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The Torkel Opsahl Lecture 2016

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## New Perspectives on Equality: Towards Transformative Justice through the Disability Convention?

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**KEYWORDS** Disability Rights; Transformative Justice; Substantive Equality; Accessibility; Convention on the Rights of Persons with Disabilities

### 1. Introduction

It is a great privilege to be invited to give this very special lecture to honour Torkel Opsahl and his legacy.<sup>1</sup> Opsahl worked at both the regional European and the United Nations (UN) level and contributed to the development of human rights, and his work is a great source of inspiration. Three years ago, Manfred Nowak, one of my predecessors at the Netherlands Institute of Human Rights (SIM),<sup>2</sup> gave a lecture reaffirming Torkel Opsahl's impact on the human rights field and the strong relationship between the Norwegian Centre for Human Rights and SIM.<sup>3</sup> Both institutes share an academic ambition to contribute to theory and practice of human rights. We share the conviction that human rights as an academic subject combines different legal and non-legal disciplines. Moreover, our institutes agree that human rights scholarship should not be merely nationally oriented. The international aspect is crucial, not only because of the international normative and supervisory framework of human rights, but also because human rights have to be applied in very different national constitutional settings, where the dilemmas and problems often appear in their clearest forms. This makes a combined international and comparative approach essential and emphasises the need for international cooperation.

Torkel Opsahl played a leading role in this field of cooperation. I often wonder what people like him would think about today's world: a world where belief in human rights and human dignity sometimes seem to fade into the background and where scepticism and ethnocentrism has seemingly come to the fore. We cannot deny the increasing social segregation in many societies, and the fact that globalisation and other trends, positive as they may be in our view, have a different impact on large parts of the world's population, who feel more and more excluded and ignored. This development affects the acceptance of human rights as universal values, and the legitimacy of international

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<sup>1</sup>This manuscript was adapted from the Torkel Opsahl Lecture given on 24 November 2016 at the Norwegian Centre for Human Rights in Oslo, Norway. Jenny E Goldschmidt is Emeritus Professor in Human Rights Law, and former Director of the Netherlands Institute of Human Rights (SIM).

<sup>2</sup>See Erin Jackson and Brianne McGonigle Leyh, *A History of SIM: The Netherlands Institute of Human Rights since 1981* (Ridderprint BV 2016).

<sup>3</sup>Manfred Nowak, 'The Right of Victims of Human Rights Violations to a Remedy: The Need for a World Court of Human Rights' (2014) 32(1) *Nordic J of Human Rights* 3.

enforcement structures. It is challenging to imagine how current trends may serve to inspire us to develop new paths to ensure that human rights are meaningful (again) for all. In this context the topic of my lecture has a certain urgency, being closely related to the question of how human rights in general, and the principle of equality in particular, can contribute to the exclusion of marginalised, vulnerable groups and individuals in today's context. I do not pretend to offer a solution: what I want to do is to map out some ways of thinking about equality and the development of concepts that may act as tools in this debate.

## 2. The Principle of Equality in an Inherently Unequal World

In the preambles of the two core UN Covenants on Civil and Political Rights and on Social, Economic and Cultural Rights the inherent dignity of human beings and equal rights are mentioned as two interlinked aspects of human rights. However, equal protection of all is not self-evident. The rights of specific groups had to be further elaborated in different Covenants, such as the International Convention on the Elimination of All Forms of Racial Discrimination (CERD), Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), Convention on the Rights of the Child (CRC), and most recently the Convention on the Rights of Persons with Disabilities (CRPD; hereafter I will refer to this Convention as the Convention, the CRPD or the Disability Convention).<sup>4</sup> Not only because discrimination is an obstinate phenomenon, being very difficult to exterminate, but also because of the fact that the mere guarantee of equal rights, and the prohibition of discrimination in general, may contribute to, but are not enough to ensure the fundamental changes that are necessary to achieve full equality. This may be due to the fact that a general, seemingly neutral, normative framework reflects only the perspective of dominant groups, and thereby cannot guarantee equal human rights to all. Failure to bring about real change is also a result of deeply rooted ideas about the existence of intrinsic differences. The first step to bring about changes that contribute to equal rights is to challenge the neutrality of the foundation of our laws and the 'normal' perspectives these laws reflect.

