling acts* (1994), at 10-13; C. Barnes, *Disabled people in Britain and discrimination* (1991).

<sup>49</sup> European Disability Strategy 2010–2020, at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT> (last visited 29 April 2015)

<sup>50</sup> M. Oliver, *supra* note 39, at 112.

<sup>51</sup> L. J. Davis, *The disability studies reader* (1997).

<sup>52</sup> M. Oliver, *supra* note 39, at 83.

<sup>53</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).

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>54</sup> laws on personal assistance services or personal budgets proofed that even classical social laws can give choice and control to disabled persons.<sup>55</sup> 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, social 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>56</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 2013, which was commented by Assistant Secretary-General Ivan Simonovic as enabling the United Nations ‘to come full circle on the normative architecture envisaged by the Universal Declaration of Human Rights’.<sup>57</sup> The universality, indivisibility and interdependence of all human rights was firmly established as a principle of international human rights law on the World Conference of Human Rights two decades earlier

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<sup>54</sup> Hvinden, ‘Redistributive and Regulatory Disability Provision: Incompatibility or Synergy?’, in G. Quinn and L. Waddington (eds), *European Yearbook of Disability Law* (2009).

<sup>55</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).

<sup>56</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>57</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: <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=12971&LangID=E> (last visited 29 April 2015).

in Vienna.<sup>58</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>59</sup> is a right commonly regarded as a civil right.<sup>60</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 would be the right to independent living.<sup>61</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>62</sup> which came into being in the 1960s and 1970s in the United States, Scandinavia, Italy and many other countries.<sup>63</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>64</sup> But 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>65</sup> to include a right to independent living

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<sup>58</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 30 April 2015).

<sup>59</sup> Art. 12 CRPD.

<sup>60</sup> Art. 16 ICCPR, Art. 6 UDHR.

<sup>61</sup> Art. 19 CRPD.

<sup>62</sup> Which in some countries was part of the disability rights movement, in other countries it was not.

<sup>63</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>64</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>65</sup> Art. 11 ICESCR.

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>66</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 obligations under Article 19 CRPD.<sup>67</sup> Most legal publications characterized this article as a social right with strong freedom and autonomy components.<sup>68</sup> In the words of the former 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>69</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>70</sup>

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<sup>66</sup> CESCR General Comment No 5 para. 33.

<sup>67</sup> For example: R. Townsley, *supra* note 56; G. Quinn and S. Doyle, *supra* note 64; C. Parker, *supra* note 64; 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>68</sup> C. Parker, *supra* note 64; G. Quinn and S. Doyle, *supra* note 64.

<sup>69</sup> T. Hammarberg, *The right of people with disabilities to live independently and be included in the community* (June 2012), at 11.

<sup>70</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’.

### **C. 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 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 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.<sup>71</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>71</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>72</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>73</sup> This critique has been shared by many other disability studies scholars. 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>74</sup> Tom Shakespeare has challenged the dichotomy on the basis that both are socially constructed and inextricable interconnected.<sup>75</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>76</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>77</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 higher support needs are mentioned in the preamble,<sup>78</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

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<sup>72</sup> J. Morris, 'Impairment and disability: constructing an ethics of care which promotes human rights', 4 *Hypatia* (2001), at 17.

<sup>73</sup> M. Corker and S. French, *Disability Discourse* (1999), at 6.

<sup>74</sup> Hughes and Paterson, 'The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment', 3 *Disability & Society* (1997).

<sup>75</sup> T. Shakespeare, *Disability Rights and Wrongs* (2006), at 35-36.

<sup>76</sup> M. Oliver, *supra* note 39, at 38.

<sup>77</sup> M. Oliver, *supra* note 39, at 42.

<sup>78</sup> Preamble, para. j) CRPD

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>79</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>80</sup> In addition, it is referred to five times in such various contexts such as discrimination,<sup>81</sup> awareness raising,<sup>82</sup> recovery from violence,<sup>83</sup> inclusive education<sup>84</sup> and care delivery by health professionals.<sup>85</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>86</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 which can be detrimental to human dignity. Thus, the CRPD is not only built 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 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

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<sup>79</sup> Petersen, ‘Human Dignity, International Protection’, in R. Wolfrum (ed), *The Max Planck encyclopaedia of public international law* (2012).

<sup>80</sup> Art. (1), (3)(a) CRPD.

<sup>81</sup> Preamble, para. h) CRPD.

<sup>82</sup> Art. 8(1) (a) CRPD.

<sup>83</sup> Art. 16(4) CRPD.

<sup>84</sup> Art. 24(1)(a) CRPD.

<sup>85</sup> Art. 25(d) CRPD.

<sup>86</sup> Preamble, para. a) CRPD.

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>87</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>88</sup> and says if rights are trumps ‘then dignity is the key that turns the lock and allows entry into society and requires that each person be treated with equal concern and respect in that society’.<sup>89</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>90</sup> 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 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 analyse politics of disablement as the denial of social and cultural recognition, which is an aspect of the critique of the social model of

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<sup>87</sup> G. Quinn and T. Degener, *supra* note 37, at 14.

<sup>88</sup> R. Dworkin, *Taking rights seriously* (1978).

<sup>89</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>90</sup> A. Honneth, *The struggle for recognition* (1996).

disability.<sup>91</sup> The human rights model of disability demands that impairment is recognized in theories of justice. Whether these are social contract theories or take a capability approach or take an ethics of care as their basis is another matter.

#### **D. 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 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>92</sup> Like deaf or hard of hearing persons, blind and deaf blind people were among the first groups who created their own organizations who are still operative today<sup>93</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

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<sup>91</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.

<sup>92</sup> P. Ladd, *Understanding deaf culture* (2003); M. Corker, *Deaf transitions* (1996).

<sup>93</sup> World Blind Union (<http://www.worldblindunion.org/English/Pages/default.aspx>), World Federation of the Deaf (<http://wfdeaf.org/>)

model of madness, way before the CRPD came into being.<sup>94</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>95</sup> Disabled people of colour followed<sup>96</sup> and others like Ayesha Vernon raised the issue of intersectional discrimination and multi-dimensional oppression.<sup>97</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 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 care takers or child-bearers are commonly denied to disabled individuals.<sup>98</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>99</sup> but it has been admitted that the social model of disability was not intended to cover all different experiences of oppression.<sup>100</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>101</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

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<sup>94</sup> Beresford, 'Madness, Distress, Research and a Social Model', in C. Barnes and G. Mercer (eds), *Implementing the social model of disability* (2004).

<sup>95</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 72.

<sup>96</sup> C. M. Bell, *Blackness and Disability* (2011).

<sup>97</sup> Vernon, 'Multiple Oppression and The Disabled People's Movement', in T. Shakespeare (eds), *The Disability Reader* (1998).

<sup>98</sup> Silvers, 'Triple Difference: Disability, Race, Gender and the Politics of Recognition', in L. A. B. Marks and M. Jones (eds), *Disability, Divers-ability and Legal Change* (1999).

<sup>99</sup> M. Oliver, *supra* note 39, at 70-78.

<sup>100</sup> M. Oliver, *supra* note 39, at 39.

<sup>101</sup> R. Burke, *'Decolonization and the Evolution of International Human Rights'* (2010); C. Bob, *'The International Struggle for New Human Rights'* (2009).

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 has been called the personification<sup>102</sup> and the pluralization<sup>103</sup> 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, 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>104</sup> and Catherine MacKinnon<sup>105</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

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<sup>102</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>103</sup> C. C. Gould, *Globalizing democracy and human rights* (2004), at 77.

<sup>104</sup> C. Chinkin and H. Charlesworth, *Feminist analysis of international law* (1998).

<sup>105</sup> C. A. MacKinnon, *Toward a feminist theory of the state* (1989).

that this legal doctrine stabilizes patriarchal subordination. Feminist critical race lawyers such as Mari Matsuda<sup>106</sup> and Angela Harris<sup>107</sup> 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’.<sup>108</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>109</sup> and that the issue of intersectionality of discrimination has yet to be solved.<sup>110</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>111</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>112</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>113</sup> For these and

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<sup>106</sup> M. J. Matsuda, *Where is your body?* (1996).

<sup>107</sup> Harris, ‘Race and Essentialism in Feminist Legal Theory’, 3 *Stanford Law Review* (1990).

<sup>108</sup> Mégret, *supra* note 103, at 497 (emphasis in the original).

<sup>109</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>110</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>111</sup> Art. 6 and Art. 7 CRPD.

<sup>112</sup> Preamble, paras. 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>113</sup> Preamble, para. p) CRPD.

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.’<sup>114</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>115</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>114</sup> Art. 30(4) CRPD.

<sup>115</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.

### ***E. 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 which aims at eliminating disabled persons. Michael Oliver has characterized these programmes as the core of ideological construction of disability.<sup>116</sup> 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.<sup>117</sup> This particular difficult subject also came up during the negotiations of the CRPD but was

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<sup>116</sup> M. Oliver, *supra* note 33, at 54-59.

<sup>117</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).

dropped due to time pressure and the unlikelihood to achieve a compromise on this matter with pro-life advocates<sup>118</sup> and many feminists in the room.

Unlike the UN World Programme of Action Concerning Disabled Persons (WPA) of 1982<sup>119</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>120</sup> Especially the WPA has been influenced not only by an upcoming international disability rights movement,<sup>121</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>122</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>123</sup> The WPA even includes a paragraph on the cost effectiveness of prevention programmes: ‘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**’.<sup>124</sup>

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<sup>118</sup> The Holy See is a permanent observer state at the UN and the delegation took a very active role in this matter.

<sup>119</sup> WPA A/37/351/Add.1 and Add.1/Corr.1, annex

<sup>120</sup> WPA, para. 13 and 52-56; StRE, para. 22.

<sup>121</sup> D. Driedger, *The Last Civil Rights Movement* (1989), at 97-99.

<sup>122</sup> WPA, para. 54.

<sup>123</sup> WPA, para. 54.

<sup>124</sup> WPA, para. 55 (emphasis added).

The WPA has been criticized for perpetuating the medical model of disability.<sup>125</sup> While the WPA and StRE are both referenced in the preamble of the CRPD,<sup>126</sup> prevention does not appear prominently in the text of the treaty. This was a deliberate decision taken during and before the negotiations.<sup>127</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>128</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>129</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, and increased rates of health risk behaviour.<sup>130</sup> This is also recognized in the CRPD in the context of the right to health. There prevention is addressed not with relation to primary prevention but to secondary prevention programmes to ‘prevent further disabilities including among children and older persons’.<sup>131</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:

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<sup>125</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>126</sup> Preamble, para. f), CRPD

<sup>127</sup> Trömel, *supra* note 35, at 120.

<sup>128</sup> Art. 12 ICESCR.

<sup>129</sup> T. Shakespeare, *supra* note 76, at 103-117.

<sup>130</sup> World Health Organisation/World Bank, *World Report on Disability* (2011), at 57-60.

<sup>131</sup> Art. 25(b) CRPD.

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>132</sup>

### ***F. 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>133</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>134</sup> There is now abundance of evidence that impairment and poverty are mutually reinforcing.<sup>135</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 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>136</sup> The United Nations, the World Bank and other development agents have long acknowledged that disability is a development issue,<sup>137</sup> however, disability was not mainstreamed in development policies. Thus, disability was initially not recognized as one of the issues in the

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<sup>132</sup> World Health Organisation/World Bank, *supra* note 131, at 8.

<sup>133</sup> M. Oliver, *supra* note 33, at 12-13.

<sup>134</sup> T. Shakespeare, *supra* note 76, at 34-35.

<sup>135</sup> World Health Organisation/World Bank, *supra* note 131, at 10-11.

<sup>136</sup> C. Barnes and G. Mercer, *The social model of disability* (2005), at 15; D. Driedger, *supra* note 122; 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>137</sup> J. Braithwaite and D. Mont, *Disability and Poverty: A Survey of World Bank Poverty Assessments and Implications* (February 2008).

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>138</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 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 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 circumstances, it was amazing to reach consensus on the text of these articles.<sup>139</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 which make up the UN common understanding of the human-rights

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<sup>138</sup> Trömel, *supra* note 35, at 132.

<sup>139</sup> Actually, because consensus could not be reached 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 35, at 125.

based approach to development cooperation which was adopted in 2003.<sup>140</sup> While the new rights based approach in development is not without shortcomings,<sup>141</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>142</sup>

### **3. Outlook**

My intention is not to abandon the social model of disability as Tom Shakespeare has recommended some years ago.<sup>143</sup> He has been strongly criticized for this proposal and I would dare to say that history has proved him wrong. 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>144</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

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<sup>140</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>141</sup> Cornwall and Nyamy-Musembi, 'Putting the 'rights-based' approach to development into perspective', 8 *Third World Quarterly* (2004).

<sup>142</sup> *Global Thematic Consultation on the Post-2015 Development Agenda* (February 2013).

<sup>143</sup> T. Shakespeare, *supra* note 76.

<sup>144</sup> Kayess and French, *supra* note 35, at 7.

legal reform. As Rannveig Traustadóttir, Mark Priestley and Tom Shakespeare<sup>145</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>146</sup> In addition to social, cultural<sup>147</sup> and individual models of disability, theories of disability have been divided into materialist and idealist typologies.<sup>148</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 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>149</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>150</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>145</sup> T. Shakespeare, *supra* note 76, at 9-28.

<sup>146</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>147</sup> Waldschmidt, 'Disability Studies: Individuelles, soziales und/oder kulturelles Modell von Behinderung?', 1 *Psychologie und Gesellschaftskritik* (2005).

<sup>148</sup> Priestley, 'Constructions and Creations: Idealism, materialism and disability theory', 1 *Disability & Society* (1998).

<sup>149</sup> G. Quinn and T. Degener, *supra* note 37, at 256-270.

<sup>150</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, paras. 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, paras. 9-10, 16, 54.

#### **4. Conclusions**

The CRPD Committee already faces a backlog of nine years relating to the review of state reports which is currently the highest backlog among all treaty bodies. The CRPD has become a victim of its own success. The ratification rate is among the highest, however the rate of overdue reports is 60%. It is hoped that these insufficiencies will be overcome once the agreed recommendations of the ongoing treaty body strengthening process are permuted.

In contrast to its nine sister human rights treaties, the CRPD contains some innovations in international human rights law which demand specific efforts from member states. Examples are the three-tiered national monitoring system,<sup>151</sup> which includes the establishment of state focal points and coordination systems, the designation of independent monitoring bodies and the participation of civil society. Member states have chosen different approaches to national monitoring of which some do not comply with the CRPD and the referenced Paris Principles. Another challenge is to implement the non-discrimination clause<sup>152</sup> of the CRPD which exceeds the hitherto existing definition of discrimination in international law. Denial of reasonable accommodation is a form of disability discrimination which often is not yet reflected in domestic anti-discrimination legislation. In addition, state parties have problems to comprehend the difference between the duty to provide reasonable accommodation and the duty to provide accessibility.<sup>153</sup> The first is individual related and the latter group oriented and different review standards apply. Another challenging provision is Article 12 CRPD which presumes all disabled persons to have legal capacity and to exercise it. Often, state parties do not comprehend the radical change that is necessary in order to break the vicious circle of substituted decision making that is an essential component of guardianship and mental health laws. The base challenge, however, underlying all other tests of the CRPD is to understand the human rights model of disability which is codified by the CRPD.

I opine that the human rights model of disability goes beyond the social model of disability for six reasons:

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<sup>151</sup> Art. 33 CRPD.

<sup>152</sup> Art. 2 and 5 CRPD.

<sup>153</sup> Art. 9 CRPD.

Firstly, 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.

Secondly, whereas the social model serves as the philosophical basis for anti-discrimination policy and citizenship, the human rights model of disability encompasses both civil and political as well as economic, social and cultural rights.

Thirdly, 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, the human rights model of disability acknowledges these life circumstances and demands them to be considered when social justice theories are developed.

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 identification.

Fifthly, 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.

Finally, 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.

To implement the CRPD means to adopt a disability policy that is firmly grounded on the human rights model of disability. The primary implementation tool to achieve this goal is to adopt a national disability strategy that accords to critical success factors.<sup>154</sup>

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<sup>154</sup> Such as elaborated by E. Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (2011).

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## The CRPD and the Role of Organizations of Persons with Disabilities

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### Executive Summary

The present contribution seeks to highlight the vital contribution that representative organizations of persons with disabilities (Disabled Peoples' Organizations, DPOs) made during the negotiation process of the UN Convention on the Rights of Persons with Disabilities (CRPD) and how this active role has evolved in the phase after the adoption and entry into force of the CRPD.

### 1. Initial Stages of the Process towards the CRPD

#### *A) First Ad Hoc Committee Meeting<sup>1</sup>*

There were two main contributions that organizations of persons with disabilities (DPOs) made during the first session of the UN Ad Hoc Committee (AHC), established by the UN General Assembly<sup>2</sup> to consider proposals towards a thematic Convention on the Rights of Persons with Disabilities; a) they made a strong and clear case to support that there was a need for such a Convention; b) they requested that the Convention should be negotiated with a strong involvement of persons with disabilities through their representative organizations.

**Support for a Thematic Convention.** The main issue discussed during the first session was the need to have a specific treaty dealing with the rights of persons with disabilities. It was argued by some that other human rights treaties already included all persons; hence persons with disabilities were already being considered in the human rights' machinery. DPOs

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<sup>1</sup> The first session was held between 29 July and 9 August 2002. This is the link to the documents of the first AHC meeting: <http://www.un.org/esa/socdev/enable/rights/ahc1.htm>

<sup>2</sup> General Assembly resolution 56/168 of 19 December 2001.

contested that while the existing human rights treaties in theory did not exclude persons with disabilities (the Convention on the Rights of the Child includes a specific article on children with disabilities), the practical evidence showed that the human rights machinery had paid little attention to persons with disabilities, both because of a low level of involvement by DPOs in the existing processes, but also because of low level of awareness and knowledge among mainstream treaty body experts on the human rights violations faced by persons with disabilities.

The testimonies made by a good number of DPO representatives showed that there was a wide range of human rights violations faced by persons with all types of disabilities and in all different regions of the world. Examples were very diverse: deprivation of liberty based on disability, institutionalization because of the lack of alternative services, inaccessible websites, lack of recognition of sign languages and many other examples.

**DPO Participation.** The other key message that DPO representatives made from the beginning during the first AHC session was that a thematic Convention on the Rights of Persons with Disabilities could only be negotiated with the active involvement of persons with disabilities themselves. Time had passed where disability issues were mostly defined by so-called (usually medical) experts. Persons with disabilities, while not necessarily experts on human rights treaties, were definitely the best experts on the human rights violations they faced. A message and request that was soon to become a slogan that was used again and again by the DPO representatives: Nothing about us without us.

This request for participation was crystallized already in the resolution of modalities of NGO participation, adopted by the AHC at the end of the session. This was a very sensitive approach, given member states' reservations to allow for NGO participation; then, to be able to reach agreement on the resolution, it was explicitly stated that it would not set a precedent for other UN processes. By then no one could have imagined the extraordinary impact this resolution would have on the process and on the final content of the CRPD.

While the modalities included the possibility of closed meetings only among states, this option was only used in a couple of occasions during the first and last session of the Ad Hoc

Committee. NGOs were able to attend all sessions, listen to all presentations and make interventions at the end of each discussion.

Last but not less important, the DPOs and NGOs present at this first session also benefitted from the session to meet with each other and to start strategizing on how to ensure an effective impact on the process. Coordinating with each other and trying to speak as much as possible with one voice soon emerged as key elements to be successful.

### ***B) Second Ad Hoc Committee Meeting***

The start of the second session of the Ad Hoc Committee, held in June 2003, was somewhat surprising: the vast majority of states indicated their support to having a Convention on the Rights of Persons with Disabilities and gave their green light to start negotiating the text.

**Creation of the International Disability Caucus.** During this second session, the DPOs and NGOs decided to establish a virtual network which initially was called IDCC (International Disability Convention Caucus), later to be simplified into the International Disability Caucus (IDC). Some internal discussions were needed to define who could become a member of the Caucus. The main discussion was if only DPOs could be members of the IDC or also other Civil Society Organizations, including those working in the area of disability. This discussion could have put in risk the cohesion of the group. However, a good compromise was struck to define the membership of the Caucus open to DPOs as well as allied NGOs, which meant NGOs committed to the Convention process and who accepted the leadership by DPOs.

