The 2008 UN Convention on the Rights of Persons with Disabilities (CRPD) provides a landmark articulation of the universality of human rights. It affirms in strong terms that all human beings have a claim to full inclusion and equal participation in society, something denied to many because of disability. The CRPD is an ambitious document with far-reaching and fundamental implications. This interdisciplinary collection of essays takes up pressing philosophical, legal, and practical issues raised by the CRPD and the ongoing process of its implementation. Combining clear legal and philosophical overviews with ground-breaking conceptual analyses, the collection aims to advance the academic debate about human rights and disability and to serve as a useful resource for policy-makers, ethicists, disability activists, jurists, and all those interested in the human rights of persons with disabilities.

Cover image taken from a restroom door at the Museu Colecção Berardo in Lisbon, Portugal.
Used with permission. Design by R2 Design <http://www.r2design.pt>. Photograph by Joel Anderson.

Disability and Universal Human Rights Joel Anderson and Jos Philips, Eds. SIM special 35

SIM

Disability and Universal Human Rights:

Legal, Ethical, and Conceptual Implications of the Convention on the Rights of Persons with Disabilities

SIM special 35 (2012)

Edited by Joel Anderson and Jos Philips

Universiteit Utrecht

Disability and Universal Human Rights

Disability and Universal Human Rights

Legal, Ethical, and Conceptual Implications of the Convention on the Rights of Persons with Disabilities

edited by

Joel Anderson and Jos Philips

SIM Special 35 (2012)

Netherlands Institute of Human Rights

Joel Anderson and Jos Philips (eds)

Disability and Universal Human Rights: Legal, Ethical, and Conceptual Implications of the Convention on the Rights of Persons with Disabilities

SIM Special 35

A Publication of the Netherlands Institute of Human Rights (SIM)

Utrecht University (October, 2012)

ISBN/EAN: 978-90-393-5863-4
NUR-code: 828

Keywords: disability, human rights, United Nations, Convention on the Rights of Persons with Disabilities (CRPD), law, ethics, social model of disability, discrimination, inclusion, capability approach

Contents

Contributors

Joel Anderson is Research Lecturer in Philosophy at Utrecht University (The Netherlands). His research focuses on philosophical anthropology (esp. links between autonomy, agency, normativity, and varying degrees of capability), ethics (esp. discourse ethics and neuro-ethics), and social theory (esp. "recognition theory", nudge paternalism, and the conditions for developing autonomy skills). He currently leads a four-year research project focused on developing assistive technology for improving individuals' capacities for self-regulation. In addition to publishing in a wide range of journals, he co-edited (with John Christman) *Autonomy and the Challenges to Liberalism* (Cambridge University Press, 2005). His current book project is entitled *Autonomy Gaps*.

Marcus Düwell is Professor of Philosophical Ethics and Head of the Ethics Institute at Utrecht University (The Netherlands). His research concentrates on questions concerning the foundation of morality and on applied ethics in its relation to ethical theory and political philosophy. He is Chair of the ESF Networking Programme "Rights to a Green Future", and leads the research project "Human Dignity as the Foundation of Human Rights?" and the research project "What Can the Humanities Contribute to Our Practical Self-Understanding?" He has published in a wide range of journals and co-edited several books. He is author of *Bioethics: Methods, Theories, Scope* (forthcoming with Routledge in 2012) and editor of *The Cambridge Handbook on Human Dignity* (forthcoming with Cambridge University Press in 2012).

Jenny E. Goldschmidt is Professor in Human Rights Law and Director of the Netherlands Institute of Human Rights (SIM) at Utrecht University (The Netherlands). She has been president of the Dutch Equal Treatment Commission for 9 years and is member of the commission Disability Studies in the Netherlands.

Sigrid Graumann is Professor at the University for Applied Sciences in Bochum (Germany). She teaches ethics in the context of special education and nursing. Her main research subjects are bioethics, disability, and human rights. She is member of the Central Ethics Commission of the German Medical Association, board-member of the Academy of Ethics in Medicine (Germany), and a member of the Commission for Genetic Diagnosis of the German Government.