One of the first scholars who did so and who emphasised the importance of a feminist perspective on law was Tove Stang Dahl, one of Torkel Opsahl's colleagues at the University of Oslo. Dahl's publication, 'Women's Law of 1988'<sup>5</sup> was an eye-opener for many legal scholars at the time.<sup>6</sup> Her approach reflected the voice of many feminist lawyers, who carefully wanted to avoid the creation of an atmosphere of 'war against men':

The fact that law reflects both men's and women's reality from a men's point of view does not mean that there exists a conspiracy of men furthering this purpose. If such were the case, it would be difficult to explain progress over the last 150 years both in Norway and many other places of the world [ ... ] Law is an important part of the cultural hegemony that men have in our type of society, and a cultural hegemony means that a ruling group's special way of viewing social reality is accepted as normal and as part of the natural order of things, even

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<sup>4</sup>International Convention on the Elimination of All Forms of Racial Discrimination (21 December 1965) 660 United Nations Treaty Series (UNTS) 195; Convention on the Elimination of All Forms of Discrimination Against Women (18 December 1979) 1249 UNTS 13; Convention on the Rights of the Child (20 November 1989) 1577 UNTS 3; Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly 24 January 2007 A/RES/61/106.

<sup>5</sup>Tove Stang Dahl, *Women's Law, An Introduction to Feminist Jurisprudence* (Norwegian University Press 1988).

<sup>6</sup>See also Rikki Holtmaat, *A Concise Encyclopaedia of Feminist Jurisprudence* (University of Leiden 2016) (published on the occasion of Holtmaat's farewell symposium).

by those who are in fact subordinated by it. In this way law contributes to maintaining the ruling group's position.<sup>7</sup>

This problem is also referred to as 'the power of law',<sup>8</sup> and it causes many feminist scholars to turn a sceptical eye to the possibility of using the law as an instrument to improve the position of women and using it as a tool for empowerment.

The inherent lack of neutrality of the law is seen as especially problematic in relation to equality, because equal treatment in and of itself cannot remove the invisible underlying male standard of the norm that is applied, and a 'blind' equality might only reaffirm the dominant male standard. Therefore, to combat the production of discrimination, the assertions of neutrality have to be uncovered. Martha Minow was one scholar who not only emphasised the relevance of the feminist approach to 'deepen the meaning of equality under the law',<sup>9</sup> but also advocated 'developing similar feminist critiques in contexts beyond gender, such as religion, ethnicity, race, handicap, sexual preference, socio-economic class and age'.<sup>10</sup> Moreover, she was also among the first who realised that feminists 'run the risk of treating particular experiences as universal and ignoring differences in racial, class, religious, ethnic, national and other situated experiences'<sup>11</sup> – which in fact defines the relevance of what we now call an intersectional approach.

More or less concurrently with the feminist debate on the role of law and the different aspects of equality, the concept of equality in legal practice developed in different, but overlapping, stages. In the first stage of this development there was an emphasis on formal equality: treating people in the same way, where different treatment is only justified if it is based on 'real differences'. The prohibition of direct discrimination was the manifestation of this approach in the positive law, as reflected in the case law of various (human rights) courts and non-discrimination acts. The relevance of formal equality and of the abolition of direct discrimination should not be underestimated. However, as mentioned above, in a society with unequal division of power, formal equality alone cannot solve the problem of discrimination when the effect of equal treatment is predicated on the difference in their situation, which is not included in the norm itself.

The substantive equality approach tries to address this problem, by not solely focusing on equal treatment, but by also incorporating the differences in outcome that may result from this same treatment. In positive law, substantive equality is reflected in the concept of indirect discrimination. The unequal effects of a seemingly neutral rule have to be taken into account. In the substantive equality approach we cannot be blind to differences, because differences should also be taken into account. Indirect discrimination as a legal concept is especially powerful in the context of the various EU equality directives that have been developed since 1975.<sup>12</sup> Whereas direct discrimination is often outright

<sup>7</sup>Dahl (n 5) 13

<sup>8</sup>Carol Smart, *Feminism and the Power of Law* (Routledge 1989).

<sup>9</sup>Martha Minow, 'Feminist Reason: Getting It and Losing it' in Katherine T Bartlett and Rosanne Kennedy (eds), *Feminist Legal Theory. Readings in Law and Gender* (Westview Press 1988) 357.

<sup>10</sup>ibid

<sup>11</sup>ibid. This aspect has been further analysed and elaborated in her book, Martha Minow, *Making All the Difference: Inclusion, Exclusion and American Law* (Cornell University Press 1990).

<sup>12</sup>Council Directive 75/117/EEC of 10 February 1975 on the approximation of the laws of the Member States relating to the application of the principle of equal pay for men and women [1975] OJ L 45 (as amended); Commission Recommendation 92/131/EEC on the protection of the dignity of women and men at work (27 November 1991) [1992] OJ L 49; Council declaration on the implementation of the Commission Recommendation on the protection of the dignity of women and men at work, including the code of practice to combat sexual harassment (19 December 1991) [1992] OJ C 27; Council

forbidden under most provisions in these directives (though perhaps with some exceptions outlined in the directives), indirect discrimination can be justified, but only under very strict circumstances, which have been further elaborated by the national equality bodies and the Court of Justice of the European Union (CJEU).