**The Working Group.** In order to advance the process of producing a first version of the Convention, the AHC discussed the need to establish a working group, which would produce a first draft text to become the basis for the future negotiation. When the IDC became aware of this proposal, it immediately requested to have a significant presence on this working group. More specifically, the Caucus requested twelve seats, in order to allow one seat for each of the existing global disability organizations and one seat per region.

The final decision of the Ad Hoc Committee was to set up a *working group* of 40 representatives, 27 from states (distributed among the five UN regions), 12 for representatives

of disability organizations and one representative from national human rights institutions.<sup>3</sup> Undoubtedly, an important success for the disability organizations, but now the challenge was linked to the selection of the representatives from such organizations.

The decision on the selection of the 12 representatives was to be taken by the Secretariat of the UN following requests to be received from DPOs and NGOs. This could have led to a fierce competition among members of the Caucus and put in jeopardy the still incipient coordination that was happening within the group. To overcome this, it was agreed that all Caucus members would jointly present a list of twelve names. This list, which was set up and agreed via electronic means, was accepted in its totality by the UN Secretariat.

To accomplish its mission of elaborating the first draft of the Convention, a working group meeting was scheduled for January 2004. With the aim of strategizing on key issues, agreeing on a coordinated advocacy strategy and learning from each other's positions and key demands, the European Disability Forum, sponsored by Fundación ONCE, organized a meeting of the 12 IDC representatives in the working group in Madrid in December 2003. Thanks to this meeting, the IDC representatives were able to significantly influence the draft document, which already included the most relevant innovative provisions that would make the Convention the advanced human rights treaty it is.

The working group meeting successfully prepared the first draft of the Convention in a very participatory manner. The participation of all working group members was equally relevant, no distinction being made between working group members representing states and those representing disability organizations. It should also be highlighted that a number of states were represented by persons with disabilities. The Chair of the working group was New Zealand's Ambassador Don McKay, who, thanks to his remarkable diplomatic skills, was to become a key player in the negotiation process. From the very beginning, Ambassador McKay showed great respect for the work of the representatives of disability organizations.

## **2. Influencing the CRPD Negotiation Process**

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<sup>3</sup> For a list of the members of the Working Group, visit the following link: <http://www.un.org/esa/socdev/enable/rights/ahcwg.htm#membership>

### ***A) IDC Presence in the Discussions***

Once the draft document was ready it was sent back to the AHC by the working group, to enable broader discussion of the text, which was done in the sessions 3 to 8 of the AHC.

The level of recognition by states of the IDC grew from meeting to meeting. It is fair to say that at the beginning of this second stage of the process, most state representatives paid little attention to the interventions from IDC representatives, which were carried out at the end of each discussion item, often preceded by long statements by the different state representatives.

The IDC was very careful when choosing its representatives to ensure disability diversity (it was probably the first time that many state representatives had been addressed by a deaf person using a sign language interpreter), regional diversity and gender balance. It was a clear objective of the IDC to show to states the coordinated view and voice of the disability community on the varying issues, in order to avoid giving the impression that there were different positions. There were obviously diverging views on a number of issues, but these views were usually settled in the internal meetings that the IDC held on a daily basis.

The influence that the IDC had on the process was well reflected in the seventh session (January-February 2006). Being aware that the process was coming to an end, the IDC had prepared a very detailed contribution, making proposals on each and every draft article. It was very impressive to see the large number of state delegates that referred back to the IDC proposals when making their own contributions.

Apart from the impact on the content of the Convention, the IDC also took a strong stand on the need for the process to be completed within a reasonable time frame. IDC representatives were aware that the negotiation process of the Convention on the Rights of the Child had taken almost ten years. IDC representatives stressed clearly that people with disabilities could not wait for so long. Beyond this political message, there was also the feeling that time could play against our interests, as much of the good progress that had been made was in risk of being revised if state delegations started to replace their representatives.

When Ambassador McKay brought the Convention for its final adoption in August 2006, he highlighted the contribution made by representatives from disability organizations by stressing that, according to him, 70% of the text of the Convention was based on proposals made by the disability organizations.

### ***B) Influence on the Innovative Provisions of the CRPD***

While the IDC contributed and influenced each and every article of the CRPD, as well as its preamble, the most relevant contribution from the IDC is to be found in the innovative provisions of the Convention, those that embody the paradigm shift that so many refer to when speaking about the Convention. I will present some of these very briefly.

Article 12 on equal recognition before the law, is probably the most relevant and groundbreaking of the provisions of the CRPD and the IDC fought for it until the very last moment, advocating for the deletion of a footnote that would have rendered the content of this article meaningless in a large number of countries. Article 12 translates into the need for an absolute revision of all legislations in the world, as none of them fully meets the provisions of Article 12. The fact that Civil Codes and other similar laws shall no longer allow that people with disabilities (usually intellectual and psychosocial) are deprived of their legal capacity and be put under guardianship, is a major breakthrough and has profound implications also on other rights foreseen in the Convention, like the right to access health services based on informed consent and the right to live in the community.

Similarly relevant and innovative, the combined impact of Article 14 on Liberty and Security of Person and Article 17 on Protecting the integrity of the person will require all mental health laws to be revised, which foresee the deprivation of liberty (usually in form of civil commitment) of persons that are “accused” to be a danger for themselves or for others. The IDC would have liked a more explicit prohibition of any form of forced treatment and institutionalization in Article 17, but the price would have been to accept a reference allowing for exceptional circumstances and pertinent safeguards in which these measures would be allowed. The IDC position was clear that there should be no exceptions.

Article 19 on Living in the community is an especially important provision, as it should lead to an end to all institutions in which so many people with disabilities still live, either because they are forced to live there or because of lack of alternative services in the community. It is also an interesting provision because it elaborates what one could define as a new right, as the notion of living in the community is so evident for the rest of the society that there had been no need to recognize it explicitly in any previous human rights treaty. It should serve as inspiration to the (possible) future convention on the rights of older persons.

Article 32 on International Cooperation makes the CRPD the first human rights treaty that includes a specific article referring exclusively to the obligation of international cooperation and that develops the content and suggested measures of such cooperation in the context of persons with disabilities. This article was strongly opposed by the European Union and other developed countries, as on the one hand, they were concerned about the financial obligations it would entail, but on the other, because they insisted that the lack of international cooperation should not be used as an excuse for inaction. IDC supported this last point, but stressed very clearly that this article should lead to a significant change in the area of international cooperation, in order to ensure that development funds, and other means of international cooperation are used in a disability-inclusive way.

A very relevant provision of the CRPD is its recognition both in Article 4 on General Obligations and in Article 33 on Implementation and Monitoring, on the need to consult and involve persons with disabilities through their representative organizations of persons with disabilities. The involvement during the negotiation process should obviously be replicated during the implementation phase at the national level.

Other areas that benefitted immensely from the proposals and advocacy work made by IDC were:

- The “definition” of persons with disabilities and the fact that disability is an evolving concept
- The exclusion of any reference to the primary prevention of disability
- The denial of reasonable accommodation as a form of discrimination

Another innovative element of the CRPD, Article 33 on Implementation and Monitoring, was largely the proposal from the network of national human rights institutions that followed the negotiation process and who benefitted from the space that disability organizations had created for non-state stakeholders to effectively participate in the negotiation process.

### **3. Impact of the CRPD on UN Processes**

#### ***A. Mainstreaming Disability Rights in the UN System***

*The role of the International Disability Alliance.* One concern that had been expressed when the negotiation process of the CRPD started, was that a thematic Convention with its own monitoring Committee could undermine the mainstreaming of disability rights in the mainstream human rights processes, in particular the take-up of disability rights by the UN Treaty Bodies in charge of monitoring the other UN human rights treaties.

The experience since 2008, when the CRPD entered into force, shows that this concern was ill-founded, as in fact the CRPD has led, not the least due to the advocacy work done by the International Disability Alliance (IDA),<sup>4</sup> to an increase in the attention by other UN Treaty Bodies to the rights of persons with disabilities. While there are still some concerns on recommendations that are not fully consistent with the CRPD, especially from the Human Rights Committee, the visibility of disability rights has increased significantly, also thanks to the increased involvement of national organizations of persons with disabilities in these mainstream human rights monitoring processes.

The CRPD and the advocacy work of the IDA and its member organizations has also led to a remarkable number of disability-related recommendations in the Universal Periodic Review (UPR) process that the Human Rights Council initiated in 2008. The increasing involvement of national DPOs in the UPR process has also often led to the establishment of alliances at

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<sup>4</sup> IDA members include the Arab Organization of People with Disabilities, Down Syndrome International, Disabled Peoples' International, European Disability Forum, Inclusion International, International Federation of Hard of Hearing, Latin American Network of Non Governmental Organizations of Persons with Disabilities and their Families, Pacific Disability Forum, World Blind Union, World Federation of the Deaf and World Federation of the Deaf-Blind and the World Network of Users and Survivors of Psychiatry.

national level with other human rights organizations. This is an important development, as until recently disability organizations were not considered as human rights organizations.

IDA, as well as other organizations like Human Rights Watch, Disability Rights Fund and the Mental Disability Advocacy Center, has supported the work of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee). The main objective of IDA has been to ensure the highest possible standard of openness by the Committee to reports from national DPOs in order to complement the information included in state reports. For all the countries that have been reviewed so far, IDA has facilitated the submission of information from national DPOs and has promoted face to face meetings between national DPO representatives and the CRPD Committee. The work done by IDA has been highly valued by the CRPD Committee and has had a significant impact on the concluding observations adopted so far by the Committee.

IDA has followed closely the Human Rights Council sessions and promoted references to persons with disabilities in a good number of mainstream resolutions and in particular attended the negotiations of the annual resolution on the rights of persons with disabilities, which is adopted at the March session of the Human Rights Council. This resolution requests each year the Office of the High Commissioner for Human Rights (OHCHR) to produce a thematic report on a specific area of the CRPD. The thematic reports of the OHCHR, to which IDA has made a contribution each year, have taken a progressive interpretation of the CRPD, especially in some of the most challenging and innovative areas.

IDA has played a key role in the holding of the annual Conference of States Parties to the CRPD. Different to other human rights treaties, the CRPD foresees the possibility for this conference to have a role beyond the (re) election every second year of the CRPD Committee. IDA worked from the very beginning to ensure that this possibility was fully used. The Conference of States Parties, which is now also being preceded by a one day Civil Society CRPD Forum, has become the most important global annual meeting bringing together all stakeholders interested in the implementation of the CRPD.

IDA has contributed to the increased attention to the rights of persons with disabilities within the UN system. Especially to be highlighted is the establishment of the so-called UN

Partnership on the Rights of Persons with Disabilities (UN PRPD), a Multi Donor Trust Fund that seeks to promote the disability rights mainstreaming in the work of UN country teams and the establishment of partnerships with representative national DPOs. IDA was instrumental in the establishment of this initiative and is an active member of its policy board and management committee.

### ***B) The CRPD at National Level***

However, the big challenge for the implementation of the CRPD is at national level, in particular in developing countries. The challenge in this respect is daunting and IDA can only aim to make a small contribution to this by providing focused technical assistance on the one hand and on the other, by initiating an ambitious capacity building initiative.

IDA started its activities in this area with a strong focus on supporting national DPOs to prepare parallel reports to the CRPD Committee and to other UN human rights monitoring processes. Especially in developing countries to be reviewed by the CRPD Committee, IDA organizes workshops for national DPOs in order to explain to them the reporting process, clarify, when needed, the content of the CRPD and encourage them to prepare a coordinated submission to the Committee, which should address all relevant issues and pay special attention to the situation of women, children and, where relevant, indigenous persons with disabilities.

While this continues to be a priority, it immediately became clear that national DPOs were and are desperately seeking support to help with the implementation of the CRPD. This has led to the design of a more ambitious capacity building strategy that should increase the pool of trainers and advisors in all regions that can provide strategic advice to national DPOs on the implementation of the CRPD.

### ***4. Concluding remarks and some future challenges***

The negotiation process of the CRPD was a success story from the point of view of most disability organizations. It showed the relevance and value of a coordinated advocacy strategy, a lesson that is also relevant for the implementation of the Convention at national

level. The human rights approach to disability can be an important unifying element among different disability constituencies.

It should be noted that as of now (September 2015), 157 states have ratified the CRPD and 159 have signed it, which will soon place the CRPD among the human rights treaties with the highest number of ratifications. This brings a tremendous opportunity to substantially advance the rights of persons with disabilities worldwide, but it also brings huge challenges.

The many references to persons with disabilities in the Sustainable Development Goals (SDGs) adopted by the UN in September 2015, should provide additional impetus to the achievement of the rights foreseen in the CRPD. The immediate next step will be to have disability-specific and disability-disaggregated indicators that will measure progress in the achievement of the SDGs, so that persons with disabilities are not left behind.

# The UN Convention on the Rights of Persons with Disabilities as an “Integral Part” of EU Law

Delia Ferri\*

**Abstract:** *Building on an ongoing reflection started in 2009, and being part of a broader research, this short paper focuses on the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as a source of EU law. In particular, it investigates the status and the effects of the UNCRPD on the EU legal order, considering that it is a human rights treaty but also a mixed agreement. After some introductory remarks, the status of the UNCRPD will be considered. Then, the effects of the UNCRPD provisions within the EU legal order will be discussed, in light of the most recent CJEU case law. The detection of certain trends in this case law allows to draw some tentative conclusions.*

**Keywords:** Mixed agreements; United Nations Convention on the Rights of Persons with Disabilities; Status of the UNCRPD in EU law; Effects of the UNCRPD

## 1. Introduction

Almost eleven years ago, in 2001, the UN General Assembly took the decision to develop an international rights-based treaty on disability. For this purpose, it established an Ad Hoc Committee to draft a foundational text that formed the basis of future negotiations. Five years later, on December 13, 2006, the UN Convention on the Rights of Persons with Disabilities (UNCRPD), together with its Optional Protocol, was adopted by the UN General Assembly.<sup>1</sup>

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This short paper is based on the speech given at the workshop organized by the European University Institute on April 27, 2012, and takes into consideration the legal developments till 10 July 2013. It is part of an ongoing research on the status and effects of the UNCRPD in the EU legal order. Special thanks go to Sondra Faccio, and Ms Aisling de Paor for the language revision of the first version of this paper and helpful comments. The usual disclaimer applies.

<sup>1</sup> On the Convention, see *ex pluribus* Kayess and French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’, *Human Rights Law Review*, (2008), 1.

It is widely recognized that the UNCRPD has been the most rapidly negotiated UN treaty, and one of the most ground-breaking pieces of legislation in the field of human rights. Whilst the Convention does not seek to create new rights for persons with disabilities, it is innovative because it elaborates and clarifies existing human rights within the disability context. It aims at ensuring the active participation of persons with disabilities in political, economic, social, and cultural life, by accommodating their difference. The Convention fills an important gap in international law, and it is not an exaggeration to call it revolutionary: it is the first legally binding instrument reflecting the ‘social model’ of disability, i.e. the view that disability stems primarily from the failure of the social environment to meet the needs of people with disabilities, and not the narrower and traditional medical model.<sup>2</sup>

For these reasons, since its adoption, the UNCRPD has received widespread support from NGOs representing people with disabilities and scholars. Irrespective of the fact that it is quite demanding, requiring Parties to challenge and ultimately change their “disability policy”, the UNCRPD has also obtained wide support from several states all over the world. On 26 November 2009, the European Community (now of course the European Union, or the “EU”) also acceded to this Convention.<sup>3</sup> This decision to conclude the UNCRPD has been positively welcomed by both NGOs and scholars, relying on the fact that the Convention was the first (and, until the Union accedes to the European Convention on Human Rights –ECHR–, it remains the only) human rights treaty that the Union has negotiated, signed and ultimately concluded.<sup>4</sup> This view is not unanimously accepted: some lawyers assert that, in a broader sense, we could consider the EU as having already signed human rights treaties earlier on.<sup>5</sup> However, regardless of one’s view in that regard, it is plain that the decision to conclude the

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<sup>2</sup> See C. Barnes, G. Mercer, *Exploring Disability*, 2<sup>nd</sup> edn. (2010), *passim*. See also Harpur, ‘Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities’, *Disability and Society* (2012), 1.

<sup>3</sup> Council Decision 2010/48/EC, OJ 2010 L 23/35.

<sup>4</sup> In this sense, see Waddington, ‘The European Union and the United Nations Convention on the Rights of Persons with Disabilities: A Story of Exclusive and Shared Competences’, *Maastricht Journal of European and Comparative Law*, (2011) 431.

<sup>5</sup> See de Witte, ‘The EU and International Legal Order: The Case of Human Rights’, in M. Evans and P. Koutrakos (eds), *Beyond the established legal orders: policy interconnections between the EU and the rest of the world* (Oxford-Portland; Hart Publishing, 2011), at 127 and 135; B. de Witte, A.H. Trechsel, D. Damjanović, E. Hellquist, J. Hien, P. Ponzano, *Legislating after Lisbon*, EUI-EUDO, 2010, at <http://www.eui.eu/Projects/EUDO/Documents/EUDO-LegislatingafterLisbon%28SD%29.pdf>.

UNCRPD is the result of a long, slow and growing engagement with human rights.<sup>6</sup> Additionally, few observers interested in EU law could be unaware that the UNCRPD is of unquestionable significance and has had a vast influence on the content of the European Disability Strategy 2010-2020,<sup>7</sup> as well as on relevant legislative proposals under discussion, such as the text for a new non-discrimination directive.<sup>8</sup>

The appreciation of the UNCRPD meaning cannot be disconnected from the acknowledgment of the challenges the implementation process presents in the EU. Those challenges are related to the UNCRPD's nature as a broad human rights treaty, i.e. to the fact that the UNCRPD covers civil, political, economic, cultural and social rights, committing the Union to higher standards of rights protection, non-discrimination, accessibility and social inclusion. They are also linked to the mixed form of the UNCRPD in the EU legal order. It is well known that "mixity" refers to the fact that part of an international agreement falls within the scope of the powers of the EU, and part falls within the scope of the powers of the Member States. It is also well known how mixed agreements present themselves: they are signed and concluded by the EU and its Member States on the one hand, and by a third party on the other. Therefore, having regard to the UNCRPD, the legal justification for mixity is that the EU competences did not cover the broad scope of the entire agreement. "Mixed agreements" are a very complex topic of scholarly debate.<sup>9</sup> This is because their existence is deeply interrelated with the autonomy of the EU legal order and with the division of powers doctrines, and their effects may not always easily be understood. With respect to the UNCRPD, Waddington,

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<sup>6</sup> De Burca, 'The Road Not Taken: The EU as a Global Human Rights Actor', *Strauss Working Paper 09/10*, at <http://www.nyustra.org/pubs/0910/index.html>.

<sup>7</sup> *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, SEC (2010) 1324 fin. For a critical overview see G. Quinn and E. Flynn, 'Transatlantic Borrowings: The Past and Future of EU Non discrimination Law and Policy on the Ground of Disability', *Am. J. Comp. L.* (2012), 23.

<sup>8</sup> Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, COM (2008) 426 fin. On the proposed directive see Waddington, 'Future Prospects for EU Equality Law. Lessons to be Learnt from the Proposed Equal Treatment Directive' (2011) 35 *E. L. Rev.* 163.

<sup>9</sup> On mixity, see *ex multis* C. Hillion and P. Koutrakos (eds.), *Mixed Agreements Revisited*, (Oxford: Hart Publishing, 2010); P. Eeckhout, *External Relations of the European Union*, 2nd edn. (Oxford: Oxford University Press, 2011), at 212; Neframi, 'Mixed Agreements as a Source of European Union Law', in E. Cannizzaro, P. Palchetti, R.A. Wessel (eds.), *International Law as Law of the European Union*, (Leiden/Boston: Martinus Nijhoff Publishers, 2011); R. Holdgaard, *External Relations of the European Community*, (The Hague: Kluwer Law International, 2008), at 205; J. Heliskosky, *Mixed Agreements as a Technique for Organizing the International Relations of the European Community and its Member States*, (The Hague: Kluwer Law International, 2001); Rosas, 'Mixed Union-Mixed Agreements', in M. Koskeniemi (ed.), *International Law Aspects of the European Union*, (The Hague: Kluwer Law International, 1998), at 125.

while reflecting on the obligations binding the EU, concludes that the accession to the UNCRPD by the EU raises several unresolved issues.<sup>10</sup>

Building on an ongoing research started in 2009, and being part of a broader research, this succinct essay briefly focuses on the role of this UN Convention as a source of EU law. It investigates the status and effects of the UNCRPD as source of EU law, considering that it has both the content of a human rights treaty and the nature of a mixed agreement. In accordance with this narrow purpose, many questions pertinent to the field of EU external relations, e.g. those on the international responsibility of the Union, may be left aside.