Caroline Harnacke is PhD Researcher in Philosophy at Utrecht University (The Netherlands). Her PhD-project aims to investigate the diverse conceptions of the human brought forward in the debates on disability and enhancement, and to examine the strategies used to justify these conceptions. The project forms part of the NWO-funded programme "What Can the Humanities Contribute to Our Practical Self-Understanding?". In addition, she is interested in foundational questions in applied ethics, especially bioethics, and conceptual questions of human rights. From 2007 until 2009 she worked at Rambøll Management, a political consultancy with a focus on policy analysis and evaluations of social and welfare policies.

Jos Philips is Lecturer in Philosophy at Utrecht University (The Netherlands). He works on global justice, human rights, and sustainability. He has published various articles on individual responsibilities in relation to poverty, on NGO responsibilities, and on conceptual questions of human rights. He is coordinator of the European Science Foundation Research Network "Rights to a Green Future".

Jackie Leach Scully is Professor of Social Ethics and Bioethics, and Co-Director of the Policy, Ethics and Life Sciences (PEALS) Research Centre at Newcastle University (UK). Her research interests focus on the processes through which moral understandings are formed, particularly around new biomedical technologies, on disability and embodiment, and on feminist bioethics. She currently leads the research project "Faithful Judgements: The Role of Religion in Lay People's Ethical Evaluation of New Reproductive and Genetic Technologies". Her books include *Disability Bioethics:*

Moral Bodies, Moral Difference (Rowman & Littlefield, 2008) and (co-edited with Petya Fitzpatrick and Laurel Baldwin-Ragaven) *Feminist Bioethics: At the Center, On the Margins* (Johns Hopkins University Press, 2010).

Jan Vorstenbosch is Assistant Professor of Applied Ethics at Utrecht University (The Netherlands). He publishes widely on issues in animal ethics, ethics of care, ethics of technology and sports ethics, and is the author of *Twaalf huishoudelijke apparaten* (Nieuwezijds, 2000), *Zorg: een filosofische analyse* (Nieuwezijds, 2005), and *Voetbalgek* (Lemniscaat, 2010).

Esther van Weele is a Legal Policy Officer at the Dutch Equal Treatment Commission, which is preparing for the establishment of a National Human Rights Institute. She is a former Researcher at the Ethics Institute at Utrecht University (The Netherlands) and a former Research Associate and Lecturer of International Public Law at the Netherlands Institute for the Law of the Sea at Utrecht University.

Acknowledgements

The present volume would not have existed without the involvement and support of a number of people and institutions. First of all, we are grateful to Esther van Weele. She made invaluable contributions to the project of which this book is a product, and she greatly helped with shaping the early versions of the present book.

We are also grateful to Utrecht University's Research Focus Area "Conflicts and Human Rights", which provided financial support to this book and an encouraging context in which to pursue research on the theme of the present book. We would like to thank Suzanne van Vliet for helping to arrange the two intense weeks of workshops in which the first drafts of these chapters were planned, written, and discussed. Finally, we want to thank Hanneke van Denderen for assistance with the final stages of preparing the volume.

Utrecht, August 2012 The Editors

Editors' Introduction

Joel Anderson and Jos Philips

In 2008 the UN adopted the Convention on the Rights of Persons with Disabilities (CRPD), and signatory states are currently in the process of ratifying and implementing this Convention. The CRPD aims at securing for those with disabilities human dignity and full participation in society, and it specifies what it takes to effectively protect their human rights, particularly in light of the distinctive vulnerability and enormous diversity of this group.

The CRPD was adopted with evidently wide support, garnering more signatories on the first day than any previous UN Convention. It has been seen as a paradigm shift in conceptions of disability and human rights, not by introducing "new rights" but by expanding and deepening our understanding of the universal scope of human rights. As a legal instrument, it establishes a global commitment to the legal protections and guarantees for persons with disabilities, one that is significantly more specific and binding than previous human rights documents.