Without explicitly using the concept of indirect discrimination, the substantive equality approach has been applied by courts such as the European Court of Human Rights (ECtHR). The case of *Thlimmenos v Greece*<sup>13</sup> is seen as an important decision which shows how the right to freedom from discrimination not only encompasses the obligation to treat persons the same in analogous situations, but to also take into account differences in situation.<sup>14</sup> In this case the applicant was not allowed to register as an accountant because he had a criminal record. However, his criminal conviction was imposed because he refused the compulsory military service, which he did on the basis of his religious conviction (Jehovah's Witness). In effect, his religious conviction prevented him from becoming an accountant. In its judgment the Court held that

The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different.<sup>15</sup>

### 3. Recognition of Difference

Substantive equality is based on the recognition of difference. Recognition of the unequal impact of human rights on different groups was also the reason to elaborate and develop the two UN Conventions in more specific treaties, such as the CERD and CEDAW, emphasising that racial discrimination and denial of the rights of women constitute barriers to human dignity. Both treaties refer to the historical backgrounds of oppression and discrimination in their preambles, and emphasise the positive aspects of difference. Perhaps the most substantive article in the Women's Convention is article 5, which obliges State parties

... to take all appropriate measures to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women.<sup>16</sup>

This provision can be seen both as a result of feminist legal studies' impact and the need to discover the assumptions and cultural values hidden in seemingly neutral legal systems. Stereotypes need to be dismantled. In the words of Alexandra Timmer, stereotypes are

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Directive 79/7/EEC of 19 December 1978 on the progressive implementation of the principle of equal treatment for men and women in matters of social security [1979] OJ L 6; Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303; Directive 2006/54/EC of the European Parliament and of the Council of 5 July 2006 on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation [2006] OJ L 204 (recast); Council Directive 76/207/EEC of 9 February 1976 on the implementation of the principle of equal treatment for men and women as regards access to employment [1976] OJ L 39, vocational training and promotion, and working conditions; Council Directive 2004/113/EC of 13 December 2004 implementing the principle of equal treatment between men and women in the access to and supply of goods and services [2004] OJ L 373; Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin [2000] OJ L 180.

<sup>13</sup>*Thlimmenos v Greece*, Application no 34369/97, ECtHR 6 April 2000.

<sup>14</sup>See e.g. Sandra Fredman, 'Emerging from the Shadows: Substantive Equality and Article 14 of the European Convention on Human Rights' (2016) 16 Human Rights L Rev 279.

<sup>15</sup>*Thlimmenos v Greece* (n 13) [44].

<sup>16</sup>CEDAW, art 5.

‘both cause and manifestation of structural disadvantage and discrimination of certain groups of people’.<sup>17</sup> Although it is easier said than done, particularly in jurisprudence, to combat and eliminate stereotypes, some good practices have been developed by both the ECtHR and the CJEU.<sup>18</sup>

The awareness of the fact that the underlying patterns and structures of laws are not always neutral is the first step towards a more fundamental form of substantive equality: transformative equality. Transformative equality is described as ‘arising from the recognition that equality is not necessarily about sameness’.<sup>19</sup> This approach recognises the need to change rules and laws in a way that includes different perspectives and not only the dominant or majority’s views and experiences.

Related to the debate on recognition of stereotypes and the necessity to discover underlying structures is the development of the concept of vulnerability. Vulnerability is ‘analytically both a descriptive and prescriptive tool’, and involves ‘exploring how societal or institutional arrangements originate, sustain, and reinforce vulnerabilities’, in much the same way we reflect on and consider stereotypes.<sup>20</sup> Recognition of difference, identification of vulnerability and the recognition and combating of stereotypes are the major achievements in equality law, which could be used in the Disability Convention.

The CRPD was adopted in 2008, and this convention can be seen as a major step forwards in the development of transformative substantive equality. Heiner Bielefeldt, in his convincing paper on the innovative power of the CRPD, hails the CRPD as a major achievement towards empowering human rights.<sup>21</sup> The strong emphasis on social inclusion, participation and individual autonomy constitutes a crucial impulse for the overall human rights debate. The innovative power of the CRPD is the reason why I will now proceed with the principles and contents of this Convention, which can be seen as a codification of transformative equality.

#### 4. The Disability Convention

The Disability Convention is first and foremost a major achievement of the worldwide disability movement, which was so closely involved in the drafting of the Convention. The CRPD embodies a paradigm shift from a medical model to a social model of disability. This is reflected in article 1 which defines the purpose of the Convention: ‘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.’ The preamble emphasises that ‘disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’.<sup>22</sup>

<sup>17</sup>Alexandra Timmer, ‘Towards an Anti-Stereotyping Approach for the European Court of Human Rights’ (2011) 11 Human Rights L Rev 708.

<sup>18</sup>ibid; see also Alexandra Timmer, ‘Gender Stereotyping in the Case Law of the EU Court of Justice’ (2016) 1 Eur Equality L Rev 37.