The essay is structured as follows. After this introduction, the status of the UNCRPD is considered: Section 2 addresses the need to both discuss the relationship between sources of law in formal hierarchical terms and to take the content of norms into account. Section 3 is devoted to the effects of the UNCRPD provisions. The case law of the Court of Justice of the European Union (Court of Justice or CJEU) on international agreements offers a picture of the way in which international rules penetrate the EU legal order, and allows detecting certain general trends and challenges. The recent *Ring and Werge*<sup>11</sup> and *Commission v. Italy*<sup>12</sup> decisions prove important to analyse the specific role of the UNCRPD within the EU framework. Finally, Section 4 concludes.

The succinct discussion presented here is part of a wider reflection, and tries to suggest a pragmatic position that goes directly to the heart of the problems raised by the UNCRPD.

## 2. The Status of the UNCRPD in the EU Legal Order

### A. The UNCRPD as EU Law

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<sup>10</sup> Waddington, 'The European Union and the United Nations Convention on the Rights of Persons with Disabilities: A Story of Exclusive and Shared Competences', (2011)18 *Maastricht Journal of European and Comparative Law*, 431.

<sup>11</sup> *HK Danmark, acting on behalf of Jette Ring v Dansk almennyttigt Boligselskab* (C-335/11) and *HK Danmark, acting on behalf of Lone Skouboe Werge v Dansk Arbejdsgiverforening, acting on behalf of Pro Display A/S, in liquidation* (C-337/11), Joined cases C- 335/11 and C- 337/11, 11 April 2013, not yet published.

<sup>12</sup> *Commission v Italy*, Case C-312/11, 4 July 2013, not yet published.

The Treaties do not address in any great detail the relationship between EU law and international law. Art. 216(2) of the Treaty on the Functioning of the EU (TFEU, ex Art. 300(7) EC) simply stipulates that international agreements concluded by the Union are binding upon the institutions and its Member States. The Court of Justice has played a vital role in interpreting these provisions and in elaborating on the legal consequences of the EU's accession to international treaties, and more generally on the relationship between EU law and international treaty law. Beginning in the early 1970s, international treaties were considered to form "an integral part of Community law"<sup>13</sup> once they entered into force. As Wessel states, the notion that international law forms an integral part of EU law seems to be upheld by recent cases such as *Intertanko* and *Kadi*,<sup>14</sup> even if these cases equally make clear that it is EU law itself that sets the conditions for the validity of international norms within its legal order.<sup>15</sup> As regards the status of international agreements within the hierarchy of sources of law, the CJEU has argued that international treaties are situated formally below the provisions of the Treaties.<sup>16</sup>

The Court has also stated that mixed agreements 'have the same status of purely Community agreements, in so far as the provisions fall within the scope of Community competence'<sup>17</sup>, without really explaining what the scope of the (current) EU's power is. If the EU has not exercised its powers and adopted provisions to implement the international obligations, this would continue to be covered by the national law of the Member States. The CJEU has repeatedly held that a specific international provision, dealing with a matter that has not yet been the subject of EU legislation, is part of EU law where it nonetheless concerns a field in large measure covered by it.<sup>18</sup> However, the clarity of this statement remains arguable, since the Court has not specified what "large measure" means. In addition, as we will discuss in

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<sup>13</sup> *R. & V. Haegeman v Belgian State*, Case 181/73, [1974] E.C.R. 449, [5]. In this decision, the Court used the notion of incorporation, according to which provisions of international agreements are not transposed and do not need further validation. They become part of the EU legal order after the conclusion of the agreement, simply by entering into force.

<sup>14</sup> *Yassin Abdullah Kadi and Al Barakaat International Foundation v. Council of the European Union and Commission of the European Communities*, Joined cases C-402/05 P and C-415/05 P, [2008] E.C.R. I-6351.

<sup>15</sup> Wessel, 'Reconsidering the Relationship between International and EU Law: Towards a Content-Based Approach?', in E. Cannizzaro, P. Palchetti, R.A. Wessel (eds), *International Law as Law of the European Union*, (2011).

<sup>16</sup> *Commission v. Germany*, Case C-61/94, [1996] E.C.R. I-3989 [52].

<sup>17</sup> *Ex multis, Etang de Berre*, Case C-239/03, [2004] E.C.R. I-07357 [25].

<sup>18</sup> *Commission v France* Case C-239/03 [2004] ECR I-9325 [29].

Section 3, those international provisions that fall under the competence of the Member States (which, if infringed, could according to the declaration entail their international responsibility) may need to be interpreted by the CJEU in order to assure their uniform application throughout the EU. To that extent, these provisions might be considered a source of EU law.<sup>19</sup>

It appears that the question on whether or not a mixed agreement is, in its *entirety* or only *partially* a source of EU law, is still unresolved.

The presence of a declaration of competence by the EU Council in its decision concluding the UNCRPD does not seem to be helpful.<sup>20</sup> This is so because the declaration does not really clarify which UNCRPD provisions fall under the EU's competence, and also because most of the fields touched upon by the UNCRPD (e.g. non discrimination or accessibility) are, in "large measure" covered by EU law. It would be no exaggeration to say that the Convention can be regarded a source of EU law almost in its entirety, with the exception of few provisions, such as Art. 12 UNCRPD on legal capacity or Art. 10 on the right to life (which involves extremely delicate ethical concerns on abortion) which could be regarded as purely international sources.

### ***B. Could the UNCRPD "engrave" EU Primary Law?***

In hierarchical terms, mixed agreements (including the UNCRPD) are, as suggested above, inferior to the provisions of the Treaty on the Functioning of the European Union (and the Treaty on European Union), but they are superior to secondary EU law.<sup>21</sup> However, in EU law there is still an ambivalent attitude towards those international treaties that could be conceived 'international supplementary constitutions', i.e. international treaties 'that act

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<sup>19</sup> Neframi, 'Mixed Agreements as a Source of European Union Law', in E. Cannizzaro, P. Palchetti, R.A. Wessel (eds.), *International Law as Law of the European Union*, (2011), at 325-349.

<sup>20</sup> Annex II of Council Decision 2010/48/EC of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities, OJ 2010 L 23/25, available at <http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32010D0048&from=EN>.

<sup>21</sup> *Commission v. Germany*, Case C-61/94, [1996] E.C.R. I-3989 [52]; *Bellio F.lli Srl v. Prefettura di Treviso*, Case C-286/02, [2004] E.C.R. I-3465 [33].

alongside the constitutional order'.<sup>22</sup> On the one hand, the CJEU has used international human rights instruments as sources of inspiration for the development of the unwritten general principles of Union law, which are a part of primary EU law and a frequently used basis for interpreting EU acts.<sup>23</sup> On the other hand, the Court has conceived of the EU as an autonomous and “supreme” legal order. Especially in *Kadi*, the Court appears to refuse categorically the possibility that any international agreement could affect the EU Treaties.<sup>24</sup> It follows that, for all intents and purposes, international law and EU law are not on an equal footing but rather “asymmetric”. Any attempt to reverse this hierarchy of norms is vigorously rejected by the Court.<sup>25</sup> This is evident in *Microsoft*,<sup>26</sup> when the Court of First Instance (now the General Court) rejected the argument of the applicant, according to which Art. 82 EC (Art. 102 TFEU) had to be interpreted in the light of the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). The CFI held that ‘the principle of consistent interpretation [...] invoked by the Court of Justice applies only where the international agreement at issue prevails over the provision of Community law concerned. Since an international agreement [...] does not prevail over primary Community law, that principle does not apply where, as here, the provision which falls to be interpreted is Article 82 EC’.

It may be inferred that the UN Convention, like any other international treaty, cannot modify the “untouchable core” of fundamental rights, values, and principles which characterize the EU’s constitutional bedrock, and that there is no obligation to interpret the Treaties or the EU Charter of Fundamental Rights in a manner consistent with the UNCRPD.

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<sup>22</sup> Robert Uerpmann Wittzack in a recently re-published book considered the ‘constitutional role of multilateral treaty systems’, insisting on what he calls international supplementary constitutions, starting from the notion of “*Völkerrechtliche Nebenverfassungen*” (international supplementary constitutions), borrowed from Tomuschat. This expression translates the basic idea that sometimes national constitutions may contain gaps ‘which are filled by referring to international law’. From this standpoint, the author analyses the importance of international documents such as the European Convention on Human Rights and the WTO Agreements. See Uerpman Wittzack, ‘The Constitutional Role of International Law’, in A. Von Bogdandy and J. Bast (eds.), *Principles of European Constitutional Law*, (2<sup>nd</sup> edn), (Oxford: Hart Publishing, 2011), 131. See also Uerpmann Wittzack, ‘International Law as an Element of European Constitutional Law’, *Jean-Monnet Working Paper* 9/03, at <http://www.JeanMonnetProgram.Org/papers/03/030901-02.html>.

<sup>23</sup> *Laserdisken ApS v Kulturministeriet*, Case C-479/04, [2006] ECR I-8089, [61].

<sup>24</sup> *Kadi*, C-402/05 P and C-415/05 P, [2008] ECR I-635.

<sup>25</sup> Lavranos, ‘Article 307 EC: The Untouchable Core of Fundamental European Constitutional Law Values and Principles’, in F. Fontanelli, G. Martinico and P. Carozza (eds.), *Shaping Rule of Law through Dialogue*, (Groningen: Europa Law Publishing, 2010), 119, at 122.

<sup>26</sup> *Microsoft Corp. v. Commission*, Case T-201/04, [2007] E.C.R. II-3601, [798].

While this is correct from a formal point of view, one should be cautious of accepting this latter statement uncritically. The Convention is (in contrast to the TRIPS Agreement) a human rights treaty and represents a clarification of rights already conferred by pre-existing international instruments (e.g. the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights...), and recognized by the constitutional traditions of the Member States. It can take for granted that, *ex littera*, the UNCRPD is entirely consistent with the rights affirmed in the Charter of Fundamental Rights (which includes two explicit references to disability and contains other provisions likely to be of interest for persons with disabilities).<sup>27</sup> Thus, it may at least be argued that the UNCRPD, as a human right treaty to which the EU has acceded, could *prima facie* be ranked as a higher source of law: it could “integrate” those fundamental rights that are part of EU primary law according to Art. 6 TFEU and to the well-established case law of the CJEU. This means that (again, in contrast to the TRIPS Agreement) the UNCRPD would serve to aid the interpretation of the provisions of the Treaties, including above all the non-discrimination principle contained in Art. 19 TFEU, as well as the provisions of the Charter of Fundamental Rights.<sup>28</sup>

A first argument to support this view might be based on the text of the Charter. Art. 53 of the EU Charter<sup>29</sup> states that the EU has to observe the standard of protection imposed by international agreements to which the Union and/or the Member States are party (while the EU could set a higher standard autonomously). The Court has been reluctant to rely on other human rights treaties (other than the ECHR) to which it is not a party. Only sporadically, in

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<sup>27</sup> Art. 21 provides for the principle of non-discrimination, on the ground *inter alia* of disability. Art. 26 reads as follows: ‘The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community’.

<sup>28</sup> This paper does not discuss the scope of applicability of the EU Charter. It should nonetheless be recalled that, according to Art. 51(1), the Charter is binding on EU bodies and on Member States when they “are implementing Union law”. The requirement to respect fundamental rights exists in all situations where Member States are acting “within the scope” of Union law. However, EU lawyers tend to agree that it is not always clear when and whether national authorities are acting within the scope of application of EU law. On this issue, see, among others, Groussot, Pech and Petursson, ‘The Scope of Application of Fundamental Rights on Member States’ Action: In Search of Certainty in EU Adjudication’, (2011), available at <http://ssrn.com/abstract=193647>.

<sup>29</sup> Art. 53 reads as follows: ‘Nothing in this Charter shall be interpreted as restricting or adversely affecting human rights and fundamental freedoms as recognised, in their respective fields of application, by Union law and international law and by international agreements to which the Union, the Community or all the Member States are party, including the European Convention for the Protection of Human Rights and Fundamental Freedoms, and by the Member States’ constitutions’.

the most recent case law, references to international human rights instruments can be found.<sup>30</sup> However, this is not an issue here since the EU has acceded to the UNCRPD. The standards imposed by it must therefore be observed, and they are properly regarded as part of the EU's fundamental rights system.

A second ground is that the UNCRPD could be regarded as a source of binding rights standards indirectly through the jurisprudence of the European Court of Human Rights (ECtHR). It must be recalled that the ECtHR has referred to the UNCRPD in a few cases. For example, in *Kiyutin v. Russia*,<sup>31</sup> the Convention was cited just *a fortiori*. In a more recent case, however, the ECtHR went further and seemed to use it as an interpretative tool. In particular, in *Stanev v. Bulgaria*,<sup>32</sup> where the ECtHR was called on to apply Art. 6 ECHR, the court also relied on the UNCRPD: 'The Court is also obliged to note the growing importance which international instruments for the protection of people with mental disorders are now attaching to granting them as much legal autonomy as possible. It refers in this connection to the United Nations Convention of 13 December 2006 on the Rights of Persons with Disabilities and to Recommendation No. R (99) 4 of the Committee of Ministers of the Council of Europe on principles concerning the legal protection of incapable adults, which recommend that adequate procedural safeguards be put in place to protect legally incapacitated persons to the greatest extent possible, to ensure periodic reviews of their status and to make appropriate remedies available ... In the light of the foregoing, in particular the trends emerging in national legislation and the relevant international instruments, the Court considers that Article 6 §1 of the Convention must be interpreted as guaranteeing in principle that anyone who has been declared partially incapable, as is the applicant's case, has direct access to a court to seek restoration of his or her legal capacity'.<sup>33</sup>

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<sup>30</sup> *Viking Line Case* (C-438/05) [2007] ECR I-10779, [43–44]. See De Witte, 'The EU and International Legal Order: The Case of Human Rights', in M. Evans and P. Koutrakos (eds), *Beyond the established legal orders: policy interconnections between the EU and the rest of the world* (2011), 127, at 134.

<sup>31</sup> ECtHR, *Kiyutin v. Russia* (Application n. 2700/10), Decision of 10 March 2011.

<sup>32</sup> ECtHR, *Stanev v. Bulgaria* (Application no. 36760/06), Decision of 17 January 2012.

<sup>33</sup> Paras. 244 and 245.

Clearly, the EU/ECHR relationship is an area in which significant changes are currently taking place,<sup>34</sup> and the value of the ECHR<sup>35</sup> and of the ECtHR's case law is a vast topic to which many extensive studies have been devoted, and it cannot be covered fully here. Nonetheless, a few reflections in this regard should be noted.

The jurisprudence of the CJEU provides numerous examples of the guiding role of the ECHR. Art. 52(3) of the Charter obliges the EU to respect the ECHR, and to guarantee at least the same level of protection, where EU Charter rights and Convention rights are substantially the same. As the Court clarified in *McB*, in so far as the Charter contains rights which correspond to rights guaranteed by the ECHR, their meaning and scope are to be the same as those laid down by the ECHR. However, ECHR rights are generally considered to represent the "minimum standard", and Art. 52 does not preclude the grant of wider protection by EU law. The content and the meaning of ECHR rights emerge from the interpretation of the Strasbourg Court.<sup>36</sup> In recent times, the Court confirmed that the case law of the Strasbourg Court is taken into consideration in interpreting the scope of those rights provided for in the Charter. In *Schecke*,<sup>37</sup> for example, the Court of Justice clearly recognised its duty, under Art. 52(3), to take into account the jurisprudence of the ECtHR, and it actually did so in construing the meaning of "private life" (which includes professional information) under Art. 8 of the Charter. In that case the CJEU also introduced the proportionality test, citing ECtHR precedent and hinting at a synergy between the case law of the two courts. As Fontanelli points out, 'it is clear that reference to the ECtHR and its case-law is no longer a matter of

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<sup>34</sup> On the EU's accession to the ECHR, see, among others, Lock, 'Walking on a tightrope: the draft accession agreement and the autonomy of the EU legal order', 48 *Common Market Law Review* (2011), 1025.

<sup>35</sup> According to De Witte, Art. 6(3) TEU makes it clear that the Convention rights are being incorporated within the category of EU general principles. As De Witte underlines: 'Article 6(3) TEU gives formal binding status to the ECHR within the EU legal order, and it is quite curious that the Court of Justice and most of the legal literature have failed to draw that conclusion; perhaps this is due to a confusion between two separate legal questions: the question whether the European Union (and, until its recent demise, the European Community) is bound by the ECHR *under international law* (it is not, since it has not signed and ratified the Convention) and the question whether the ECHR is binding for the EU institutions *as a matter of European Union law* (this is so, in view of the unambiguous language of Article 6 TEU)'. De Witte, 'The EU and International Legal Order: The Case of Human Rights', in M. Evans and P. Koutrakos (eds), *Beyond the established legal orders: policy interconnections between the EU and the rest of the world* (Oxford-Portland; Hart Publishing, 2011), 127, at 130.

<sup>36</sup> *McB*, Case C-400/10 PPU, [2010] ECR I-8965.

<sup>37</sup> *Volker und Markus Schecke and Eifert*, Joined Cases C-92/09 and C-93/09, [2010] ECR I-11063.

nicety and comity but an actual precondition for the application of the Charter'.<sup>38</sup> The CJEU's case law also seems to reveal a determination to avoid divergent interpretation of EU law provisions with ECHR rights: in *Elgafaji*,<sup>39</sup> for example, the Court was asked the meaning of subsidiary protection of Art. 15(c) of the Asylum Qualification Directive<sup>40</sup> as compared with Art. 3 ECHR. In this case, while affirming that Art.15(c) of the Directive was different from Art. 3 ECHR, and that its interpretation was therefore to be carried out independently, the EU judges formally and clearly state that the interpretation was to be done with due regard for fundamental rights as guaranteed under the ECHR.

This leads to the conclusion that the ECtHR decisions on disability, based on the European Convention,<sup>41</sup> could set a minimum standard for rights of persons with disabilities, and since the ECtHR has recently started to cite the UNCRPD, its interpretation of the ECHR in compliance with (or rather, in light of) the UNCRPD could become "binding" to the EU. This would also mean that the UNCRPD would become a blueprint for EU human rights protection.

To sum up, it is argued here that the UNCRPD, irrespective of its formal sub-constitutional status, might be regarded as a part of the EU fundamental rights system and could even establish itself as being equivalent to EU primary law.

### **3. Invoking the UNCRPD as EU Law before the Court of Justice**

#### ***A. The Interpretation of the UNCRPD under the Preliminary Ruling Procedure***

The first and preliminary issue to be dealt with here is the jurisdiction of the Court of Justice to interpret the UNCRPD.

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<sup>38</sup> Fontanelli, 'The European Union's Charter of Fundamental Rights two years later', 3 *Perspective on Federalism* (2011), 39, available at [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2007831](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2007831) [Accessed January, 30, 2012].

<sup>39</sup> *Elgafaji v Staatssecretaris van Justitie*, Case C-465/07, [2009] E.C.R. I-00921.

<sup>40</sup> Council Directive 2004/83/EC of 29 April 2004, [2004] OJ L304/12.

<sup>41</sup> Björgvinsson, 'The Protection of the Rights of Persons with Disabilities in the Case Law of the European Court of Human Rights', in G. Quinn and O.M. Arnardottir (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, at 141.

The CJEU has firmly asserted its competence to interpret international agreements,<sup>42</sup> including mixed agreements,<sup>43</sup> under the preliminary ruling procedure. In the *Lesoochránárske zoskupenie VLK* case<sup>44</sup>, which concerned the Aarhus Convention, the CJEU stated that ‘where a case is brought before the Court in accordance with the provisions of the EC Treaty, in particular Article [267 TFEU] thereof, the Court has jurisdiction to define the obligations which the Community has assumed and those which remain the sole responsibility of the Member States in order to interpret the Aarhus Convention’.<sup>45</sup>

Even though the outer limits of the Court’s jurisdiction over mixed agreements still remains ill-defined,<sup>46</sup> generally speaking, the CJEU ‘has been unwilling to restrict that jurisdiction to those parts or provisions of mixed agreements agreement which can be considered as covered by exclusive Community [now Union] competence’.<sup>47</sup>

In *Hermes*,<sup>48</sup> the CJEU affirmed its jurisdiction to interpret Art. 50 of the TRIPs Agreement in broad terms. Like a Delphic oracle, the Court stated that, ‘where a provision can apply both to situations falling within the scope of national law and to situations falling within the scope of Community law, it is clearly in the Community interest that, in order to forestall future differences of interpretation, that provision should be interpreted uniformly, whatever the

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<sup>42</sup> *Hauptzollamt Mainz v. Kupferberg*, Case 104/81 [1982] E.C.R. 3641.