More particularly, the paradigm shift implicit in the CRPD has two aspects. First of all, the CRPD asserts that a diverse array of disability-related claims and requirements are no longer to be regarded as a matter of charity but rather as a matter of human rights. Secondly, the CRPD provides a particularly emphatic statement of how human rights protections of vulnerable persons cannot legitimately be limited to prohibiting interference with individuals (negative rights) but require active measures aimed at supporting and enabling persons and their communities. The human rights of persons with disabilities thus include not only "negative" rights, such as freedom from assault or reproductive liberties, but also "positive" rights, such as assistive technologies, accommodating workplace practices, and effective access to information and public services – all of which require extensive actions on the part of states.

Not surprisingly, then, the CRPD is widely considered to be an especially ambitious document, giving rise to concerns about its implementation. States face extremely difficult questions about how to go about meeting their obligations under the Convention. However true it may be that human rights are all of equal priority, states have limited resources and cannot avoid making decisions about the specifics of their implementation strategies: whether to focus on infrastructural investments that improve accessibility or on providing assistive devices that allow individuals to navigate less accessible environments; whether to focus on early-childhood programs addressing mild cognitive impairments or programs for seniors with sensory impairments; and so on. As ethicists are quick to point out, without principled guidelines, priority-setting runs the risk of becoming an ad-hoc exercise, which could be harmful to the cause of disabled persons.

There is thus an urgent need for systematic analysis of implementation and prioritization issues raised by the CRPD. More generally, the Convention requires a better understanding of its concepts and backgrounds, and of the transformations that it implies. These are the themes with which the present volume is concerned, with a focus on three specific tasks. Firstly, it provides a state-of-the-art overview of the CRPD. Second, it analyzes several transformative aspects of this Convention (social, juridical, philosophical etc.). And third, it examines questions of priority-setting that arise in relation to the implementation of the CRPD.

The essays in this book were written by a multidisciplinary research group that includes philosophers, lawyers, and social scientists. In addition, some researchers also have a background in the human rights movement and/or the disability movement. The book addresses itself to a diverse audience. Readers will find in-depth chapters probing overlooked aspects of the CRPD, as well as chapters that provide background for nonspecialists. There is much of relevance to practitioners in the disability and human-rights movements and policymakers at different levels (local, national and transnational), as well as original research for researchers from various disciplinary backgrounds. Moreover, taken as a whole, this collection of essays provides an integrated statement of pressing philo-

sophical, legal, and practical issues raised by the CRPD and the ongoing process of its implementation.

Part One provides a thorough briefing on the CRPD. *Esther van Weele* discusses its juridical background, as well as the ways in which (and the extent to which) the Convention constitutes a transformation from a juridical perspective. She stresses, in particular, the ways in which the Convention differs from preceding disability-related law and policy in its more binding character and in addressing the specific needs and obstacles that persons with disabilities face. *Caroline Harnacke and Sigrid Graumann* identify the defining conceptual and ethical dimensions of the CRPD, along with the social and theoretical context in which it was adopted. In particular, they highlight the extent to which the Convention reveals that, once disability is seen from the perspective of recognition of the centrality of disability, many human rights that are typically understood as "negative rights" (in the sense of "freedom from") turn out to have a fundamental "positive-rights" or claim-rights dimension to them.