<sup>19</sup>Sandra Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (OUP 2008) 11.

<sup>20</sup>Lourdes Peroni and Alexandra Timmer, ‘Vulnerable Groups: The Promise of an Emerging Concept in European Human Rights Convention Law’ (2013) 11(4) Intl J of Constitutional L 1059.

<sup>21</sup>Heiner Bielefeldt, *Zum Innovationspotenzial der UN-Behindertenrechtskonvention*, (Deutsches Institut für Menschenrechte, Berlin, June 2009).

<sup>22</sup>CRPD, pmbI, para c.

In essence these descriptions show how equality must be seen as a two-sided phenomenon and that equality demands a transformative approach. The impairments of a person and the barriers in society (including prejudices and stereotypes) in combination with each other make a person ‘disabled’.

The CRPD embodies a shift from a medical model to deal with people with disabilities (‘we take care of you’) to a social model (we are both part of the same society) and thus entails a human rights approach: people with disabilities do not have to wait for favours, but are rights-holders. This is reflected in the first sentence of article 1 of the Convention describing the purpose as ‘to promote, protect and ensure the full and equal enjoyment of all fundamental rights and freedoms by all persons with disabilities, and to promote respect for inherent dignity’.

The CRPD reemphasises that all human rights are interrelated, and that civil and political and economic, social and cultural rights are equally necessary to guarantee full enjoyment without discrimination. Thus, the CRPD adopts

... a particular conceptual view of the state’s role in securing individual human rights as involving more than simple abstinence from the abuse of civil and political rights. Instead, the state is expected to play an active role in creating social conditions necessary for individuals to be treated with dignity.<sup>23</sup>

O’Cinneide sees the protection of persons with disabilities as an acid test for the major human rights instruments, as this group is among the most marginalised and disadvantaged in contemporary society.<sup>24</sup>

The CRPD is, as explained by Arnardóttir, based on the premise ‘that previous efforts to secure the rights of people with disabilities had been unsuccessful in fact’.<sup>25</sup> The CRPD does not enact any new rights, but the obligations of the state to realise the existing rights for people with disabilities are thoroughly established in the CRPD, and the Convention allows for individuals to claim rights on the basis of these collective duties. In the CRPD, the state has both positive and negative obligations to guarantee equal rights for all persons with disabilities.

The idea that states have duties to guarantee equal freedom for all is elaborated in theories like that of Amartya Sen on agency and Martha Nussbaum on capabilities, and entails ‘a series of positive duties on the State to ensure the [minimum] threshold of functioning’.<sup>26</sup> Capacities and empowerment of people play a central role in ensuring equal rights for all. This idea is not just applicable to people with disabilities, but has a far broader relevance: Fredman explains how also ‘poverty can be construed as deliberate state intervention, or as an obstacle to freedom which the State has the means to remove ...’.<sup>27</sup>

It is because of this possible outreach that the CRPD is seen as a tool for transformative equality and justice. The principles that have been incorporated in the human rights framework of this Convention have a broader meaning beyond the context of disability rights and thus reflect a more general development of fundamental aspects in human

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<sup>23</sup>Colm O’Cinneide, ‘Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities’, in OM Arnardóttir and G Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) 164.

<sup>24</sup>ibid 167.

<sup>25</sup>Oddný Mjöll Arnardóttir, ‘A Future of Multidimensional Disadvantage Equality’ in Arnardóttir and Quinn (n 20) 45.

<sup>26</sup>Fredman, *Human Rights Transformed* (n 19) 12, author insertion.

<sup>27</sup>ibid 13.



rights doctrine. These principles are: Equality, Accessibility, Autonomy, Participation and Inclusion.

## 5. The Principles of the Disability Convention

### a. Equality

The principle of equality is described by Liisberg as ‘the most central principle informing the position of persons with disabilities under human rights law’.<sup>28</sup> Equality lies at the heart of the CRPD. However, the concretisation of equality as a principle in legal practice is a very complex and demanding exercise.

The CRPD gives direction to the way the principle has to be interpreted by adopting the ‘Substantive Disadvantage (Diversity) approach of equality’.<sup>29</sup> This approach aims to transform the legal system into a more balanced structure by taking asymmetrical power structures into account. Other human rights principles such as participation and accessibility are instrumental to reach this level of equality.

The obligation to take differences into account as part of the realisation of equal treatment entails several positive obligations. For example, reasonable accommodation is defined in article 2 of the CRPD as a ‘necessary and appropriate modification and adjustments’ to ensure ‘enjoyment or exercise on an equal basis with others of all human rights and freedoms’. The importance of reasonable accommodation is specifically listed as an obligation in article 5. This clearly demonstrates that reasonable accommodation is not conceived as an exception to the prohibition of discrimination, but as an intrinsic element of the duty of equal treatment. The refusal to provide reasonable accommodation constitutes discrimination. Similarly, temporary special measures necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered to be discrimination;<sup>30</sup> they are part of the duty to promote equal treatment.