<sup>43</sup> *Meryem Demirel v. Stadt Schwäbisch Gmünd*, Case 12/86, [1987] E.C.R. 3719. See J. Heliskosky, *Mixed Agreements as a Technique for Organizing the International Relations of the European Community and its Member States*, (The Hague: Kluwer Law International, 2001), 4.

<sup>44</sup> *Lesoochránárske zoskupenie VLK v Ministerstvo životného prostredia Slovenskej republiky*, Case C-240/09, [2011] E.C.R. I-1255.

<sup>45</sup> [31].

<sup>46</sup> Koutrakos, ‘Interpretation of Mixed Agreements’, in C. Hillion and P. Koutrakos (Eds.), *Mixed Agreements Revisited. The EU and its Member States in the World*, (Oxford and Portland: Hart Publishing, 2010), 116, at 136.

<sup>47</sup> Timmermans, ‘Opening Remarks-Evolution of Mixity since the Leiden 1982 Conference’, in C. Hillion and P. Koutrakos (‘ds.), *Mixed Agreements Revisited. The EU and its Member States in the World*, (Oxford and Portland: Hart Publishing, 2010), 1, at 5. In a recent judgment, the Court interpreted the Aarhus Convention and provided guidance as to the legal value of the Aarhus Convention Implementation Guide. This clearly shows the wide scope of the CJEU’s jurisdiction with regard to the use of an international supporting document when interpreting a mixed agreement. *Marie-Noëlle Solvay and Others v Région wallonne* Case C-182/10, [2012] not yet reported.

<sup>48</sup> *Hermès International v. FHT Marketing*, Case C-53/96, [1998] E.C.R. I-3603. See also *Schieving-Nijstad vof and Others v. Robert Groeneveld*, Case C-89/99, [2001] E.C.R. I-5851.

circumstances in which it is to apply'.<sup>49</sup> It seems that, in principle, the Court is not precluded from interpreting the whole mixed agreement, from establishing the sphere of EU and national competence, and from defining the EU's obligations. However, the jurisprudence has shifted slightly, and in more recent cases the confines of the Court's control were defined by reference to the Member States' exclusive competences.<sup>50</sup>

In light of the case law, it appears that the Court potentially has the power to interpret the UNCRPD Convention almost in its entirety, since the relevance of such convention's provisions for existing EU legislation might be enough for the CJEU to establish its jurisdiction to interpret those provisions.

### ***B. Does the UNCRPD Have Direct Effect?***

Even if international agreements form an integral part of the EU legal order, the principle of direct effect –which implies enforceable rights for the individual *vis-à-vis* the EU and its Member States– cannot automatically be extended to them.

The direct effect of a provision of an international agreement determines the ability of parties to rely on it not only before a national court but also before an EU court. Whether a provision of mixed agreements (including, therefore, those of the UNCRPD) have direct effect is a matter that must be decided by the CJEU when the provision itself falls either under the EU's exclusive competence or within a field of shared competence in which EU legislation has been adopted.<sup>51</sup> In *Merck Genéricos*, on a reference from the Portuguese Supreme Court concerning the effect of Art. 33 of the TRIPs Agreement, the Court held that, 'when the field is one in which the Community has not yet legislated and which consequently falls within the competence of the Member States, the protection of intellectual property rights and measures taken for that purpose by the judicial authorities do not fall within the scope of Community law, so that the latter neither requires nor forbids the legal order of a Member State to accord

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<sup>49</sup> Para. 23.

<sup>50</sup> *Parfums Christian Dior SA and Others*, (Joined cases C-392/98 and C-300/98) [2000] E.C.R. I-11307, [44].

<sup>51</sup> Opinion of AG Maduro in *Fabbrica italiana accumulatori motocarri Montecchio SpA (FIAMM) and Fabbrica italiana accumulatori motocarri Montecchio Technologies LLC- Giorgio Fedon & Figli SpA*, Joined cases C-120/06 P and C-121/06 P, E.C.R. [2008] I-6513, [28].

to individuals the right to rely directly on a rule laid down in the TRIPs Agreement or to oblige the courts to apply that rule of their own motion'.<sup>52</sup> Consequently, in the latter case, it is up to the national judge to accept or deny the direct effect of international provisions in those areas that fall within the competence of the Member States.

More precisely, we now should try to assess whether the UNCRPD does in fact have direct effect, i.e. whether it could be relied on before a national court or an EU Court (irrespective of the nature of the action in which a plea based on infringement of an international agreement is raised). In general, to determine whether a provision displays direct effect, the Court has examined whether the Parties to the agreement have established the effect of its provisions in their internal legal order.<sup>53</sup> If not, it has considered whether an agreement is capable of stipulating directly effective provisions by examining 'the purpose, the spirit, the general scheme and the terms' of the agreement.<sup>54</sup> Moreover, it has examined whether the relevant provision contains a clear and sufficiently precise obligation, which is not subject, in its implementation or effect, to the adoption of any subsequent measure.<sup>55</sup> Drawing on the discussion above, *in abstracto* the UNCRPD seems capable, in light of its objectives and spirit, of conferring rights upon individuals, but its provisions are literally addressed to the Parties, and they are formulated in very general terms. The Court could not conclude that the Parties themselves contemplated that the UNCRPD's provisions would have direct effect, since the Convention requires the Parties to put its provisions 'into effect' (*inter alia* Article 4,1). In addition, interpreted in the light of the subject matter and purpose, the UNCRPD does not determine the means for its appropriate execution, but leaves the Parties a wide margin for

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<sup>52</sup> *Merck Genéricos-Produtos Farmacêuticos v. Merck & Co. Inc. and Merck Sharp & Dohme Lda*, Case C-431/05, [2007] E.C.R. I-7001. For comment, see Ruotolo, *Applicazione interna del diritto OMC in materia brevettuale tra giurisprudenza comunitaria e prassi extraeuropea*, (2008) *Diritto pubblico comparato ed europeo*, 457.

<sup>53</sup> *Kupferberg*, Case 104/81, [1982] E.C.R. 3641; *Fabbrica italiana accumulatori motocarri Montecchio SpA (FIAMM) and Others v Council of the European Union and Commission of the European Communities*, Joined Cases C-120/06 P and C-121/06 P, [2008] E.C.R. I-6513, para. 108.

<sup>54</sup> *Germany v Council*, Case C-280/93, [1994] E.C.R. I-4973, para. 110]

<sup>55</sup> *R v Department of Transport ex parte IATA*, Case C-344/04, [2006] E.C.R. I-403 para 39. As stated by Advocate General Maduro in *Fiamm and Fedon*, it is apparent that an international agreement has direct effect in the EU legal system only subject to the dual condition that the terms, nature and general scheme of the agreement do not prevent it from being relied upon, and that the provisions relied upon appear, in the light of both the object and purpose of the agreement and of its context, to be unconditional and sufficiently precise, or in other words that they contain a clear and precise obligation which is not subject, in its implementation or effects, to the adoption of any subsequent measure (para. 27).

manoeuvre. It might be also argued that none of its provisions is sufficiently clear, precise and unconditional to have direct effect under the standards established by the CJEU.

### ***C. The UNCRPD and EU Secondary Law: Between Consistent Interpretation and Judicial Review***

Leaving aside, for the moment, the issue of direct effect, it seems interesting to look in a more general fashion at how to resolve conflicts that may arise between the UNCRPD and EU (secondary) norms. In such cases, could the CJEU rule on the validity of an EU measure *vis-à-vis* the UNCRPD under art. 267 TFEU, and under art. 263 TFEU?

As mentioned above, EU secondary law must be interpreted in the light of the EU's international obligations, and so in light of the UNCRPD: if the wording of secondary EU legislation is open to more than one interpretation, preference should be given, as far as possible, to the interpretation which renders the European provision consistent with the Convention.<sup>56</sup> The Court recognises the existence of this duty of consistent interpretation, by virtue of the “sub-constitutional” rank of mixed agreements, independently of the direct effect of the international law provisions concerned.<sup>57</sup>

In the case of the UNCRPD, consistent interpretation has already had overriding effects. The archetypal example is the concept of disability itself. It is well known that there is (as yet) no definition of disability in EU law: the most important piece of legislation on disability discrimination in the employment context, Directive 2000/78, does not provide any clarification in that regard. Although the UNCRPD does not contain a precise definition, Art. 1 of the Convention states that ‘Persons with disabilities *include* those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (emphasis added). This means that implementing legislation should treat disability as

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<sup>56</sup> *Commission v. Germany*, Case C-61/94, [1996] ECR I-3989, para 52. See Casolari, ‘Giving Indirect Effect to International Law within the EU Legal Order: The Doctrine of Consistent Interpretation’, in E. Cannizzaro, P. Palchetti, R.A. Wessel (eds.), *International Law as Law of the European Union*, (Leiden/Boston: Martinus Nijhoff Publishers, 2011), 394, and the literature referred to there.

<sup>57</sup> *Řízení Letového Provozu ČR, s. p. v. Bundesamt für Finanzen*, Case C-335/05, [2007] ECR I-4307, para 52. *Interfood GmbH v. Hauptzollamt Hamburg*, Case 92/71, [1972] E.C.R. 231, para. 6.

a socially constructed phenomenon, and that it might include in its definition of disability (since Article 1 uses the word “include”), for example, short-term conditions, psychosocial disabilities, or genetic differences.

In the absence of a legislative definition, the Court of Justice, in *Chacón Navas*,<sup>58</sup> had developed a concept of disability based on the antiquated medical model of disability.<sup>59</sup> According to the Court, in that case, the cause of the disadvantage was the “impairment”. This interpretation was based on the medical model (which is centred on the disadvantage of the individual, and neglects the reaction of society to the impairment). In addition, the Court had clearly distinguished sickness from disability. According to Flynn and Quinn, the formal legal arguments employed by the Court obscured other objectives pursued in the judgment. They suggest that the Court opted for a definition of disability which entailed the least amount of costs for Member States. In their view, a careful analysis of the Court’s arguments reveals that ‘the issue of costs (and the need not to unduly intrude on the prerogatives of Member States) was one factor to bear in mind when determining the boundaries of the definition of disability’.<sup>60</sup> This opinion was probably not far from reality, but the Court has recently embraced a more wide-ranging definition of disability in line with Art. 1 UNCRPD and reflective of the social model of disability.

In *Ring and Werge*<sup>61</sup> the CJEU distanced itself from the position it took in *Chacón Navas*. This decision is also instructive in terms of clarifying the concept of reasonable accommodation, in light of Article 2 UNCRPD, and is certainly welcomed in terms of acknowledging the significance of the UNCRPD (and its conclusion by the EU), but also in adopting the method of consistent interpretation.

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<sup>58</sup> *Sonia Chacón Navas v. Eurest Colectividades SA*, Case C-13/05, [2006] E.C.R. I-6467. See Waddington, ‘Case C-13/05, *Chacón Navas v. Eurest Colectividades SA*’, 44 (2007) C.M.L.R., 487; Horvath, ‘EU Equality Law: three Recent Developments’, 17 *European Law Journal* (2011), 785, at 793.

<sup>59</sup> See *supra* nt. 2.

<sup>60</sup> Quinn and Flynn, ‘Transatlantic Borrowings: The Past and Future of EU Non discrimination Law and Policy on the Ground of Disability’, (2012) 60 *Am. J. Comp. L.* 23, 29.

<sup>61</sup> *HK Danmark, acting on behalf of Jette Ring v Dansk almennyttigt Boligselskab* (C-335/11) and *HK Danmark, acting on behalf of Lone Skouboe Werge v Dansk Arbejdsgiverforening, acting on behalf of Pro Display A/S, in liquidation* (C-337/11), Joined cases C- 335/11 and C- 337/11, 11 April 2013, not yet published.

The most recent case, in line with *Ring and Werge*, is *Commission v Italy*.<sup>62</sup> The case originated from action for failure to fulfil EU obligations brought by the Commission against Italy. The Commission affirmed that Italy did not correctly transpose Directive 2000/78 into its national law, and, in particular, it did not ensure, in breach of the Directive, that reasonable accommodation in the workplace is to apply to all persons with disabilities, all employers, and all aspects of the employment relationship. In its decision the CJEU confirmed that, while it is true that the concept of a ‘disability’ is not directly defined in the Directive 2000/78, it should be interpreted, on the basis of the UNCRPD. It also affirmed that, in light of the UNCRPD, the concept of reasonable accommodation must be interpreted broadly and covers the adjustments to be made to ensure to a person with disabilities the enjoyment or exercise of all human rights and fundamental freedoms on an equal basis with other workers. As in *Ring and Werge*, the Court held that that concept refers to the elimination of the barriers that hinder the full and effective participation of persons with disabilities in professional life on an equal basis with other workers. The CJEU noted that the obligation to provide reasonable accommodation covers all employers. Thus, further having examined the various measures adopted by Italy for the integration of persons with disabilities into the labour force, the Court concluded that those measures did not actually fulfil such standard as they did not require all employers to adopt effective and practical measures, where needed in particular cases, for all persons with disabilities, covering different aspects of work and enabling them to have access to, participate in, or advance in employment, and to undergo training.

*Ring and Werge* and *Commission v. Italy* are certainly relevant examples of the use of consistent interpretation. However, in some cases the method of consistent interpretation can prove inefficient or insufficient. It is likely that, in few cases, interpretation may not avoid a conflict between the UNCRPD and EU secondary law provisions. In these cases, would the Court be able to invalidate the EU provision in contrast with the UNCRPD? Despite the sub-constitutional status of mixed agreements, it is well established that the legality of an EU instrument can be called into question on grounds of breach of international agreements only if the provisions of those agreements have direct effect.<sup>63</sup> There are two famous exceptions to this statement. The legality of EU measures can be reviewed in the light of international rules

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<sup>62</sup> *Commission v Italy*, Case C-312/11, 4 July 2013, not yet published.

<sup>63</sup> *Portugal v Council*, Case C-268/94, [1996] E.C.R. I-6177.

when the EU measure under review is intended to implement a particular obligation (*Nakajima*)<sup>64</sup> or when the EU measure refers expressly to the precise provisions of the international agreement (*Fediol*).<sup>65</sup> A closer look to the *Nakajima* principle shows, however, that the CJEU and the Court of First Instance (General Court) have almost exclusively applied this exception in the context of reviewing the compatibility of EC Anti-Dumping Regulations with the provisions of the Anti-Dumping Codes adopted as a part of the WTO General Agreement on Tariffs and Trade (GATT). In addition, the Court appears to adopt a rather narrow understanding as to what is to be considered a “specific reference”: for instance, in the *Intertanko* case, the Court ignored the fact that the measure to be assessed was actually implementing the UNCLOS and the MARPOL conventions.<sup>66</sup> It is submitted here that the *Nakajima* and *Fediol* exceptions leave the door open to the review of EU measures in light of the UNCRPD, in particular where the EU intends to implement a specific obligation entered into within the framework of the Convention, or where the act expressly refers to specific provisions of the Convention. This could be the case, for example, with regard to the proposal for a new non-discrimination directive which cites the UNCRPD: even if it is quite unlikely that a conflict would arise between this forthcoming piece of legislation and the UNCRPD, at least in theory the *Nakajima* exception could apply.

In addition to these exceptions, *The Netherlands v European Parliament and Council* case deserves mention.<sup>67</sup> Here the Court did not consider the requirement of direct effect to be necessary for judicial review with regard to the Rio de Janeiro Convention on Biological Diversity (CBD), and it focused on the content of the CBD. According to the Court, even if the CBD provisions did not have direct effect, review by the Court of an EU act with respect to the compliance with the obligations incumbent on the EU as a party to the agreement was not precluded. The judgment also highlighted that it is for the Court, in its review of the compatibility of acts of the institutions with the general principles of EU law, to ensure that the fundamental right to human dignity and integrity is observed. The somewhat ambiguous

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<sup>64</sup> *Nakajima v Council*, Case C-69/89, [1991] E.C.R. I-2069, confirmed in *Italy v Council*, Case C-352/96, [1998] E.C.R. I-6937.

<sup>65</sup> *Fediol v Commission*, Case 70/87, [1989] E.C.R. 1781.

<sup>66</sup> *The Queen, on the application of International Association of Independent Tanker Owners (Intertanko) and Others v. Secretary of State for Transport*, Case C-308/06, [2008] E.C.R. I-4057.

<sup>67</sup> *Kingdom of the Netherlands v European Parliament and Council*, Case C-377/98, [2001] E.C.R. I-7079, [99].

statement of the Court, and the reference to the content of the international treaty and to fundamental rights, may not be persuasive. Unfortunately, the Court does not further explain the circumstances in which direct effect is not a precondition for judicial review. However, this case provides good grounds to consider that the review of EU measures in light of the UNCRPD may be possible regardless of whether the Convention has direct effect, having regard to its nature as a human rights treaty and to its non-discrimination rationale.

An “indirect” judicial review, i.e. judicial review on the basis of the UNCRPD as an indirect parameter, could offer an alternative way out. The validity of EU measures could be challenged in light of the EU Charter of Fundamental Rights, as confirmed by the *Schecke* and *Tests-Achats* cases,<sup>68</sup> but we have to assume that its provisions (at least) meet the same standards (and meaning) as those of the UNCRPD, which is the point made in the previous section.

#### **4. Tentative Conclusions**

The conclusion of the UNCRPD by the Union fits well in the increasing legal activity of the EU on the international forum, and characterizes an ever-stronger commitment to the protection of human rights. However, as recognized by many scholars, it raises several questions: the label of “mixed agreement” is difficult to reconcile with its nature as a human rights treaty. This paper has tried to elaborate on this latter point, attempting to frame the UNCRPD as an integral part of EU law.

The UNCRPD has a “sub-constitutional” status, but what seems likely to happen is that the UNCRPD will turn into a *constitutional* standard for the protection of rights of persons with disabilities. It cannot be predicted, at this early stage, whether the Court of Justice would accept the UNCRPD as a “supplementary international constitution”. However, via the interpretation of the ECHR by the European Court of Human Rights (and thus *independently* of the future EU accession to the ECHR), or via the EU Charter of Fundamental Rights, the Convention might provide for a binding term of reference for fundamental rights in the EU.

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<sup>68</sup> *Volker und Markus Schecke GbR and Hartmut Eifert*, Joined Cases C-92/09 and C-93/09, [2010] E.C.R. I-11063; *Association belge des Consommateurs Test-Achats ASBL, Yann van Vugt, Charles Basselier*, Case 236/09, [2011] E.C.R. I-773.

The practical way out of a theoretical dilemma concerning the UNCRPD's hierarchical status is to look, as this paper has done, at the effects the Convention might have as a mixed agreement, while taking into account its human rights content. *Ring and Werge* and *Commission v. Italy* show that the UNCRPD has the potential to produce paramount "indirect" effect on EU secondary legislation, via the principle of consistent interpretation. What we can infer from these decisions is that the judicial references to the UNCRPD will be more and more suitable. The UNCRPD provisions are becoming a decisive guide for the EU judiciary when adjudicating claims involving disability.

The weak point is that, while the UN Convention seems capable, in light of its objectives and spirit, of conferring rights upon individuals, none of its provisions is sufficiently clear, precise and unconditional to have direct effect under the standards established by the CJEU. However, this probable lack of direct effect does not preclude any judicial review of EU secondary legislation *vis-à-vis* the Convention. The judgments in *Nakajima*, *Fediol*, and *The Netherlands v European Parliament and Council* provide good grounds to consider that the review of EU measures in light of the UNCRPD may be possible, regardless of whether its provisions have direct effect.