Part Two focuses on the ways in which the CRPD brings with it a transformation of our thinking about specific domains of human rights. The interview conducted by *Joel Anderson and Jos Philips* with *Jenny Goldschmidt* highlights how the CRPD, while not actually identifying any wholly new rights, does significantly change our understanding of the universality of human rights. The interview is also particularly thought-provoking with regard to the difference between juridical and ethical approaches to issues of implementation (a theme that returns in Part Three). *Jackie Leach Scully* argues, in her contribution, that the Convention implies a shift in our cultural understanding of disability by re-framing disability as an abiding and fundamental part of human diversity and no longer as a condition that all would doubtlessly be better off without. *Sigrid Graumann* then goes on to argue that the Convention contains a much richer concept of discrimination than had been used before, and one that is much more closely connected with the concept of recognition. *Joel Anderson* examines, in his chapter, the implications of the Convention for our understanding of the voting rights of persons with intellectual disability, focusing especially on the recent

conclusions of the UN Human Rights Committee that voting restrictions based on mental capacity are incompatible with the CRPD. In the final essay of Part Two, *Jan Vorstenbosch* discusses difficult tensions and conflicts between the "logic" of particular practices and a "logic" of rights, including disability rights. He shows this by discussing two case studies taken from the sports practices of golf and athletics. Taken together, the essays in the second part of this book highlight a rich palette of transformative aspects of the Convention.

The chapters in Part Three are concerned with issues of priority-setting that arise in implementing the Convention. *Jos Philips* considers whether the human rights practice should strive to determine principled priorities between and within rights – and to give such priorities a prominent place in human rights practice. He argues that it is in the end most important to stress the priority *of* human rights vis-à-vis other policy considerations. In contrast, the two essays that follow aim to discuss possible ways of setting priorities between and within rights. *Caroline Harnacke* examines the potential, for principled priority-setting, of Martha Nussbaum's influential Capability Approach. She concludes, however, that this approach is insufficiently helpful with regard to the task of setting priorities in implementing the CRPD. *Marcus Düwell* proposes a number of features that an ethical theory would have to display in order to justify the moral claims underlying the CRPD, and he makes several suggestions concerning how such a theory could go about setting priorities.

Taken together, the essays in this book aim to advance our critical appreciation of the rich transformative aspects of the CRPD – including the Convention's reconceptualization of disability as an abiding part of the human condition, and its view of discrimination, which is more expansive than has been common in the past. Furthermore, by reflecting on the underlying approach of the Convention and of the human rights framework as a whole, the essays aim to advance our understanding of the problems of priority-setting that arise in relation to this Convention. We hope this offers insights that can lead to an improved implementation of the CRPD, which is of the highest urgency if the human rights of persons with disabilities are to be effectively protected and promoted.

The present volume is thus not only an examination of where we are now but also an attempt at agenda-setting. We hope it will be helpful for policymakers, ethicists, disability activists, jurists, and all those interested in the human rights of persons with disabilities, and that it will serve as a catalyst for further research and reflection.

Part I

Background and Context

1 The UN Convention on the Rights of Persons with Disabilities in the Context of Human Rights Law

Esther van Weele

1 Introduction

The UN Convention on the Rights of Persons with Disabilities[1] (CRPD) and its Optional Protocol[2] were adopted on 13 December 2006 at the United Nations Headquarters in New York by general consensus. The Convention and its Optional Protocol were opened for signature on March 30, 2007, with 82 signatories to the Convention, 44 signatories to the Optional Protocol, and one ratification of the Convention, the highest number of opening-day signatories ever for a UN Convention. The Convention entered into force on May 3, 2008, and today[3] there are 112 ratifications of the Convention and 64 ratifications of the Optional Protocol.

The adoption of the CRPD and its Optional Protocol is considered a milestone for the 650 million people around the world living with disabilities.[4] Why is this Convention of historic importance even though the human rights of persons with disabilities are also protected under other human rights instruments? That is the question this chapter seeks to answer. Section 1 considers the position of persons with disabilities in other human rights law. For this purpose, not only the eight other core United Nations human rights conventions are examined (Section 2) but also non-legally binding soft law

---

[1] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 70.

[2] Optional Protocol to the Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) GA Res. A/RES/61/106 (13 December 2006).

[3] United Nations Enable, *Ratifications and Signatories of the Convention and Its Optional Protocol,* available at <www.un.org/disabilities> accessed 22 April 2012.