### b. Accessibility

Accessibility is another important principle of the CRPD. Accessibility is not only a human rights principle, but also a condition to exercise other rights, and a right *per se*. The monitoring committee of the Convention emphasised that even though there are no new rights introduced by the Convention, there is a specification of the right to access that has been recognised under the ICCPR and the CESC. In the CRPD, accessibility is linked to equality:

States’ obligation to provide accessibility is an essential part of the new duty to respect, protect and fulfil equality rights. Accessibility should therefore be considered in the context of the right to access from the specific perspective of disability. The right to access for persons with disabilities is ensured through strict implementation of accessibility standards. Barriers to access to existing objects, facilities, goods and services aimed at or open

<sup>28</sup>Maria Ventegodt Liisberg, *Disability and Employment: A Contemporary Disability Human Rights Approach Applied to Danish, Swedish and EU Law and Policy* (Intersentia 2011) 21.

<sup>29</sup>See Andrea Broderick, *The Long and Winding Road to Equality and Inclusion for People with Disabilities* (Intersentia 2015) 44ff, who refers to the work of Liisberg and Arnardóttir, mentioned above.

<sup>30</sup>CRPD art 5, para 4.



to the public shall be removed gradually in a systematic and, more importantly, continuously monitored manner, with the aim of achieving full accessibility.<sup>31</sup>

This close link between accessibility and equality means that a denial of access may amount to discrimination, and therefore the clarification of the contents of this obligation in the CRPD is of general relevance. Broderick explains the role that accessibility plays under the two major Conventions: accessibility is one of the core obligations that the CDESCR defined under the right to health for example.<sup>32</sup>

The scope of the state's accessibility obligation is broad. Whereas most people think first, or only, of removal of stairs to create accessibility for wheelchairs (including accessible toilets), a wide range of other measures is included. But access is not always about entry. Another often forgotten aspect is that the right to access also includes right to access an *exit*: I wonder how many of you are aware that as a deaf person, I will not survive a fire in many hotels.

It is also important to consider other important measures such as digital accessibility for blind people and people with other visual impairments, as well as for people with mental disabilities. Another urgent problem with accessibility is the (lack of) accessibility of the most important institutions of a democracy: voting stations (and the voting process, including the information thereon), courts, parliaments, and other government institutions. Taking into consideration the diversity of persons with disabilities, the CRPD measures not only include general measures but also individual measures, such as sign language interpretation.

### **c. Personal autonomy**

The Preamble of the CRPD recognises 'the importance for persons with disabilities of their own autonomy and independence, including the freedom to make their own choices'.<sup>33</sup> In fact, the first principle mentioned in the Convention is 'Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons'.<sup>34</sup>

This principle is related to the previous principle of accessibility and to the next one, participation, but has a broader, more individually oriented scope. A crucial aspect is the right to legal capacity, as guaranteed in article 12 (equal recognition before the law). The shift from a medical to a social and human rights based model becomes very clear here: we can no longer accept that others may decide 'what is good for the disabled'. The right to be an independent person with legal capacity, who is entitled to have as much say as possible on all matters related to his/her own private and public life, is crucial in order to realise our human rights.

At the same time this is one of the provisions that demands fundamental changes in many legal systems: changes in the regulation of financial and legal custody and changes of medical regulations of consent,<sup>35</sup> which often deny an independent voice to people with disabilities.

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<sup>31</sup>General Comment no 2, 22 May 2014, CRPD/C/CG/2.

<sup>32</sup>See Broderick (n 29) 236.

<sup>33</sup>CRPD, pmbi, para (n).

<sup>34</sup>CRPD, art 3.

<sup>35</sup>See also Aart Hendriks and Oliver Lewis, 'Disability' in Bartha Maria Knoppers and Yann Joly (eds), *Routledge Handbook of Medical law and Ethics* (Routledge 2014) 78–97.

The Committee on the Rights of Disabilities has elaborated article 12 in its very first General Comment which illustrates the importance attached to this principle.<sup>36</sup> The Committee reaffirms the fact that legal capacity is indispensable for the exercise of all human rights and is a universal attribute inherent in all persons by virtue of their humanity. Legal capacity and mental capacity are distinct concepts: whereas legal capacity is related to the ability to hold rights and duties, mental capacity is about the decision-making skills of a person, which may vary from one person to another.<sup>37</sup> Crucial is paragraph 3 of article 12, which obliges the States to provide persons with disabilities access to support in the exercise of their legal capacity, and as the Committee states: this ‘should never amount to substitute decision-making’.<sup>38</sup> The support may take various forms and modalities, but the distinction between support and substitution is essential: substituted decision-making has to be replaced by supported decision-making as much as possible.