## A Note on the Experimentalist Nature of the Rights of Persons with Disabilities

Philippe Reyniers\*

The United Nations Convention on the Rights of Persons with Disabilities (hereafter, ‘the Convention’) is an act of faith in a context of growing scepticism. It entrusts the law of human rights with its most ambitious hopes of emancipation. And yet, it intervenes in a context where the capacity of the law to effectively alleviate unfair disadvantage is cast in doubt. The prohibition of discrimination, on which the Convention is founded, has done very little to end the exclusion and subordination of groups stigmatised for their colour, sex or religion. Why then trust the law to empower people with disabilities and end their oppression? In fact, the Convention is no classical instrument: it builds on a tradition of egalitarian treaties (the Convention on the Elimination of Discrimination Against Women –CEDAW- and the International Convention on the Elimination of all Forms of Racial Discrimination –ICERD-, mainly) and brings something new.

The main innovation of the Convention is to include the denial of reasonable accommodation in the definition of discrimination (Articles 2 and 5). This and other novelties relate to a legal pragmatic framework. It means that the rights of persons with disabilities are entwined with ideas of *problem-solving process* and *experiment*. Legal pragmatism seeks to overcome the limits of liberal legalism, which postulates that rights are *rules* (“trumps”) founded on high-level *values* and *principles*. It claims that contemporary social problems cannot be remedied by rules and binary criteria of permissibility, and proposes to engage people into experimentation and deliberative processes. Perhaps the Convention will better deliver its promises if its pragmatic dimensions are well captured by its addressees. Experimentalism entails a different method for claiming rights. Legalism gravitates evidently around the application of a rule between parties with conflicting interests and right-claims seek compliance with a predetermined substantive norm. Experimentalism requires the

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\* I am doctoral researcher at the European University Institute. I would like to thank Prof. Theresia Degener for her attentive comments, and all the participants of this stimulating workshop. I especially thank Dorothy Estrada Tanck for organising it.

participation of all interested parties to a deliberation that involves creativity and imagination, and destabilization.

I have a single main goal in following lines. I would like to convince the reader that the rights of persons with disabilities are not business as usual, and they indeed relate to the legal pragmatic framework of experimentalism. I leave aside the main task of articulating experimentalism and legalism. One framework (legal pragmatism) does not replace the other (liberal legalism). Last but not least, I also need to leave important questions aside. I plead guilty to exaggerating the distinction between the two frameworks, especially since I do not include in my analysis doctrines of proportionality and the conception of rights as optimization requirements. Liberal legalism is also a theory of political legitimacy, and experimentalism undoubtedly raises questions of substance, on the nature of the right to equality or the version of justice that it defends. I have no space to address these questions here.

### ***1. The Convention as an Act of Faith in the Law***

As the General Assembly of the United Nations adopted the Convention on 13 December 2006, the dignity of persons with disabilities was given the protection of the law. Hailed as the pinnacle of a struggle for recognition initiated in the United States in the wake of the civil rights movements,<sup>1</sup> the Convention constitutes the legal affirmation of the equal status of persons with disabilities. Doing so, it becomes part of a series of treaties<sup>2</sup> that seek to redress social exclusion and second-class citizenship *through rights*.

There is a special attention to the moral dimension of rights consecrated at international level: their validity would not depend on their legal recognition. There is also a general agreement (and, I believe, an expectation) that moral rights can and should be completed by their legal enactment, hence take advantage of enforceability. If the Convention entrenches the language

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<sup>1</sup> Literature on the American disabilities movement is too large to cite. To name a general piece, see John David Skrentny, *The Minority Rights Revolution* (Belknap Press of Harvard University Press 2002), identifying the origins of rights of the disabled with the progressive staff of the US Congress. A lawyer's perspective can be found in Samuel R. Bagenstos, *Law and the Contradictions of the Disability Rights Movement* (Yale University Press 2009). For a European perspective, see Anna Lawson and Caroline Gooding, *Disability Rights in Europe: from Theory to Practice* (Hart 2005) and R. Daniel Kelemen, *Eurolegalism: the Transformation of Law and Regulation in the European Union* (Harvard University Press 2011), chapter 6.

<sup>2</sup> Mainly the International Convention on the Elimination of All Forms of Racial Discrimination, G. A. Res. 2106 (XX), at 47; U.N. GAOR, Supp. n° 14, U.N. Doc. A/6014 (12 Dec. 1965) and the Convention on the Elimination of All Forms of Discrimination Against Women, G. A. Res. 34/180, at 193; U.N. GAOR, 34<sup>th</sup> Sess., Supp. n° 46, U.N. Doc. A/34/46 (17 Dec. 1979).

of rights of people with disabilities, it then rests on the faith of instrumental efficacy and ethical sufficiency of law as a principle of government, a mode of governance, and a method of social regulation.<sup>3</sup> This belief is not founded on mere guidance, but on norms and obligations. And it certainly was the project of the promoters of the convention: enact a legal instrument providing for binding rules imposed on designated (institutional) actors, and set up mechanisms of enforcement and judicial review to ensure compliance with the said rules. This is particularly clear since the Convention results from a series of non-binding initiatives.<sup>4</sup> But there is more to the puzzle: the Convention is not just a dry strategic, rational choice for its promoters: it embodies the conscience of a group. The language of rights shaped the identity of the social movement carrying the claims of persons with disabilities; it spelled out its moral purpose and determined its strategies. Theresia Degener and Gerard Quinn, in their study on the human rights dimensions of disability addressed to the UN High Commissioner on Human Rights in 2002, made clear that the growing number of non-governmental organizations resorted to the language of rights to denounce the common experience of persons with disabilities despite the diversity of their ailments.<sup>5</sup>

This experience is made of persistent forms of exclusion, segregation and demeaning treatments. The disability suffered here is a disablement in the effective exercise of fundamental rights, and does not lie with a physical or mental impairment. As the disability takes a social form, the purpose of the language of rights is to obtain the respect of the social duty (share by the state and other actors) to treat people with disabilities as *subjects*. As such, what lies underneath the claim of the disability rights movement is a demand for a *substantive*<sup>6</sup> expression of the rule of law. And if the Convention itself does not compel states

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<sup>3</sup> See Stuart A. Scheingold, *The Politics of Rights: Lawyers, Public Policy, and Political Change* (Yale University Press 1974), at 17. On the role of movements and international human rights law, see Aryeh Neier, *The International Human Rights Movement: a History* (Princeton University Press 2012).

<sup>4</sup> Principally the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, G. A. Res. 48/96, at 202; U.N. GAOR, 48<sup>th</sup> Sess., Supp. n° 49, U.N. Doc. A/RES/48/96 (20 Dec. 1993). See Bengt Lindqvist, 'Standard rules in the disability field - a new United Nations instrument' in Theresia Degener and Yolán Koster-Dreese (eds), *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments* (M. Nijhoff 1995).

<sup>5</sup> Theresia Degener and Gerard Quinn, 'Human Rights and Disability, the Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability' (United Nations 2002), at 1 and 25. See also Lisa Vanhala, *Making Rights a Reality?: Disability Rights Activists and Legal Mobilization* (Cambridge University Press 2011).

<sup>6</sup> Formal theories of the rule of law are founded on the formal properties of the legal process (general, prospective, clear and certain). Formality is problematic if the mechanistic application of the law it presupposes fails to promote and make effective the respect due to persons as human beings. Substantive

to set up modes of judicial protection for the rights it guarantees, courts are commonly viewed as the natural venues for enforcement. The liberal philosopher Ronald Dworkin should identify his defence of the rule of law in the claims of persons with disabilities. For him, the rule of law “assumes that citizens have moral rights and duties with respect to one another, and political rights against the state as a whole. It insists that these moral rights be recognized in positive law, so that they may be enforced *upon the demand of individual citizens* through courts or other judicial institutions of the familiar type, so far as this is practicable. The rule of law on this conception is the ideal of rule by an accurate public conception of individual rights. It does not distinguish (...) between the rule of law and substantive justice, on the contrary it requires, as a part of the ideal of law, that the rules in the rule book capture and enforce moral rights.”<sup>7</sup>

The Convention appears to be designed to do just that. As it determines general principles and obligations, its first principle is the “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (Article 3). Dignity is only one amongst many other abstract and high-level moral commitments relating to the necessity of non-discrimination, full and effective participation, respect for difference, equality of opportunity, accessibility, sex equality, and respect for the rights of children. These general principles are directly associated with a number of specific (positive) obligations set out in Article 4: adopt all appropriate measures to implement the Convention, take all measures to eradicate discrimination against persons with disabilities, mainstream the objectives of the Convention, refrain from engaging in practices inconsistent with the Convention, adopt measures to eliminate discrimination in the private sector, promote the universal design of goods and services, promote the accessibility of new technologies, provide information on all forms of assistance, and train professionals in the content of the Convention. In that regard, the Convention builds on the legacy of the ICERD and the CEDAW. From the ICERD, it takes the association of the value of dignity with a central mandate of prohibition of discrimination. From the CEDAW, it adopts the “appropriate

(Contd.) \_\_\_\_\_

theories found the rule of law on the substantive values it carries: respect for rights and public values, the dignity of persons in particular. Human dignity, it is said, is of particular importance in moving from a formal to a substantive doctrine of equality, as it is the case with the Convention. See Denise Réaume, ‘Discrimination and Dignity’ (2003) 63 *Louisiana Law Review*, at 645–695.

<sup>7</sup> *A Matter of Principle* (Harvard University Press 1985), at 11. Dworkin developed his liberal theory of rights in a constitutional context, but applies his concept of rights as trumps in international human rights law with little variation: see ‘A New Philosophy for International Law’ 41 *Philosophy & Public Affairs* (2013), 2.

measures” approach, which assumes that the effective enjoyment of rights necessitates a number of political, economic or social reforms.<sup>8</sup> But it goes further. For Frédéric Mégret, the appropriate measures required by the Convention come close to formulate genuine entitlements, which could provide for the basis of a condemnation of the state if they were not executed.<sup>9</sup>

The Convention is thus fully in line with the practice of human rights in today’s world: the claims of persons with disabilities are “not only a belief that all humans have certain rights as a matter of theology or moral philosophy but also the belief that they have them as a matter of law and practical politics.”<sup>10</sup> In that regard, the Convention fulfils the expectations of a movement which has sought to constrain states by legal obligations that can potentially be reviewed by judicial actors, in the domestic or international arenas. It does maintain legal rights as the medium of the fundamental values modern societies must abide by. The Convention will be the basis of “transnational public law litigation”: it will constitute a public international norm and be the basis for relief for the rights of persons with disabilities.<sup>11</sup>

## **2. Questioning Faith in Law**

Can subordination be eradicated through judicial remedies? There is a very long tradition of critique addressed to the language of rights.<sup>12</sup> Edmund Burke criticised the *tabula rasa* operated by the *Déclaration des droits de l’homme et du citoyen*: societies, in his view, can only evolve by incremental improvements. Jeremy Bentham famously dismissed rights as “nonsense on stilts”, preferring contextualised evaluations of social utility to the deontological constraints of individual entitlements. Karl Marx saw in rights (and in equality!) no more than a figure of bourgeois ideology under a discourse of universality. More recently, the intellectual movement of Critical Legal Studies has pointed at the negative effect of the language of rights on constitutional culture and consciousness in the United States, in particular for the emancipation of groups and the elimination of social structures of

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<sup>8</sup> For a study of the measures of implementation, see Eilionóir Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press 2011).

<sup>9</sup> Frédéric Mégret, ‘The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?’, 30 *Human Rights Quarterly* (2008) 594, at 506.

<sup>10</sup> Richard T Ford, *Universal Rights Down to Earth* (W. W. Norton & Co. 2011), at 5.

<sup>11</sup> Harold Hongju Koh, ‘Transnational Public Law Litigation’, 100 *Yale Law Journal* (1991), at 2347–2402.

<sup>12</sup> For a recent overview, see Robert Dickinson, Elena Katselli, Colin Murray, and Ole W. Pedersen (eds), *Examining Critical Perspectives on Human Rights* (Cambridge University Press 2012).

subordination. Nevertheless, as the Convention shows, the practice of rights and the faith in the law remained generally resilient. All the positions mentioned have attacked rights from the standpoints of comprehensive political and theoretical backgrounds: conservatism, utilitarianism, socialism and postmodernism. These are generally broad critiques that concern both the foundations and actual working of systems of rights. But these do not exactly relate to the reasons why persons with disabilities should question their faith in the law. The interrogation that must preside this appraisal should only concern its instrumental validity: are rights, as legal entitlements, the best tool to obtain what we are looking for? And the context makes a positive answer rather uncertain. Consider the case of school desegregation in the United States. The decision of the Supreme Court in the case of *Brown v. Board of education* was celebrated as a major victory for the right of African-Americans to equal protection in the context of education.<sup>13</sup> Decades later, the racial stratification of American public schooling is maintained and has perhaps worsened.<sup>14</sup> The authoritative status of the decision of the Court is nevertheless undisputed, and has provided material for the struggle of segregated groups elsewhere.<sup>15</sup>

We must be as hesitant in the field of disability. The prime example concerns the matrix of the Convention itself. The Americans with Disabilities Act (ADA), voted by the American Congress in 1990 and which is the first legislative instrument to guarantee a right to reasonable accommodation, suffered from a “judicial backlash.”<sup>16</sup> The definition of protected class proved problematic before the courts, where judges perpetuated the medical model by considering that the definition of disability required taking into account the effect of “mitigating measures.”<sup>17</sup> The decision of the courts in these cases may seem like docket-control measures, in circumstances of increased litigation finding its cause with the ADA itself. Against that background, Christine Jolls researched the empirical effect of anti-

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<sup>13</sup> See Michael J Klarman, *From Jim Crow to Civil Rights: the Supreme Court and the Struggle for Racial Equality* (Oxford University Press 2006).

<sup>14</sup> Martha Minow, *In Brown's Wake: Legacies of America's Educational Landmark* (Oxford University Press 2012).

<sup>15</sup> See *ibid.*, chapter 7.

<sup>16</sup> Linda Hamilton Krieger, *Backlash against the ADA* (University of Michigan Press 2003).

<sup>17</sup> *Sutton v. United Air Lines, Inc.*, 527 U.S (1999) at 487. The persistence of the medical model of disability is not confined to the US: see Vlad Perju, ‘Impairment, Discrimination and the Legal Construction of Disability in the European Union and the United States’, 44 *Cornell International Law Journal* (2011), at 279–348.

discrimination legislation for persons with disabilities and confirmed that it had near-term negative effects on their employment.<sup>18</sup>

The conclusions that one can draw from the disability discrimination law are not alien to equality law generally. Sandra Fredman has been a strong critic in the Anglo-Saxon world of the “complaint model” or “dispute resolution model”<sup>19</sup> implied by a classical approach to legal regulation. This model is a paradigm of enforcement where the victim of an unlawful act of discrimination is expected to bear the burden of litigation herself. Even if no system of discrimination law relies entirely on liability rules and all include mechanisms of administrative enforcement, the latter remains marginal or ineffective in many jurisdictions.<sup>20</sup> Faith in the law and rights-based strategies for emancipation encounter here both practical and legal difficulties. The main practical obstacle is obvious: litigation is costly and requires nearly inexhaustible energy from claimants.<sup>21</sup> This is particularly true for claims based on equality, which cannot be reduced to their individual dimensions. But even if practical problems can be overcome, legal and interpretative hesitations remain. The law here is far from being clear, precise and unconditional. Discrimination has been given different definitions over time and space. One can understand discrimination to be the unjustified differentiated treatment of persons in a comparable situation. Does this definition entail a specific animus on the part of the actor of the treatment, like prejudice? Should we take into account the expressive dimension of the treatment, its demeaning signification for the victim or the group she belongs to? How do we assess the comparability of situations in which persons are? Does it make sense, as in our case, to compare a person with a disability with a person without a disability?

The definition of discrimination can shift to a more “complainant-friendly” approach in which the impact of social rules or practices can be considered in breach of the law. Then, acts or

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<sup>18</sup> Christine Jolls and J.J. Prescott, ‘Disaggregating Employment Protection: The Case of Disability Discrimination’ (National Bureau of Economic Research 2004).

<sup>19</sup> See, for instance, Sandra Fredman, ‘Changing the Norm: Positive Duties in Equal Treatment Legislation’, 12 *Maastricht Journal of European and Comparative Law* (2005), 369–398.

<sup>20</sup> See Julie Suk, ‘Antidiscrimination Law in the Administrative State’, *University of Illinois Law Review* (2006), 405–473, arguing that administrative agencies are under-used in the US.

<sup>21</sup> See the words of Justice Pelletier in a case of equal pay: “pay equity claims are like education savings plans: they are investments made by one generation for the benefit of the next.” *Bell Canada v. Canadian Telephone Employees Assn.*, 2000 CanLII 15753 (FC), paragraph 1.

events that have the effect of placing some group at a particular disadvantage should be considered discriminatory. Most jurisdictions fail to consider this form of discrimination as an important concern for the law: it is simply secondary ('indirect'), and multiple causes of justification apply.<sup>22</sup> The basic prohibition of discrimination does not, by and of itself, indicate which interpretation is the best. Traditional conceptions on the role of courts and rules of procedure do not help much either. As a figure of impartiality, the judge appears as an oracle called to solve a dispute. It implies tort-like reasoning, and a burden of proof carried by the claimants. If the purpose of an equality claim is the disestablishment of a hierarchy and the improvement of a collective condition, there is then a discrepancy between the reasons of the claim and its procedural expression in front of a court. There cannot be a single proved perpetrator responsible of a systemic disadvantage. Against this background, some claimed that judges are under a duty to take an active stance. In the name of an anti-subordination principle, Owen Fiss argued that the law has to integrate the concept of "disadvantaged group" (to overcome the individualism attached to personal claims), and judges had to adopt an imperial role (to obtain the compliance of recalcitrant institutions).<sup>23</sup> Fiss's goal is in line with the expectations of any social movement expressing a faith in the law: despite the intractability of public ideals such as equality and the difficulty of its realization, its moral authority has to be preserved and affirmed. But the effort of Fiss goes further: what matter are the remedies themselves. If courts are to be Promethean enforcers of noble ideals, they must not only identify disadvantaging practices, they also have to deliver injunctive orders to eliminate them.<sup>24</sup>

We thus should be wary of the limits of the law in deciding to keep faith in it. Social structures reproduce hierarchies, and the law (and its processes) seem to have had very marginal capacity to reform them. Two interpretations are possible here. Either the law is weak and allows recalcitrant social actors to remain unshaken in their persistent disobedience. Or the rule-based legalist approach to rights enforcement is inadequate.

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<sup>22</sup> On the order of priorities between different legal definitions of discrimination, see Oran Doyle, 'Direct Discrimination, Indirect Discrimination and Autonomy', 27 *Oxford Journal of Legal Studies* (2007), at 537–553.

<sup>23</sup> Owen M. Fiss, 'Groups and the Equal Protection Clause', 5 *Philosophy & Public Affairs* (1976), at 107–177.

<sup>24</sup> Owen M. Fiss, 'The forms of justice', 93 *Harvard Law Review* (1979), at 1–58.

### **3. Beyond Faith in the Law: Experimentalism**

Experimentalism makes the hypothesis of inadequacy. Law and legalism imply the existence of a stable norm and a set of long-standing institutions. Stability and constancy may mean ossification and lack of adaptation in the face of new or poorly understood circumstances. Experimentalists posit this normative and factual uncertainty: we do not know exactly what the proper norm of equality is, and we do not know how to realise it. In this kind of situation, learning and reflexivity are needed: norms and policies have to be tested, tried, experimented. Experimentalists defend a particular strand of reflexivity, as they stress the importance of “institutional design”: the distribution of roles between actors, their respective capacities and systemic interactions and effects between them.<sup>25</sup> Experimentalism also shares the philosophical premises of pragmatism. To understand is to participate, not theorise. And to participate in public life is participating in collective problem-solving. John Dewey, the primordial philosopher of pragmatism, imagined democracy to be the collective experience of learning: the process of discovery of provisional solutions to shared problems. Obviously inspired by the model of science, advised that public policies be considered “experimental in the sense that they will be entertained subject to constant and well-equipped observation of the consequences they entail when acted upon, and subject to ready and flexible revision in the light of observed consequences.”<sup>26</sup> The task of public lawyers then becomes the design of institutions allowing the optimization of the collective experimentation. Experimentalists defend, in matters of institutional design, the following organizing principles. Decision-making processes should be as *participative* as possible: involving more actors increases the information basis on which collective decisions are to be made. Ideally, participation should be sought at the many stages of the legal process: legislation, implementation, and enforcement. Increased participation blurs the boundaries between public and private spheres: citizens are no longer passive addressees of the law, while the state, the market and civil society are necessarily in a condition of partnership.