This subject is closely related to the condition of ‘informed consent’ as the ECtHR and others develop among others in relation to ‘vulnerable groups’ such as Roma, recognising that it is the obligation of the State to take

... any additional measures to ensure that the Roma parents received all the information they needed to make an informed decision or [to see that they] were aware of the consequences that giving their consent would have for their children’s futures.<sup>39</sup>

Thus here too, it is crucial to ensure accessibility of information for all citizens in a way that they are able to receive and understand the information.

At the basis of the personal autonomy lie the freedom of choice and the attribution of agency to all human beings, as explained by Sen and Nussbaum’s capabilities approach.<sup>40</sup> In the capability approach, and in the CRPD the perspective has changed towards recognising what people CAN, what they are capable of, instead of what they can NOT.

#### **d. Participation**

‘Nothing about us without us’ was the much-heard slogan during the preparations of the Disability Convention and is a motto based on the principle of participation.<sup>41</sup> The active involvement of persons with disabilities in the preparations of the CRPD is a great example of how the principle of participation can be put into practice. Participation is also related to equality, as the preamble refers to ‘... participation as equal members of society’ (para k) and one of the principles of the Convention, ‘Full and effective participation and inclusion in society’, is included in article 3.

Participation is a basic condition for human rights, both civil political and ESC rights, and means participation at all levels: from the right to vote to the right to participate in social organisations and sport clubs.<sup>42</sup>

<sup>36</sup>General Comment No 1 (2014), 19 May 2015, CRPD/C/GC/1.

<sup>37</sup>ibid para 12.

<sup>38</sup>ibid para 17.

<sup>39</sup>*DH and others v the Czech Republic*, Application no 57325/00, ECtHR, 13 November 2007, [204].

<sup>40</sup>See e.g. A Sen, ‘Human Rights and Capabilities’ (2005) 6 J of Human Development 151; MC Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard University Press 2011).

<sup>41</sup>From the Latin phrase ‘Nihil de nobis, sine nobis’, a widely used motto by disability rights activists in the 1990s.

<sup>42</sup>See Mark Priestley and others, ‘The Political Participation of Disabled People in Europe: Rights, Accessibility and Activism’ (2016) 42 Electoral Studies 1.

Active measures are required in order to enable all to participate. People with disabilities have to be facilitated to participate, and active measures have to be taken to consult or involve them and their representative organisations. The CRPD itself contains provisions on participation in political and public life, and cultural life, recreation, leisure and sports.<sup>43</sup> A new feature in this Convention is the obligation to ensure that persons with disabilities are involved and fully participate in the monitoring process of the Convention itself: this is not an easy task for many States. Participation is linked to *inclusion* in the Convention, which I name as the fifth underlying principle.

### **e. Inclusion**

In my view, inclusion is the overarching value of the Convention. Inclusion is more than toleration and acceptance. ‘Including others requires a willingness to facilitate or accommodate difference: a willingness to make changes to the game.’<sup>44</sup> Inclusion, in the words of Melinda Jones, is

... the right of the individual and the responsibility of society as a whole. Inclusion requires the removal of barriers and social structures which impede participation. It requires proactive policy making, lateral thinking and on-going commitment.<sup>45</sup>

Inclusion is not described as an independent principle in the CRPD, but in combination with participation. Still, inclusion, the opposite of exclusion, is much broader and is an intrinsic part of many provisions in the Convention, such as the obligation to promote universal design,<sup>46</sup> inclusive education<sup>47</sup> and others.

Since my first steps in the field of feminist legal studies I have been inspired by Martha Minow’s book about making *all* the difference.<sup>48</sup> Again and again I am surprised by how much her analysis still resonates, how much we can learn from it. Minow starts by challenging the way legal analysis uses categories and labels, assuming that they are neutral, when in fact they are not. And how we divide the world into classifications: ‘we use our language to distinguish, to exclude, to discriminate’ and we respond to a person’s ‘traits rather than their conduct, we may treat a given trait as a justification for excluding someone we think is “different”’.<sup>49</sup> She draws attention to the relational aspect and how rights are embedded in relationships.<sup>50</sup> She applies the same shift in perspective as the CRPD does 20 years later, shifting from merely recognising a difference in the other to considering difference as a two-sided phenomenon, or even multi-sided. Minow also argues that an equality approach with an absolute view of difference may exclude those who have ‘different’ traits within the discriminated group, e.g. minority women. Very often people are excluded because of a combination of aspects (e.g. black women, LGBT disabled) and the recognition of this combination of discriminatory factors is known as the intersectionality approach. For this reason, Minow proposes strategies for

<sup>43</sup>CRPD, arts 29–30.

<sup>44</sup>ibid art 63.

<sup>45</sup>Melinda Jones, ‘Inclusion, Social Inclusion and Participation’ in M Jones and others (eds), *Critical Perspectives on Human Rights and Disability Law* (Brill Leiden 2011) 57.

<sup>46</sup>CRPD art 4, para 1(f).

<sup>47</sup>ibid art 24; elaborated recently in a General Comment, see GC 4, 2 September 2016, CRPD/C/GC/4.

<sup>48</sup>Minow, *Making All the Difference* (n 11).

<sup>49</sup>ibid 3.

<sup>50</sup>ibid 15.

... remaking difference including challenging and transforming the unstated norm used for comparisons, taking the perspective of the traditionally excluded or marginal group, disentangling equality from its attachment to a norm that has the effect of unthinking exclusion, and treating everyone as though he or she were different.<sup>51</sup>

Leaving aside here what this proposal to treat every case as ‘different’ entails for lawmakers and lawyers and judges (who simply have to classify and compare, and mould our complex reality into a legal system), I will say that for us, as academics, it is a challenging exercise to think about inclusion and human rights.

The CRPD makes some efforts to include this multiple discrimination perspective by drawing attention to Women and Children with Disabilities in articles 6 and 7.<sup>52</sup> Moreover, apart from the fact that some individuals and groups may experience multiple or additive forms of discrimination and exclusion, the Convention recognises the diversity among persons with disabilities.<sup>53</sup> Inclusion demands inclusion of *all*. Inclusive accessibility is not guaranteed by providing only a ramp for wheelchairs, without provisions for other disabled groups. Inclusion is the core of human rights: all human beings deserve to be part of society in all aspects. Inclusion can be seen as the sum of equality, participation, accessibility, and personal autonomy.

## 6. Towards a ‘Transformative’ Substantive Equality

In fact, these principles of the CRPD reflect what Martha Fredman has described as the four dimensions of substantive equality: ‘redressing disadvantage (the redistributive dimension); addressing stigma, stereotyping, prejudice and violence (the recognition dimension); facilitating voice and participation (the participative dimension) and accommodating difference, including through structural change (the transformative dimension).’<sup>54</sup>

The redistributive dimension is reflected in the way the concept of equality is conceived, including the duty to provide accommodations. This will demand certain redistribution as well. The participative dimension can be found in the principles of participation and accessibility in the CRPD which provides concrete tools and rights to the persons concerned. This concretisation and clarifying language is relevant for other marginalised groups as well. The transformative dimension underlies the principles of autonomy, demanding different approaches of ‘the other’ and inclusion which can only be realised when we are willing to adapt the rules of the game where justice and substantive equality may demand it. The emphasis on the interaction between impairments (and other differences) and attitudinal and environmental barriers illustrates a fundamental shift in perspective.

The transformative dimension is also reflected by O’Cinneide who emphasises that before the CRPD the ‘... mainstream legal vocabulary of human rights struggle[d] to cope with the articulation of disability right claims’.<sup>55</sup> Now that the CRPD has provided

<sup>51</sup>ibid 16.

<sup>52</sup>This is also affirmed in the preamble; where race, property, birth, age and other forms of discrimination are mentioned. See General Comment no 3, 2 September 2016, CRPD/C/GC/3.

<sup>53</sup>CRPD, pmb1 (i).

<sup>54</sup>Fredman, ‘Emerging from the Shadows’ (n 14) 274.

<sup>55</sup>O’Cinneide (n 23) 171.

us with a proper vocabulary, this same vocabulary has become part of the mainstream of human rights and will in turn affect the broader human rights debate. O’Cinneide suggests that the CRPD’s potential impact lies in the possibility of developing ‘... a language of rights that is capable of articulating the needs and entitlements of more individuals than just those who form the liberal archetype of the autonomous, self sufficient individual’.<sup>56</sup>

The way the CRPD conceives, defines and describes the rights of people with disabilities potentially outweighs the disadvantages of the present use of the concept of vulnerable groups. Peroni and Timmer argue that using the concept of vulnerable groups to conceptualise rights of persons with disabilities runs the risk of ‘... sustaining the very exclusion and inequality it aims to redress’.<sup>57</sup> Now that the CRPD’s principles of inclusion, participation and autonomy reflect the necessary empowerment of those who are excluded, treated unequally and whose own will is substituted, the risk of reconfirming vulnerability decreases. In other words, the CRPD’s reciprocity approach of difference and the emphasis on participation, accessibility, inclusion and thus empowerment and assistance, the mainstreaming of the perspective of the ‘vulnerable’ group, in this case persons with disabilities, are measures to ensure a less ‘vulnerable’ approach of vulnerability.