From participation stems *collaboration*: citizens are not only called to participate, but to share the responsibility of generating norms. The collaborative dimension is meant to discourage

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<sup>25</sup> See Michael Dorf, ‘Legal Indeterminacy and Institutional Design’, 78 *New York University Law Review* (2003), at 875–981. On institutionalism in general, see also Jeff A. King, ‘Institutional Approaches to Judicial Restraint’, 28 *Oxford Journal of Legal Studies* (2008), at 409–441.

<sup>26</sup> John Dewey, *The Public and its Problems* (1927).

involvement as the assertion of a rigid, narrow political or economic interest. Participation and collaboration does not imply the crafting of unique policy solutions. On the contrary, the appeal of experimentation lies in its capacity to *pluralise* solutions. One-size-fits-all logics are thus usually kept at the margins. At the same time, public experimentation welcomes and fosters *decentralization*: “it advocates a movement downward and outward”.<sup>27</sup> Decentralization not only promotes openness, partnership and experimentation, but is also an affirmation of humility of human knowledge: what we know is, almost by definition, dependent on circumstances and locality.<sup>28</sup> Locality is where the best information can be found, and it shapes the efforts of *coordination* by the “higher units” of delegating authorities. Indeed, in order to avoid becoming an “institutional self-oblivion”<sup>29</sup> where information is produced and processed locally but not shared at larger scale, a function of the central units of government becomes the pooling of information and the monitoring of collective performance. Coordination itself entails, finally, the *integration* of policy domains. It is here assumed that social problems are interconnected and necessitate a holistic approach: for instance, issues of poverty are also issues of education, employment and health. The resulting structure of decision-making, in the perspective of the theories of experimentalism, is a model of radical democracy called a “directly-deliberative polyarchy”.<sup>30</sup>

These principles seem to be perfectly relevant to regulation<sup>31</sup> and the crafting of policies. In other words, experimentalism is at home in administrative law and in matters of implementation of goals of public interest. In contrast, experimentalism will appear alien in matters of rights, which, as constraints, cannot be deliberated, and must be put beyond the realm of daily politics. However the last assertion is exaggerated: rights are goals too and they require measures of execution. The Convention can be seen as an experimentalist

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<sup>27</sup> Orly Lobel, ‘Renew Deal: the Fall of Regulation and the Rise of Governance in Contemporary Legal Thought’, 89 *Minnesota Law Review* (2004) 342, at 381.

<sup>28</sup> It is said that our rationality is necessarily bounded. In that aspect, experimentalism draws on the premises of behavioural law and economics. See, *inter alia*, Christine Jolls, C. R. Sunstein, and Richard Thaler, ‘A Behavioral Approach to Law and Economics’, 50 *Stanford Law Review* (1998), at 1471–1550.

<sup>29</sup> Michael Dorf and Charles F. Sabel, ‘The Constitution of Democratic Experimentalism’, 98 *Columbia Law Review* (1998) 267, at 295.

<sup>30</sup> Joshua Cohen and Charles F. Sabel, ‘Directly-deliberative Polyarchy’, 3 *European Law Journal* (1997), at 313–342.

<sup>31</sup> Experimentalism is indeed often coined “new governance”.

instrument.<sup>32</sup> As its drafting-process was open to non-governmental organizations, the Convention differs from traditional instruments of public international law, which are the result of diplomatic negotiations. Not only this mode of open participation relates to an experimentalist idea to the extent that it is not imposed unilaterally, the “stakeholder regime” is also an epistemic regime: its *raison d’être* is both to democratize the decision-making process on the one hand, and to gather the best information available on disabilities, on the other. The Convention also includes many open-ended notions, which leave room for experimentation and choices of policies to contracting parties and stakeholders. The most central example is the definition of disability itself, which remained undefined to be as inclusive as possible. This form of flexibility allows for adaptation to change, as a topical expression of reflexivity. Last but not least, the Convention relies on a special system of monitoring. Traditional human rights instruments set up an international committee of experts, which monitor compliance by the contracting states on the basis of national reports transmitted to them. The Convention establishes the Committee on the Rights of Persons with Disabilities, and stipulates an obligation of reporting. But, as Grainne De Burca *et al.* note, the Convention mandates the inclusion of persons with disabilities in the mechanisms of review, expressing thereby “a willingness to engage with civil societies (...).”<sup>33</sup> The Convention also relies on statistics, data collection, and national monitoring systems (Articles 31 and 33) and shares the premise of experimentalism that policies fail to deliver when they do not adapt to changing circumstances and do not generate information at the most local level.

Is that all? We may go further and see how the Convention combines the generality of rights and the need for individual assessments in adapting social practices to various impairments. It has been said, in that regard, that the Convention overcomes a number of legalist dichotomies.<sup>34</sup> It no longer relies on distinctions made between negative and positive rights, between first and second generation rights, between the public and the private, between the absolute and the relative, etc. The Convention proposes a specific model of rights: “one which

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<sup>32</sup> Grainne De Búrca, ‘The European Union in the negotiation of the UN Disability Convention’, 35 *European Law Review* (2010), at 174–196; and Grainne De Búrca, Robert O. Keohane, and Charles F. Sabel, ‘New Modes of Pluralist Global Governance’, 45 *New York University Journal of International Law and Politics* 1 (2013).

<sup>33</sup> Article 34(4). See De Búrca, Keohane, and Sabel, ‘New Modes of Pluralist Global Governance’, *ibid.*

<sup>34</sup> Frédéric Mégret, ‘The Disabilities Convention: Towards a Holistic Concept of Rights’, 12 *International Journal of Human Rights* (2008), at 261–278.

is grounded in a plural, relational concept of the human in society.”<sup>35</sup> This relational concept is particularly visible in the idea of rights to accommodation. The legalist perspective would require the identification of a right-holder, the obligation attached to her protected interest, and a corresponding obligation for a designated social actor. As one understands from Article 1 of the Convention, more than the existence of persons with disabilities; there are primarily disabling social structures, rules and practices.<sup>36</sup> If a disability is basically identified as the result of the impact of an environment on a person, understanding a right to accommodation in a strictly legalist perspective becomes difficult. We cannot truly decide upon *ex-ante* criteria for identifying right-holders: we only know that they include people with “long-term physical, mental, intellectual or sensory impairments (...).”<sup>37</sup> Likewise, we cannot determine in general what needs to be done to accommodate persons with disabilities, except by resorting to very general terms that can only be substantiated in their context of application. Under the Convention, reasonable accommodation relates to “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, when 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.”<sup>38</sup> And who is bound by the duty to accommodate? Article 5 provides that States Parties are to take all appropriate steps to ensure that reasonable accommodation is provided. But as the prohibition of discrimination on the basis of disability is generalised, any actor will be under a mandate of reasonable accommodation. Only the intensity of the obligation will vary according to the reasonableness of the accommodation or the hardship it might cause. There is thus, as expected in a legalist approach, no clear, precise and unconditional rights which “become part of the legal heritage”<sup>39</sup> of persons with disabilities.

What then, do persons with disabilities have by virtue of the Convention? A person with a disability is discriminated against if she is denied reasonable accommodation. What can be denied has to be requested. This leads the right to reasonable accommodation down the deliberative path. See the definition given by the Canadian Supreme Court: “[reasonable

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<sup>35</sup> *Ibid.*, at 274.

<sup>36</sup> Persons with impairments “which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

<sup>37</sup> Article 1, second paragraph.

<sup>38</sup> Article 2, 4<sup>th</sup> paragraph.

<sup>39</sup> Case 26/62 *Van Gend & Loos* [1963] ECR 1.

accommodation] envisions a dynamic process whereby the parties (...) adjust the terms of their relationship in conformity with the requirements of human rights legislation, up to the point at which accommodation would mean undue hardship for the accommodating party.”<sup>40</sup> “The process required by the duty of reasonable accommodation takes into account the specific details of the circumstances of the parties and allows for dialogue between them. This dialogue enables them to reconcile their positions and find common ground tailored to their own needs.”<sup>41</sup> On other occasions, the same court underlined that the right to reasonable accommodation is a matter of shared responsibilities: “[t]he search for accommodation is a multi-party inquiry. The complainant also has a duty to assist in securing an appropriate accommodation and his or her conduct must therefore be considered in determining whether the duty to accommodate has been fulfilled.”<sup>42</sup>

There is no doubt that the drafters of the Convention did not have the principles of experimentalism in mind. And the same is true for the justices of the Canadian Supreme Court. But like Mr. Jourdain has been speaking prose without knowing it, the features of experimentalism seem to operate immanently in the system of rights of the persons with disabilities. The Convention itself adopts in many respects a stakeholder regime: it does not concern only public actors and engages civil society organization in the application of its rules and principles. The stakeholder regime implies a decentralised or multilevel implementation: the processes put in place by the Convention are international, national, and sub-national. And the right to reasonable accommodation, the baseline rule of the Convention, has a deliberative content. As it has to be requested, and if it potentially concerns any social practices that have a disadvantaging impact on persons with impairments, one cannot anticipate all possible kinds of accommodations.<sup>43</sup> Any rules or standards will have to be revised to ensure maximum inclusiveness, and the actor under a duty to accommodate is simply under a duty to respond in the first stage of a solution-searching process.

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<sup>40</sup> *Alberta v. Hutterian Brethren of Wilson Colony* [2009] 2 SCR 567, paragraph 68.

<sup>41</sup> *Multani v. Commission scolaire Marguerite-Bourgeoys* [2006] 1 SCR 256, paragraph 131.

<sup>42</sup> *Central Okanagan School District No. 23 v. Renaud*, [1992] “To facilitate the search for an accommodation, the complainant must do his or her part as well. Concomitant with a search for reasonable accommodation is a duty to facilitate the search for such an accommodation. Thus in determining whether the duty of accommodation has been fulfilled the conduct of the complainant must be considered.”

<sup>43</sup> It does not mean, obviously, that no anticipatory obligation can be imposed. See Anna Lawson, *Disability and Equality Law in Britain : the Role of Reasonable Adjustment* (Hart 2008), at 92.

#### 4. Creativity, not Rule Application

To the reader convinced that there exist experimentalist traits in the Convention on the Rights of Persons with Disabilities, I suggest that some practical conclusions need to be drawn, but I can only superficially allude to them. Some would relate to the judicial function, which we would need to be valued for its capacity to “catalyse” or facilitate experimentation between stakeholders.<sup>44</sup> Some would concern the function of rights. Instead of providing “trumps” over competing concerns and interests, rights are meant to “destabilize”, or “breaking open (...) extended areas of social practice that remain closed to the destabilizing effect of ordinary conflict and thereby sustain insulated hierarchies of power and advantage.”<sup>45</sup> As experimentalists say, the goal of destabilization is to induce society to reform itself in “a process in which it must respond to previously excluded stakeholders.”<sup>46</sup> But my conclusion will be an invitation to modify a typically legalist attitude that concerns the application of rules. Rights like the right to reasonable accommodation do not function on a dyad entitlement-obligation: they operate on the basis of *creativity*. The Canadian Supreme court exhorted *all* parties to a case of workplace accommodation in the following manner: “[t]he skills, capabilities and potential contributions of the individual claimant and others like him or her must be respected as much as possible. Employers, courts and tribunals should be innovative yet practical when considering how this may best be done in particular circumstances.”<sup>47</sup> This sufficiently shows that an accommodation is not determined in advance, and if the Convention is indeed a promise of equality and emancipation, the promise will be delivered by engaging into a process of imagining and creating practical alternatives.<sup>48</sup> When persons with disabilities will claim the right to obtain the adaptation of all social practices, they will not demand the imposition of a legal blueprint. They will formulate specific demands, fitting the actual needs of all, and confront the issues raised by their

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<sup>44</sup> Joanne Scott and Susan Sturm, ‘Courts as Catalysts: Re-thinking the Judicial Role in New Governance’, 13 *Columbia Journal of European Law* (2007), at 565–594; Alana Klein, ‘Judging as Nudging: New Governance Approaches for the Enforcement of Constitutional Social and Economic Rights’, 39 *Columbia Human Rights Law Review* (2008), at 351–422. See also Katharine G. Young, *Constituting Economic and Social Rights* (Oxford University Press 2012), chapter 6.

<sup>45</sup> Roberto Mangabeira Unger, *False Necessity: Anti-necessitarian Social Theory in the Service of Radical Democracy* (Verso 2004), v. 1, at 350.

<sup>46</sup> Charles F. Sabel and William H. Simon, ‘Destabilization Rights: How Public Law Litigation Succeeds’ 117 *Harvard Law Review* (2004), 1015–1101, at 1056.

<sup>47</sup> *British Columbia (Public Service Employee Relations Commission) v. BCGSEU* [1999] 3 SCR 3, paragraph 64.

<sup>48</sup> Roberto Mangabeira Unger, *What Should Legal Analysis Become?* (Verso 1996), at 18.

feasibility: they will experiment. And this is how the prestige of the faith in law will, at the end of the day, be persevered.

# The UN Convention on the Rights of Persons with Disabilities as a Tool for Stronger Social Rights Realisation

Masa Anisic\*

## 1. Introduction

The 2006 United Nations Convention on the Rights of Persons with Disabilities<sup>1</sup> (herein: the CRPD or the Convention) is the first specific disability-oriented UN convention. As such it establishes minimum standards for protecting and safeguarding a full range of civil, political, social, economic, and cultural rights for this group, thus introducing important changes in the field of national and international disability law. Quinn, for example, deems its approach to legal capacity revolutionary, and claims it goes beyond a non-discrimination convention, providing for a wide range of classical and substantive rights,<sup>2</sup> De Burca finds its embrace of the social model of disability groundbreaking,<sup>3</sup> and Kayess finds that the Convention presents a paradigmatic shift in the perception of persons with disability.<sup>4</sup> This paper, in contrast, examines the wider implications of the CRPD for international human rights law, by exploring the general principles and substantive rights in the Convention and their potential for stronger social rights realisation. The paper uses as its basis the premise that the CRPD's adoption of the social model of disability,<sup>5</sup> which emphasises structural barriers as the primary causes of social exclusion for persons with disabilities, aims to remove these barriers<sup>6</sup> through its innovative use of non-discrimination, equality, and social participation as

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<sup>1</sup> On 13 December 2006, the General Assembly, by general consensus, officially adopted the United Nations Convention on the Rights of Persons with Disabilities, along with its Optional Protocol., <http://www2.ohchr.org/english/law/disabilities-convention.htm>.

<sup>2</sup> Quinn, G.; "The UN Convention on the Human Rights of Persons with Disabilities," Dublin 19 April 200, pp. 57.

<sup>3</sup> de Burca, G.; "The European Union in the Negotiations of the UN Disability Convention," *European Law Review*, Vol. 35, No. 2, April 2010, pp.46

<sup>4</sup> Kayess, R. and French, F.; "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities," *Human Rights Law Review*, 2008, oo. 184

<sup>5</sup> Kayess, R. & Fogarty B.: 'The Rights and Dignity of Persons with Disabilities', *Alternative Law Journal* 22, 32(1), 2007, at 122.

<sup>6</sup> Quinn, G and Degener, T. et al; *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*, Office of the High Commissioner for Human Rights, United Nations, New York and Geneva, 2002, pp. 86.

entitlements that guide the interpretation of each individual right. This paper builds on this notion and argues that the Convention's innovative use of these mechanisms presents a new tool that moves social rights closer to civil rights and consequently provides an effective framework for their stronger realisation.

First, this paper focuses on the notion of reasonable accommodation. It begins by reflecting on the theoretical framework of the substantive equality model of the Convention and later analyzes the concept of reasonable accommodation as a mechanism of non-discrimination as articulated in the CRPD and the implications of its direct linkage to the non-discrimination provision for the social rights included in the Convention.

Second, this paper analyses the systematic coupling of first and second generation rights seen throughout the Convention. It argues that the Convention blurs the traditional distinctions between civil and political rights on one side and social rights on the other by attaching the notion of non-discrimination to all rights in the Convention, rather than applying it only to civil and political rights. Further, by framing the specific substantive articles as encompassing both sets of rights, the Convention binds these types of rights together, blurring the divide and consequently bringing social rights closer to first generation rights.

Third, this paper argues that the Convention uses the right to participate to enhance the claim to social rights by elevating it to the status of a general principle. This subsequently obligates the states to take the notion of 'inclusion and participation' into consideration whenever they interpret substantive rights, which inevitably legitimizes a stronger claim on positive duties. As well, the Convention's participatory approach introduces society as a strong actor in the fulfilment of social rights, which provides a more powerful claim for social rights litigation.

Finally, the paper offers some concluding remarks on the Convention's potential for fostering the stronger realisation of social rights as well as its potential to produce effects beyond the scope of disability law.

## **2. Reasonable Accommodation as a Tool of Non-Discrimination**

As noted above, positive action measures on the part of the states are increasingly accepted as a necessary element of the effective protection of human rights, rather than an extraordinary

tool of achieving equality.<sup>7</sup> An example can be found within the UN treaty system: the Committee monitoring compliance with the Convention on the Elimination of Discrimination Against Women (CEDAW Committee) already defined this acceptance in its General Recommendation No. 25,<sup>8</sup> in which it viewed temporary special measures as a part of the norm itself and not an exception to the principle of non-discrimination.<sup>9</sup>

Similarly, the underlying premise of the CRPD is that the universal principle of equality needs adaptation to the specific situation of protected groups. The equality framework of the CRPD reflects precisely the awareness that securing the human rights of persons with disabilities through universal human rights treaties had been unsuccessful.<sup>10</sup> As such, the Convention's equality approach incorporates 'the express adaptation of what is perceived as universal rights to the unique situation of persons with disabilities,'<sup>11</sup> largely through its use of positive action measures and the institute of reasonable accommodation.

The following argues that the adoption of reasonable accommodation and its innovative link to the non-discrimination provision is of great significance for the strengthening of social rights realisation since it produces an effect of immediate application, not only with regard to civil and political rights, but as well to economic, social, and cultural rights.

This section first provides a brief analysis of the CRPD's notion of equality against the notions of equality in the preceding conventions as a means to explain its use of positive action measures. Second, reasonable accommodation is defined through its comparison to

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<sup>7</sup> Human Rights Committee (HRC) General Comment No. 31, 'Nature of the General Legal Obligation Imposed on States Parties to the Covenant', 26 May 2004, available at <http://www.unhchr.ch/tbs/doc>

<sup>8</sup> Committee on the Elimination of Discrimination against Women, General Recommendation, No. 25, e.g. at 7-10

<sup>9</sup> HRC General Comment No. 31, 'Nature of the General Legal Obligation Imposed on States Parties to the Covenant', 26.05.2004, available at <http://www.unhchr.ch/tbs/doc>

<sup>10</sup> Disability is not mentioned in any of the three initial human rights instruments, whereas, within the subsequent thematic human rights treaties, only the Convention on the Rights of the Child (CRC) contains a disability-related provision in Article 23(1). Theoretically, a disabled person could invoke protection based on these treaties, if he or she either falls under a universal provision or possesses a separately protected characteristic in addition to his or her disability. In practice, however, thirteen out of seventeen disability-related complaints submitted to the UN core instruments between 1980 and 1993 have been declared inadmissible by the respective monitoring committees. See: Despouy, I.; Report on Human Rights and Disabled Persons; at 280-81 (1993). <http://www.un.org/esa/socdev/enable/dispaperdes0.htm>; last accessed: 2 April 2012.

<sup>11</sup> Quinn, G.; 'The International Covenant on Civil and Political Rights and Disability: A Conceptual Framework', in T. Degener and Y. Koster-Dreese (eds), *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments* (Leiden: Martinus Nijhoff 1995), at 70.

positive action measures. Subsequent to these introductory remarks, this section addresses how the reasonable accommodation instrument fortifies the social rights in the Convention.