Focusing on the basic principles of the Convention, I have no more time in the context of this lecture to analyse more profoundly the way these principles have been translated into concrete state obligations, which have to be realised progressively. This realisation is a long-term process, and the states have to take measures ‘... to the maximum of its available resources’,<sup>58</sup> actively involving persons with disabilities.<sup>59</sup> What is clear, however, is that the ‘common’ majority perspective can no longer be taken as the assumed standard in human rights and democracy debates and that we have to come out of our comfort zone, the central question is no longer about whether or not a person is different, but how a maximum inclusion of all can be realised in our society.

## 7. New Perspectives on Transformative Equality for All

Now, when we consider the transformative potential of the CRPD, and link that to the current debates: where lies this potential? What does it mean for today’s world?

It may be too pessimistic to say that human rights are in a crisis, but still, I have the impression (and I certainly hope that you can convince me that I am wrong) that human rights are not so ‘sexy’ anymore, that they are less self-evident than they have been (human rights have never been self evident, of course, but within some parts of the world they have enjoyed a certain general acceptance and moral authority).

Symbolic are the attacks on the (human rights) courts who offer protection against the will of the majority in a country, the challenging of the legitimacy of these judgments, which may even amount to risks for the independence of the judiciary. Another feature is the fact that attacks on human rights of specific (minority) groups are more often accepted in the public debate and even applauded. This development is not easy to

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<sup>56</sup>ibid 189.

<sup>57</sup>Peroni and Timmer (n 20) 1057.

<sup>58</sup>CRPD art 4, para 2.

<sup>59</sup>ibid para 3.

combat without unduly restricting the freedom of speech, with all the risks this would entail.

Without having expert knowledge of the general social background of this development, but as an ‘informed layman’, reading about the increasing education-gap and the persistence of poverty of many groups, I am struck by the feeling that perhaps we have not (or at least not sufficiently) noticed the emergence of new, less well-defined, forms of exclusion in our societies. This new exclusion provides a negative common voice to the groups concerned, who somehow seem to feel that ‘human rights are not for me, but only for those who get my jobs, my houses, threaten my children and my security’. These people or groups, united perhaps solely by negative aspects of perceiving themselves as ‘have-nots’, feel excluded, and in some cases they may be right in a certain way. This allows them to perceive themselves as vulnerable, so they claim the right to defend themselves by all possible means. Of course, this is a simplistic impression, but I am just trying to put a name to some impressions.

The concept of vulnerability may offer tools to understand their position and incorporate their needs in a human rights frame, but that implies that we have to reconceptualise vulnerability, not only to avoid the stigmatising effects of the term,<sup>60</sup> but we may have to reconsider the contextual aspect of vulnerability. In Timmer and Peroni’s analysis of the concept of vulnerable groups, they refer to Anna Grear, who argues that ‘many groups that do not fit the liberal archetype – women, dispossessed, people of colour and (especially) asylum seekers – (...) fall outside the purportedly universal protection of human rights’.<sup>61</sup> This is exactly how the persons I refer to perceive themselves: falling outside the protection of human rights.

Indicators that Peroni and Timmer distinguish in the approach by the ECtHR of vulnerability may be helpful here: prejudice and stigma, social disadvantage and material deprivation. They are linked to Fredman’s four aims of substantive equality, as mentioned above. The complaint of large groups that ‘their voice is not heard’ refers to the need to find more positive ways to increase the participation of these persons, to make them feel that their views are taken into account. This implies probably different, more accessible forms of communication. Transformation demands due attention for the perspective of the less privileged, even when they are not so easily identifiable, and the impact of (lack of) education and poverty has to be recognised. Redistribution is necessary to break out of the spiral of reinforcing and reaffirming patterns of disadvantage, poverty, lack of educations and opportunities. Finally, Fredman’s plea for recognition demands ‘respect for dignity and worth’. As these aims are connected to prejudice and stigma it will be necessary to analyse what precisely are the stereotypes and stigmas that are applied to these groups: what are their common characteristics, how are they defined by others and by themselves?

This brings me back to the CRPD and the overarching goal of inclusion, based on concrete principles and defined in terms of concrete duties of accessibility, equality, participation and autonomy, demanding a shift in perspective to the interaction between the characteristics of a person and the barriers that hinders full and effective participation.

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<sup>60</sup>As suggested by Martha Fineman: see Peroni and Timmer (n 20) 1059.

<sup>61</sup>ibid 1061.

Perhaps we need this type of shift in a much broader sense, beyond the field of what we define now as disability, to understand why an increasing number of people do not see human rights as a reaffirmation of *their* human dignity. A first step in the right direction may be to realise our inability to do so and seek assistance in order to become more aware of our own stereotypes and prejudices. Needless to say that this also demands real 'leaders' with a true commitment to human rights as did the founders of our human rights framework.

Human rights are never self-evident, and usually give no easy solutions. We need human rights scholars, such as Torkel Opsahl, to challenge us. I can only hope that he would and you have been challenged by my words and of course, that you all will embrace the values embedded in the Disability Convention.