- Equality is a fundamental principle central to the international protection of human rights. The Universal Declaration of Human Rights proclaims that, ‘All human beings are born free and equal in dignity and rights,’<sup>12</sup> and that ‘everyone is entitled to all the rights and freedoms...without distinction of any kind,’<sup>13</sup> thus exhibiting the idea that everyone is equally entitled to the same rights simply by virtue of their humanity. Ideally, the principle of equality, as promulgated within the framework of the universal human rights treaties, should have secured human rights to all persons on an equal basis.<sup>14</sup> However, experience has shown that in fact the general ‘universal’ human rights regime has not proved to be effective in the context of specific vulnerable groups.<sup>15</sup> As such, the notion that specific mechanisms are necessary in order to secure equality has gradually gained acceptance. This attitude stems from theories of social construction, which claim that certain identity features are not natural but rather social constructs, and thus focuses on the systemic disadvantages posed by society.<sup>16</sup> This attitude first appeared in feminist and critical race theories, which have paved their path to the international legal sphere. In a General Recommendation, the CEDAW Committee put forth the social construction of gender.<sup>17</sup> In the sphere of race, the UN Committee on the Elimination of Racial Discrimination (CERD), interpreting the

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<sup>12</sup> UDHR, Article 1.

<sup>13</sup> UDHR, Article 2.

<sup>14</sup> Obviously, the adoption of numerous thematic conventions after the UDHR signifies the need for specification of the universal principle of equality.

<sup>15</sup> Ambassador Don MacKay, who chaired the Ad Hoc Committee negotiating the Convention, summarized this problem at the adoption ceremony: ‘Theoretically there was no need for a new convention because the existing human rights instruments apply to persons with disabilities in just the same way that they do to everyone else. The reality, unfortunately, has not followed the theory. [ ... ] ...many of the obligations under other instruments are set out in quite a broad and generic way, which can leave grey areas for their practical implementation in respect of particular groups.’ ‘Statement on behalf of New Zealand,’ by Ambassador Don MacKay (Chair of the Ad Hoc Committee), at the adoption of the Convention on the Rights of Persons with Disabilities by the United Nations General Assembly on 13 December 2006’, <http://www.un.org/disabilities/default.asp?id=155#nz>, last accessed: 11 June 2008.

<sup>16</sup> See Ian Hacking’s elaboration of social construction theory: ‘The existence or character of X is not determined by the nature of things. X is not inevitable. X was brought into existence or shaped by social events, forces, history, all of which could have been different.’ Hacking, I.: *The Social Construction of What?* (Cambridge, MA: Harvard University Press, 1999) at 6-7.

<sup>17</sup> Committee on the Elimination of Discrimination against Women, General Recommendation No. 25, ‘on article 4, paragraph 1, of the Convention on the Elimination of All Forms of Discrimination against Women, on temporary special measures’, thirtieth session, 2004, [http://www.un.org/womenwatch/daw/cedaw/recommendations/General %20recommendation%2025%20\(English\).pdf](http://www.un.org/womenwatch/daw/cedaw/recommendations/General%20recommendation%2025%20(English).pdf); paras. 8 & 11, last visited: 21 July, 2012

International Convention on the Elimination of Racial Discrimination (ICERD), immediately viewed race as combining both biological and social factors;<sup>18</sup> however, it should be noted that social factors have been gaining in importance, as visible from CERD General Comment No. 8<sup>19</sup> and General Comment No. 29.<sup>20</sup>

The primary focus in CEDAW and ICERD remains on the equal treatment approach and negative state obligations, with positive action measures being an exception to the rule,<sup>21</sup> even though both conventions demonstrate an understanding that this approach, which strives to achieve equality by securing identical treatment for everyone, does not foster substantive equality. However, the equal opportunities approach which acknowledges that equality as an ideal must accommodate and fit within the scope of individualised settings and realities,<sup>22</sup> and therefore legitimizes affirmative action on the part of the state,<sup>23</sup> and places an obligation of result on the states in the process of implementing human rights,<sup>24</sup> as is expressly recognized in Articles 1(4) and 2(2) ICERD<sup>25</sup> and Article 4 CEDAW,<sup>26</sup> may be found in several articles. CEDAW connects equal access to the right to education,<sup>27</sup> the right to employment,<sup>28</sup> and

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<sup>18</sup> ICERD, Article 1.

<sup>19</sup> That the question whether an individual belongs to a particular racial or ethnic group should be based on the person's own self-identification, Committee on the Elimination of Racial Discrimination, General Comment No.8, 'Identification with a particular racial or ethnic group (Art.1, par. 1 & 4)', 22.08.1990, [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/13ae0a87b5bd69d28c12563ee0049800f?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/13ae0a87b5bd69d28c12563ee0049800f?Opendocument), last visited 22 July 2012.

<sup>20</sup> In 2000 it elaborated descent as a social construct, as part of its concept of racial discrimination under Article 1 (1) of the International Convention on the Elimination of Racial Discrimination, Committee on the Elimination of Racial Discrimination, General Comment No. 29, Article 1, at 1 of the Convention (Descent), 11 January 2002, at 1. [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/f0902ff29d93de59c1256c6a00378d1f?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/f0902ff29d93de59c1256c6a00378d1f?Opendocument), last visited 8 August 2012.

<sup>21</sup> Traustadottir, R.; 'Disability Studies, the Social Model and Legal Developments,' from Quinn, G. and Arnarottir; *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden: Brill, 2009), at 32.

<sup>22</sup> Stein, M. & Stein, P.; 'Beyond Disability Civil Rights', 58 *Hastings L.J.* 1203 2006-2007, at 8.

<sup>23</sup> Lawson, A.; 'UN Convention on the Rights of Persons with Disabilities and European Disability Law: A Catalyst for Coercion?' from Quinn, G. and Arnarottir; *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden: Brill, 2009), at 92.

<sup>24</sup> Lord, J., & Brown, R.; 'The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities', 2010, at 275 <http://ssrn.com/abstract=1618903>, last accessed: 11 August 2012.

<sup>25</sup> Stipulating that 'special measures ... shall not be deemed racial discrimination,' and that 'States Parties shall... take, in the social, economic, cultural and other fields, special and concrete measures,' respectively.

<sup>26</sup> Stipulating that 'temporary special measures aimed at accelerating de facto equality between men and women shall not be considered discrimination...'

<sup>27</sup> CEDAW, Art. 10.

<sup>28</sup> CEDAW, Art. 14.

assigns temporary special measures to achieving equality of opportunity,<sup>29</sup> while ICERD connects equal access to political rights.<sup>30</sup>

By comparison, the CRPD initiates a further step within the sphere of affirmative action. The Convention is expressly based on the social model of disability, which strongly impacts its equality approach in that it clearly places intricate structural social factors as the root cause of discrimination (instead of personal characteristics such as impairment). The social model of disability further recognizes that both stereotypes and structural barriers are primary obstacles to inclusion, as visible from Preamble (e), as well as in Article 1, where it emphasizes ‘the interaction of impairment with various barriers’ in order to provide an open ended definition of disability.<sup>31</sup> Therefore, the CRPD’s equality notion is defined by its focus on the eradication of practices and policies that increase or sustain a disadvantage through highly individualised positive action mechanisms.

Even though it retains some notion of the equality of treatment,<sup>32</sup> in order to enhance the functionality of the principles of equality, the Convention recognizes the importance of adapting them to the particular situation of its protected group. Its innovation compared to its predecessors lies precisely in the fact that it perceives positive action measures as a required tool for the achievement of this aim, and not as an exception from the identical treatment rule.<sup>33</sup> Both the number of instruments and their level of detail point to this fact. While in both CEDAW and ICERD only temporary special,<sup>34</sup> concrete<sup>35</sup> and appropriate measures<sup>36</sup> are envisioned; in its elaboration of positive action measures, the CRPD envisages positive action,<sup>37</sup> positive duties (namely universal design<sup>38</sup> and accessibility<sup>39</sup>), and reasonable

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<sup>29</sup> CEDAW, Art. 4.

<sup>30</sup> ICERD, Art. 5.

<sup>31</sup> CRPD, Preamble (e) recognizes that ‘...disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society...’.

<sup>32</sup> Article 13 of the CRPD stipulates that ‘State Parties shall endeavour to provide for procedural accommodations to each and every legal process for persons with disabilities such that they may participate effectively and equally within the judicial system.’

<sup>33</sup> Kimber; ‘Equality or Self-determination’, in Gearty and Tomkins (eds), *Understanding Human Rights*, (Mansell Publishing: London, 1996) at 273.

<sup>34</sup> CEDAW, Art. 4, ICERD, Art. 2.

<sup>35</sup> ICERD, Art. 2.

<sup>36</sup> CEDAW Art. 2, ICERD, Art. 2.

<sup>37</sup> CRPD, Articles 22, 27.

accommodation<sup>40</sup> as a mechanism for achieving equality for persons with disabilities. The main difference between positive action measures and reasonable accommodation is that the former are general and the latter is individualised, which results in the former generally not creating subjective rights (thus not enabling the individual to challenge their implementation), whereas the latter creates clear legal standing precisely because of its direct link to non-discrimination.

Two factors account for the Convention's firm reliance on the use of positive action measures. The first can be attributed to the difference between disability and other discriminatory grounds, such as race and gender. For disability, the potential discriminator is actually required to positively take disability into account and provide for specific measures in order to ensure equality, whereas in other grounds, the requirement on the potential discriminator is mostly to disregard the difference.<sup>41</sup> Another possible reason to account for this is that CRPD borrows from the vast national and regional frameworks developed over the past two decades, which all show a trend towards positive action measures on the part of the state in the securing of human rights. However, rather than speculate on this issue, this paper focuses on reasonable accommodation and its innovative use for the realisation of social rights.

The concept of reasonable accommodation was first introduced in the 1968 United States Civil Rights Act, and has later been incorporated into the Americans with Disabilities Act.<sup>42</sup> It entered the international human rights arena in General Comment No. 5 of the UN Committee on Economic, Social and Cultural Rights (CESCR),<sup>43</sup> but the CRPD is the first legally

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<sup>38</sup> CRPD, 2, 4(f).

<sup>39</sup> CRPD, 3(f), 9.

<sup>40</sup> CRPD, Article 2, 5.

<sup>41</sup> Quinn, G. & Flynn, E.; 'Transatlantic Borrowings: The Past and Future of EU Non-Discrimination Law and Policy on the Ground of Disability', *The American Journal of Comparative Law*, Vol. 60 (2012), at 26.

<sup>42</sup> Cooper, J.; 'Overcoming Barriers to Employment: The Meaning of Reasonable Accommodation and Undue Hardship in the Americans with Disabilities Act', *Univ. of Penn. Law Review*, Vol. 139, No. 4 (1991), at 1423–36

<sup>43</sup> UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 5, Persons with disabilities (Eleventh session, 1994), U.N. Doc E/1995/22 at 19(1995), reprinted in *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.6 at 24 (2003), at 9.

binding international human rights treaty to introduce reasonable accommodation.<sup>44</sup> Article 2 of the CRPD defines it as:

‘[N]ecessary 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.’

Further, the CRPD is innovative in that it directly and explicitly links reasonable accommodation to the notion of discrimination through the inclusion of the ‘denial of reasonable accommodation’ in the definition of discrimination. This approach, for example, contradicts the EU’s Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation which defines discrimination through four forms of action (direct discrimination, indirect discrimination, harassment, and instruction to discriminate against another person), but does not explicitly define a denial of an accommodation as a form of discrimination.<sup>45</sup>

In its definition, Article 2 of the CRPD states:

Discrimination on the basis of disability’ means 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 accommodation.

Since the non-discrimination norm is generally considered to be immediately effective (i.e., giving rise to immediate obligations and justiciable in the courts), making reasonable accommodation an anti-discrimination mechanism gives rise to an obligation of immediate effect.<sup>46</sup> Therefore, embedding the concept of reasonable accommodation within the non-discrimination domain creates an immediate effect for all of the rights in the Convention,

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<sup>44</sup> Lord, J., & Brown, R.; ‘The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities’, 2010, at 281, <http://ssrn.com/abstract=1618903>, last accessed: 11 August 2012.

<sup>45</sup> Article 2, Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation.

<sup>46</sup> Quinn, G. & Flynn, E.; ‘Transatlantic Borrowings: The Past and Future of EU Non-Discrimination Law and Policy on the Ground of Disability.’ *The American Journal of Comparative Law*, Vol. 60 (2012), at 31.

including the social rights, which have traditionally fallen under the progressive realisation scheme.

Further, the reasonable accommodation obligation is found not only in the general application provisions of the Convention (applying across all of the articles), but also in the specific substantive articles on liberty and security of the person (Article 14(2)), education (Article 24), employment (Article 27), as well as in access to justice (Article 12), thus implying that the non-discrimination provision does not stand alone, but is connected to more specific substantive rights.<sup>47</sup> Therefore, the reasonable accommodation obligation of general value should be analysed together with the specific reasonable accommodation obligations in the substantive provisions of the Convention, giving an immediate effect to the realisation of the substantive rights in question to the maximum of available resources.

However, the precise implications of the reasonable accommodation obligation remain somewhat unclear due to the unfortunate wording of Article 2, which defines it as:

‘Reasonable accommodation’ means 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;

‘Disproportionate or undue burden’ creates a two-element test that may allow states to evade the obligation at the lower end of either threshold.<sup>48</sup> In addition, the wording injects a strongly negative implication on the perception of the needs of persons with disabilities. It activates precisely the construction of persons with disability as ‘burdens’ on the community that the CPRD otherwise attempts to overcome.<sup>49</sup> This regrettable wording, resulting from a controversial debate during the drafting of the Convention, weakens the original potential of the notion of reasonable accommodation<sup>50</sup> by introducing the notion of progressive realisation

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<sup>47</sup> *Ibid.*, at 34.

<sup>48</sup> Lord, J.; ‘Accessibility and Human Rights Fusion in the CRPD: Assessing the Scope and the Content of the Accessibility Principle and Duty under the UN CRPD’, Presentation for the General Day of Discussion on Accessibility, CRPD Committee, UN: Geneva, 7 October 2010.

<sup>49</sup> Megret, F.; ‘*The Disabilities Convention: Towards a Holistic Concept of Rights*’, *The International Journal of Human Rights*, <http://www.tandfonline.com/loi/fjhr20>, last accessed on 24 March 2012.

<sup>50</sup> Fifth session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, (24 January - 4 February 2005)

into the otherwise immediately applicable non-discrimination model.<sup>51</sup> However, even when conservatively analysed, the obligation to take steps to realize disability rights remains immediate, yet the question of what entails ‘available resources’ weakens its effect. On the whole, it does present the first step in moving social rights closer to civil and political rights by allowing some immediate effect, even if it is only to the maximum of viable resources. A clear example of this is *Glor v. Switzerland*,<sup>52</sup> where the European Court of Human Rights (ECHR) detailed the numerous ways in which Switzerland could have provided reasonable accommodation (although this particular terminology was not invoked) for the complainant in light of his disability. The CRPD’s interpretation of reasonable accommodation has strong potential to influence the realisation of social rights for the disabled in the international human rights sphere as visible in the ECHR judgement in the *Glor* case, where the Court cited the CRPD as the most contemporary understanding of the content of disability rights, to which it should look when interpreting the ECHR.<sup>53</sup>

The *Glor* case shows that the CRPD’s application of reasonable accommodation presents new opportunities for the realisation of the rights of persons with disabilities under its Optional Protocol, yet its full potential remains to be explored.

### **3. Bridging the Traditional Gap**

Human rights have traditionally been perceived through the prism of negative and positive rights. The former have been understood as a requirement on the part of the state to ‘refrain’ from certain conduct (‘freedom from’), while the latter as entitlements of individuals to have the state take determined steps to secure rights (‘entitlement to’).<sup>54</sup> These distinctions correlate to the division of rights into civil and political rights as ‘negative,’ and social, economic, and cultural rights as ‘positive.’ Negative civil and political rights require little positive action or investment of resources on the part of the state<sup>55</sup> since they are duties of restraint preventing the state from interfering with individual freedoms. Positive economic,

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<sup>51</sup> Lawson, A.; ‘*The United Nations Convention on the Right of Persons with Disabilities: New Era or False Dawn?*’ *Syracuse J. Int’l L. & Com.*, Vol. 34, No. 563 (2007), at 571.

<sup>52</sup> *Glor v Switzerland*, European Court of Human Rights, Application No. 13444/04, 30 April 2009.

<sup>53</sup> *Ibid.*, at 91, 94, and 95.

<sup>54</sup> S. Fredman, ‘Human Rights Transformed: Positive Duties and Positive Rights’, *Oxford Law Studies*, Research Paper No.38/2006 (2006).

<sup>55</sup> Lawson, A. *Disability and equality law in Britain: The role of reasonable adjustment*. (2008). Portland: Hart Publishing.

social, and cultural rights cast positive duties on the state to act, therefore requiring a certain level of investment. While the Universal Declaration of Human Rights (UDHR) made no such distinctions, this separation originated in the two UN Covenants succeeding the UDHR. The International Covenant on Economic, Social and Cultural Rights (ICESCR) is almost entirely focused on positive rights ('right to'), while the International Covenant on Civil and Political Rights (ICCPR), highlights certain rights as being negative in essence ('no one shall be') and others as essentially positive ('everyone or anyone or X shall be'). As such, civil and political rights have been considered more appropriate for judicial resolution than socio-economic rights, a view confirmed by the European Convention on Human Rights (ECHR) as the first binding human rights treaty, which puts significant emphasis on civil and political rights. Making only civil and political rights justiciable reflects a well-established view that protection by the state against want or need are assigned to the realm of policy, and immediately realizable, whereas socio-economic rights remain in the realm of aspiration, to be progressively realisable depending on means.<sup>56</sup>

However, the traditional division of rights has increasingly been replaced by the idea of their essential interrelatedness, indivisibility, and interconnectedness.<sup>57</sup> Indeed, many so-called negative rights involve positive obligations from the state. If one examines the case of torture, states must not only legally condemn citizens from taking part in such conduct (a negative right), but also take positive steps to ensure its eradication is comprehensive (material investments in training programmes, etc.) Likewise, many social, economic, and cultural rights also involve negative components. For example, the right to employment entails the right of an individual to choose her own job without interference on behalf of the state.

As the first international convention to be drafted after the adoption of the Vienna Declaration and Program of Action in 1993,<sup>58</sup> the CRPD recognizes human rights as universal, indivisible,

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<sup>56</sup> Fredman, S.; 'Human Rights Transformed: Positive Duties and Positive Rights,' *Legal Research Paper Series*, Paper No 38/2006, Aug. 2010, at 39.

<sup>57</sup> *Ibid*, at 51.

<sup>58</sup> World Conference on Human Rights, Vienna Declaration and Programme of Action, UN Doc. A/CONF.157/23, 1993. The Optional Protocol to the Convention Against Torture (CAT) was adopted in 2002, but this is an accessory instrument to the CAT itself, thus leaving the CRPD as the first substantive international instrument adopted after the Vienna Declaration and the end of the Cold War. The International Convention for the Protection of All Persons from Enforced Disappearance was adopted a few days after the CRPD, on 20 December 2006.

interdependent, and interrelated,<sup>59</sup> which follows the trend of defying the traditional division of rights to negative (civil and political) and positive (socio-economic). This can be attributed to the specificity of disability as a ground of discrimination discussed above. As Quinn notes, ‘there can be few more obvious areas than the field of disability in which to emphasize the inter-connectedness of the civil and political rights tradition with the more avowedly egalitarian social and economic rights tradition.’<sup>60</sup>

Already in Article 1, the Convention challenges the division of the Universal Declaration of Human Rights<sup>61</sup> into two Covenants,<sup>62</sup> by announcing its purpose:

[T]o 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 should be noted that the express statement of purpose in a specific provision is in itself innovative in the international human rights system.<sup>63</sup> The CRPD uses it to emphasise that persons with disabilities are rights holders, detaching them from the perception of welfare recipients.

The Convention further emphasises the indivisibility of all human rights via two pathways: its use of the non-discrimination principle; and its specific architecture of individual substantive rights. The Convention uses the non-discrimination notion to adapt the entire array of rights to

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<sup>59</sup> CRPD, Preamble (c).

<sup>60</sup> Quinn, G.; ‘The International Covenant on Civil and Political Rights and Disability: A Conceptual Framework,’ in T. Degener and Y. Koster-Dreese (eds), *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments* (Leiden: Martinus Nijhoff 1995), at 70.

<sup>61</sup> Universal Declaration of Human Rights, G.A. Res. 217A (III), U.N. GAOR, 3d Sess., U.N. Doc. A/810 (Dec. 12, 1948); The UDHR encompasses civil, political, economic, social, and cultural rights in one holistic instrument. Academic commentary on the subsequent separation of civil and political rights on the one hand and economic, social, and cultural rights on the other in the two Covenants and the ensuing debate on negative and positive liberty are ubiquitous. See especially Carter, I. (2007). Negative and positive liberty. *Stanford Encyclopedia of Philosophy*, <http://plato.stanford.edu/entries/liberty-positive-negative/#Bib>, last accessed on 14 August 2012. See also MacCallum, C. (1967): Negative and positive freedom. *Philosophical Review*, 76, 312–334.; Young, R. (1986): Beyond negative and positive liberty. New York: St. Martin’s Press; Berlin, I. (1969): Two concepts of liberty. In I. Berlin (Ed.), *Four essays on liberty* (at 118–172). London: Oxford University Press

<sup>62</sup> International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI), U. N. GAOR, Supp. No. 16 at 52, U.N. Doc. A/6316 (1966); International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), U.N.GAOR, Supp. No. 16, U.N. Doc. A/6316 (1966).

<sup>63</sup> Provisions stating the purpose of the treaty are not a common feature of international human rights treaties but are present in for example environmental international agreements. See: United Nations Framework Convention on Climate Change, art. 2, May 9, 1992, 31 I.L.M. 849. The CRPD’s express inclusion of its purpose makes clear that the CRPD is a rights-based instrument, whose aim is protecting human rights as opposed to disability prevention or social welfare.

the specific situation of persons with disabilities, thus obscuring the traditional division of rights.<sup>64</sup> It directly connects the non-discrimination provision to the substantive obligations arising not only from civil and political rights, but as well as from economic, social, and cultural rights in the Convention in order to ensure that these obligations truly fulfil their purpose of removing obstacles and creating pathways for inclusion. For example, in the field of education the CRPD's Article 24 stipulates that 'States Parties shall ensure an inclusive education...', a much stronger obligation than CEDAW's corresponding Article 10, where 'States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education...'

Moreover, the explicit linkage of reasonable accommodation to the realisation of all human rights (through its linkage to the non-discrimination provision) has a dual effect: one of creating an immediate obligation (as opposed to a traditionally progressive effect connected to social rights, as described in the previous section), and one which establishes that the realisation of fundamental civil and political rights (traditionally thought of as negative rights) requires implementation through positive measures in order to address ongoing systemic discrimination against persons with disabilities.<sup>65</sup> For example, the right to liberty (a negative right) in the CRPD contains the reasonable accommodation provision detailing the states' obligations in circumstances concerning the deprivation of liberty (Article 14(2)).

Further, the Convention takes the existing human rights and tailors them to the specific needs and/or situations of persons with disabilities. The result of this 'amplification, transformation, and extension of the existing human rights'<sup>66</sup> is the conversion of formerly (and essentially) non-interference based rights into positive state obligations. Thus the Convention further expands on the notion of the indivisibility of all rights by elaborating that they can give rise to positive as well as negative obligations on the state, or as Fredman puts it; 'duties to respect,

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<sup>64</sup> Quinn, G. & Flynn, E.; 'Transatlantic Borrowings: The Past and Future of EU Non-Discrimination Law and Policy on the Ground of Disability', *The American Journal of Comparative Law*, Vol. 60 (2012), at 28.

<sup>65</sup> Lord, J.E. & Stein, M.A. (2010), *Assessing economic, social and cultural rights: The Convention on the Rights of Persons with Disabilities*, in Langford & Reidel (Eds.), (2010), *Equality and economic and social rights*, at 4–28.

<sup>66</sup> French, P.; 'Human Rights Indicators for People with Disability: A Resource for Disability Activists and Policy Makers', (Brisbane: Queensland Advocacy Incorporated, 2007), at 15.

protect, and fulfil.’<sup>67</sup> Due to the specific nature of its substantive provisions, the Convention often contains both types of obligations in the same right. This is due to the specific structural obstacles persons with disabilities face. Positive duties (by eliminating these barriers) grant them access to the right at the core of a given provision. Thus civil rights are depicted as a means of ensuring economic rights; civil rights in fact become social rights at the fulfilment level.<sup>68</sup> For example, the right to privacy (a civil right) covers the ‘health and rehabilitation information of persons with disabilities.’ Another example is Article 21, which stipulates a positive obligation on the part of the state to provide public information in accessible formats and to recognize sign languages, Braille, and augmentative and alternative communication. On the other hand, positive rights, as well, incorporate negative obligations. For example, the right to be free from torture incorporates in itself the duty of the state to establish mechanisms preventing torture.

However, the Convention remains vague on the issue of realising such rights. Even though it is not divided into civil and political rights (to be immediately achieved) and social and economic rights (to be progressively achieved as resources become available), it characterizes social rights as less burdening on the States in Article 4(2):

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...

Using the language ‘undertake,’ ‘to the maximum,’ and ‘progressively,’ the Convention connects social rights to ‘obligations of conduct,’<sup>69</sup> to be realised progressively, while in the case of civil and political rights, states are to ‘ensure’ them, and ‘shall’ take certain action, implying an ‘obligation of results,’<sup>70</sup> and one that is to be implemented immediately.

The ambiguity of the Convention causes confusion since the application of non-discrimination does not necessarily transform an obligation to “progressively achieve” into

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<sup>67</sup> Shue, H.; ‘Basic Rights: Subsistence, Affluence, and US Foreign Policy’ (2nd ed., Princeton: Princeton University Press, 1996), at 117.

<sup>68</sup> Kayess, R. & French, F.; ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’, *Human Rights Law Review*, 2008, at 4.

<sup>69</sup> The Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, 20 *Human Rights Quarterly* 691, 694 (1998).

<sup>70</sup> Geneva Convention Relative to the Treatment of Prisoners of War, Aug. 12, 1949, 6 U.S.T. 3316, 75 U.N.T.S. 135, available at <http://wwwl.umn.edu/humanrts/instree/y3gctpw.htm>

one of immediate results.<sup>71</sup> Article 12, for example, stipulates the obligation that supports for decision-making to be put in place. If legal capacity is seen exclusively as a civil right, this obligation is immediate (even though it places significant monetary and structural demands on the states). If it is not, then it can be progressively realised, i.e., introduced gradually over time. The right to education, on the other hand, includes both an immediate dimension (persons with disabilities must not be excluded from education) and various more gradual ones (enabling persons with disabilities to learn social development skills). Since the Convention does not specify whether the rights are to be achieved progressively or immediately, this issue will require an analysis of each particular right in question.<sup>72</sup>

Regarding the justiciability of the substantive rights enshrined in the CRPD, the Optional Protocol stipulates: ‘The Committee on the Rights of Persons with Disabilities can receive communications from or on behalf of individuals or groups of individuals who claim to be victims of a violation of the Convention.’<sup>73</sup> It is therefore possible to file communications not only with regard to the civil and political rights of the CRPD but also with regard to the economic, social, and cultural rights listed in the Convention.

In time, it will be interesting to observe what course of action the Committee on the Rights of Persons with Disabilities takes concerning the justiciability of resource-demanding rights. While it is too early to predict accurately, it is likely that the Committee will draw on the practice of other UN monitoring bodies as well as regional bodies such as the European Court of Human Rights and the European Committee on Social Rights, and particularly the work of the UN Committee on Economic, Social and Cultural Rights.

In conclusion, the Convention presents a new step in the trend of the indivisibility of human rights. Moreover, the specificity of the ground of disability, mirrored in its need for significantly more positive action in securing of all rights, provides a clear proof of their interdependence. Even though it retains to some extent the language of separation, the content of individual substantive articles, explicitly calling for both positive and negative measures;

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<sup>71</sup> Quinn, G. & Flynn, E.; ‘*Transatlantic Borrowings: The Past and Future of EU Non-Discrimination Law and Policy on the Ground of Disability*’, *The American Journal of Comparative Law*, Vol. 60 (2012), at 27.

<sup>72</sup> Quinn, G.; ‘The UN Convention on the Human Rights of Persons with Disabilities’, Dublin, 19 April, 2007.

<sup>73</sup> CRPD Optional Protocol, Article 1.

the immediate applicability of all rights insinuated through the definition of discrimination; and the potential justiciability of social rights through the Optional Protocol's complaints procedure have widely opened the door for a human rights system which does not discriminate against the different generations of rights. One of the most significant contributions of the CRPD will therefore arise from the interpretation and application of its specifically elaborated substantive rights. At some point, the temporal issues of the social rights' realisation will have to be answered, which could lead to the possible acceptance of the justiciability of social rights in the Convention. Accepting justiciability in one context will have an indirect bearing in other contexts, as it contributes to the gradual softening of the strict categorization of rights, as belonging either in the socio-economic or in the civil-political sphere.<sup>74</sup>

#### **4. Social Participation as a Tool for Rights Realisation**

With the Convention relying on the social model, which perceives disability through disabling social, environmental, and attitudinal barriers rather than the lack of ability, the CRPD's main aim is to break down these structural barriers. While the previous section focused on the elimination of these obstacles via mechanisms of equality and non-discrimination envisioned by the Convention, this section examines the Convention's notion of the right to participate and assesses its potential in the further realisation of social rights in the Convention and beyond.

Previous UN treaties have called for the protection of the right to participate, but only within the context of a specific substantive right. ICERD cites the right to participate only in connection to civil rights, particularly the right to participate in election processes.<sup>75</sup> CEDAW goes further, connecting the notion of participation to not only civil and political rights (it expressly mentions participation in the formulation of government policy, in non-governmental organizations, and in the work of international organizations),<sup>76</sup> but as well in

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<sup>74</sup> Koch, I.; 'From Invisibility to Indivisibility: The International Convention on the Rights of Persons with Disabilities', from Quinn, G. and Arnarottir; *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden: Brill, 2009), at 75.

<sup>75</sup> ICERD, art. 5(c): „Political rights, in particular the right to participate in elections...’.

<sup>76</sup> CEDAW, Article 7.

relation to social rights, providing express reference to participating actively in sports and physical education,<sup>77</sup> as well as in recreational activities and all aspects of cultural life.<sup>78</sup>

The CRPD represents a further elaboration of the right to participate. Similar to its predecessors, the CRPD connects the right to participation to particular substantive rights. Yet not only does the CRPD expand upon the number of rights, but as well it broadens the participation claim to society at large. Article 24(3) grants full and equal participation in education, and Article 24(1)(c) connects the right to education to the full participation of persons with disability in society, while Article 26(1)(b) connects habilitation and rehabilitation services to participation, as well as inclusion in the community and all aspects of society. Lastly, Article 30(5) encourages and promotes participation in recreational, leisure, and sporting activities.

Moreover, the CRPD makes a further step in broadening the right to participate by ensuring that persons with disabilities and their organisations (DPOs) take part in the monitoring and implementation of the Convention, including Article 4(3), Article 32(1), and Article 33(3), which are analyzed in detail in the following section.

Most significantly, the CRPD makes full participation one of the guiding principles of the Convention in Article 3(c) which stipulates that, ‘The principles of the present Convention shall be: Full and effective participation and inclusion in society...’ The inclusion of a general principles article is an innovation in itself, the aim of which is to guide the interpretation of the entire text of the treaty. Therefore, by elevating participation to the status of a general principle, the Convention ensures its application in all spheres of life (beyond substantive articles which stipulate it expressly).<sup>79</sup> Applying the general principle of participation to social rights is imperative given that the principles of autonomy, independence, and participation strengthen inclusive approaches to social rights implementation.<sup>80</sup> The state

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<sup>77</sup> CEDAW, Article 10.

<sup>78</sup> CRPD, Article 13.

<sup>79</sup> Stein, M.A. & Lord, J.: ‘Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities’, *Texas Journal on Civil Liberties and Civil Rights*, Vol. 13, No. 2 (2008), at 174.

<sup>80</sup> Koch, I.; ‘From Invisibility to Indivisibility: The International Convention on the Rights of Persons with Disabilities’, from Quinn, G. and Arnarottir; *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden: Brill, 2009), at 80.

parties will thus have to take an inclusive approach when interpreting their obligation to respect, protect, and fulfil human rights of persons with disabilities in relation to various substantive articles.

In addition to attributing it the status of a general principle, the Convention, by referencing society, broadens the scope of the right to participate. By doing so, the Convention understands the lack of (or insufficient) participation in society as an inherent feature of the very definition of disability.<sup>81</sup> Therefore, one of the primary aims of the Convention is to combat this lack of participation<sup>82</sup> by asserting attitudinal changes throughout its structure: 'social awareness,'<sup>83</sup> 'nurturing receptiveness to the rights of persons with disabilities,'<sup>84</sup> and the 'fostering at all levels of the education system...an attitude of respect.'<sup>85</sup>

Therefore, the Convention's view on the right to participation most closely resembles tenBroek's theories on participatory justice.<sup>86</sup> Noting that persons with disabilities were not prevented from participation because of their actual physical limitations but rather 'a variety of considerations related to public attitudes,' tenBroek argued that the solution to disability-based exclusion is the fulfilment of their right to participate.<sup>87</sup> He further elaborated that 'individuals cannot flourish without their joining with other humans in some sort of collective activities,'<sup>88</sup> and are 'greatly harmed by their isolation.'<sup>89</sup> As such, full inclusion encompasses

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

<sup>82</sup> CRPD, Preamble (m), (y).

<sup>83</sup> CRPD, Art. 8(1(c)).

<sup>84</sup> CRPD, Art. 8(2(i)).

<sup>85</sup> CRPD, Art. 8(2(b)).

<sup>86</sup> CRPD, Preamble (j) and Article 32(1).

<sup>87</sup> tenBroek, J.: 'The Right to Live in the World: The Disabled in the Law of Torts', 54 *California Law Review*, at 841, 841 (1966). This article is considered notable; however it is but just example drawn from Professor tenBroek's many critiques. See generally: Matson, F. 'Blind Justice: Jacobus tenBroek and the Vision of Equality,' (Government Printing Office 2005).

<sup>88</sup> *Ibid.*, at 852, 859 ("Architectural barriers... make it very difficult to project the physically handicapped into normal situations of education, recreation, and employment.").

<sup>89</sup> See: tenBroek, *The Law of the Poor* (1966); tenBroek, California's Dual System of Family Law: Its Origin, Development, and Present Status, 16 *STAN. L. REV.* 257 (1964); tenBroek, California's Dual System of Family Law: Its Origin, Development, and Present Status 11, 16 *Stanford Law Review*, 900 (1964).

<sup>90</sup> See tenBroek at 213 (characterizing dependency as invoking "a feeling of inferiority as to their status in the community that may affect their hearts and minds in a way unlikely ever to be undone"); tenBroek & Matson at 814 ("The psychological and socio-economic handicap suffered by disabled persons far outweighs the actual physical restrictions from their impairment.").

both physical accessibility<sup>90</sup> as well as ‘a basic right indispensable to participation in the community, a substantive right to which all are fully and equally entitled.’<sup>91</sup>

With the introduction of society as an important actor within the right to participate, the Convention makes ‘a broader demand, made not only to the state but also to society, to allow persons with disabilities to fully become members of society and the various communities of which they are part.’<sup>92</sup> The Convention thus departs from human rights’ traditional emphasis on the relationship of the individual to the state and ‘displays more sensitivity to issues of structural power and oppression than the mainstream human rights framework has typically done,’<sup>93</sup> taking into account the fact that persons with disabilities have just as often been vulnerable to restrictions of freedoms by a private actor or society in general, as they have from the state itself.

The Convention affirms this view by referencing the private sector in its general obligations provisions. It is worth noting that the Convention is the first international human rights treaty to impose explicitly an obligation on the state to ‘take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization, or private enterprise.’<sup>94</sup> This non-discrimination obligation, by expressly referencing private actors, is of particular significance to social rights given that breaches of social rights more frequently manifest in the private sector than breaches of civil and political rights.

As well, the Convention references the public and private spheres in Article 9 on accessibility, which seeks to dismantle the various forms of discriminatory barriers.<sup>95</sup> Since accessibility is as well an article of general application, this reference strengthens social rights claims by facilitating the fulfilment of the right to participate contained in the substantive provisions of the Convention.

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<sup>90</sup> See tenBroek, at 848.

<sup>91</sup> *Ibid.*, at 858. See also *ibid.*, at 918 .

<sup>92</sup> Megret, F.; "The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?" *Human Rights Quarterly*, No. 30, 2008, at 31.

<sup>93</sup> DeBurca, G.; ‘The European Union in the Negotiations of the UN Disability Convention,’ *European Law Review*, Vol. 35, No. 2, April 2010, at 52.

<sup>94</sup> Disabilities Convention (note 1), Article 4(1).

<sup>95</sup> Article 9 CRPD (a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public; (b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities.

Therefore, the states' obligations in the Convention are further strengthened by the Convention's use of the right to participate. Not only does its incorporation into the specific substantive articles broaden the scope for potential claims of breach, but its incorporation into the general principles obligates the states to define all rights through the prism of all-encompassing inclusion, thus adding new substance and a positive duty into every substantive right. Further, its incorporation into the accessibility provision broadens the aim of accessibility, which again permeates every life situation. This participatory framework would have negated the ECHR decision in the *Botta v. Italy* case.<sup>96</sup> Here the Court held that Article 8 ECHR could require the State to take positive measures, which include regulating private conduct, but that these obligations are present only where there is a direct and immediate link between the positive measures sought and the applicant's private or family life. According to the Court, this requirement was not fulfilled since Mr. Botta had been trying to gain access to the beach and sea at a place distant from his normal place of residence during his holidays, which constituted interpersonal relations of such a broad and indeterminate scope that there could be no conceivable direct link between the measures the state was urged to take and his private life. Without delving into the issue of the danger of segregating civil and political rights from social rights, it can be concluded that the right to participate in the Convention would have determined an obligation on the part of the state to regulate private conduct in the way to provide accessible facilities, either based on its inclusion in the particular substantive right to recreation (in this case Article 30 CRPD), or based on its inclusion in the accessibility provision.

The CRPD's commitment to inclusion and substantive equality thus presents a potentially powerful tool for comprehensive, inclusive policy implementation, as well as for promoting social rights through supranational litigation.

## **5. Conclusion**

By embracing the social model of disability, the CRPD aims to mitigate the specific structural, attitudinal, and societal barriers faced by persons with disabilities. In doing so the Convention produces effects that reach beyond the context of disability. As such, the purpose

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<sup>96</sup> *Botta v Italy*, 26 EHRR 241 (1998).

of this paper has been to capture and analyse the innovations directly or indirectly linked to the issue of social rights realisation, and assess their potential for impacting the general international scheme of human rights.

The social model of disability is the foundation of the Convention's equality approach, which progressively uses positive action measures and reasonable accommodation as a means of achieving equality for this group. Through its definition of discrimination, which encompasses the denial of reasonable accommodation, the Convention attributes the notion of immediate effect to what are traditionally-considered programmatic rights, and implies their justiciability, which is further confirmed through the Optional Protocol's provision on the complaint procedure, thus blurring the traditional division of human rights in civil-political, on the one hand, and economic, social and cultural, on the other. Further, the Convention systematically merges first and second generation rights throughout its normative framework and within individual substantive rights, which almost exclusively hold negative as well as positive obligations due to the specific barriers they are intended to overcome. Moreover, by introducing the right to participate as a general principle and as a specific right found in several substantive provisions, the Convention provides new pathways for invoking social rights.

Indeed, the implications of the Convention's normative context regarding its social rights may prove to be groundbreaking outside of the disability context. The 1993 Vienna Declaration and Program of Action facilitated the re-integration of all human rights. The Convention follows in the same vein, and the newly adopted 2008 Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, in force since 5 May 2013, will further provide for social rights claims, and hopefully the stronger immersion of all rights.

Yet, even though it introduces new pathways, the Convention remains both silent and unclear on several important issues regarding the realisation of social rights, which most likely will hold up the original intentions of the drafters. By attaching the 'undue burden' and 'reasonable' test to the reasonable accommodation provision, the Convention introduces some notion of progressive realisation, while at the same time allows for immediate effect. Further, by not defining these terms, it leaves a wide margin of interpretation to states, potentially rendering this mechanism ineffective. The Convention, as well, does not distinguish between

first and second generation rights, but does provide different language regarding social rights, thus implying their traditional status quo of 'lesser importance'.

The overall result is confusion. The work of the CRPD Committee, as well as the other UN treaty bodies will prove to be an invaluable resource on how to interpret the Convention, since the Convention itself remains silent. In addition, the case law of international and regional human rights bodies may aid in the interpretation of the Convention, and eventually translate the effects of the Convention beyond the sphere of disability.