[4] United Nations, *From Exclusion to Equality – Realizing the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention of the Rights of Persons with Disabilities and its Optional Protocol*, (Geneva: United Nations, 2007), 1.

instruments such as General Assembly resolutions (Section 3). The subsequent section addresses how the CRPD may change the state of the art described in the previous sections (Section 4). In the concluding section, one of the distinctive characteristics of this Convention is highlighted, namely, the requirement of a focal point within national governments and an independent mechanism for the national implementation and monitoring in Article 33 of the CRPD (Section 5). This chapter neither elaborates on the paradigm shift that is embodied by the Convention, nor on the content of the principles, rights and obligations in the CRPD. Caroline Harnacke and Sigrid Graumann delve into these topics in their chapter. Given the historical focus of this chapter, it only considers the protection of persons with disabilities before the CRPD entered into force on 3 May 2008.

2 Disability in the History of United Nations Human Rights Instruments

Before the adoption of the CRPD, none of the eight United Nations human rights treaties expressly protected the rights of people with disabilities. Individuals with disabilities could in theory appeal to universal provisions or claim protection on the basis of another characteristic such as gender or race. In practice these legal obligations were, however, rarely applied to persons with disabilities because they were not designed to address the specific needs and obstacles that a person with disabilities faces.[5]

The International Covenant on Civil and Political Rights (ICCPR),[6] the International Covenant on Economic, Social and Cultural Rights

[5] O.M. Arnardóttir, "A Future of Multidimensional Disadvantage Equality?" in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* edited by O.M. Arnardóttir and G. Quinn, (Leiden: Martinus Nijhoff, 2009), 45.

[6] International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171.

(ICESCR),[7] the Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (CAT)[8] and the International Convention for the Protection of All Persons from Enforced Disappearance (CPED)[9] include rights that are universal in scope. These four treaties are hence also applicable to individuals with disabilities, although these are not explicitly mentioned. Article 2 and 26 of the ICCPR and Article 2(2) of the ICESCR aim to protect against discrimination of any kind and mention the following grounds: race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Disability is encompassed by the notion "and other status".[10] Although these non-discrimination clauses call for immediate implementation according to the Limburg Principles,[11] previous efforts have proven to be unsuccessful. One exception of minor importance is Article 7 of the CPED stating that persons with disabilities are particularly vulnerable and that therefore States Parties may determine aggravating circumstances when the offence of enforced disappearance is punished.

Four other human rights treaties that have been adopted by the General Assembly protect people with specific identity characteristics, such as race, gender, children or migrant workers. These conventions are the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)[12]; the Convention on the

---

[7] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3.

[8] Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (adopted 10 December 1984, entered into force 26 June 1987) 1465 UNTS 113.

[9] International Convention for the Protection of All Persons from Enforced Disappearance (adopted 20 December 2006, entered into force 23 December 2010) GA Res. A/RES/61/177 (2007).

[10] I.E. Koch, "From Invisibility to Indivisibility," in *The UN Convention on the Rights of Persons with Disabilities,* 73 and General Comment No. 9, *The Rights of Children with Disabilities*, Committee of the CRC (2006).

[11] The Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights, UN doc. E/CN.4/1987/17, Annex.

[12] International Convention on the Elimination of All Forms of Racial Discrimination (adopted 7 March 1966, entered into force 4 January 1969) 660 UNTS 195.

Elimination of All Forms of Discrimination against Women (CEDAW)[13]; the Convention on the Rights of the Child (CRC)[14]; and the International Convention on the Protection of All Rights of Migrant Workers and Members of Their Families (ICPMW)[15]. The CRC is the only treaty that refers to disabilities, requiring that "States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (Article 23(1)). However, this obligation does not require that children with disabilities be treated or considered equal to children without disabilities. Moreover, the obligation to provide special care for children with disabilities is weakened because it is "subject to available resources".[16] Besides this provision, persons with disabilities can only invoke the rights in the treaties when there is an overlap with the characteristic targeted by the Convention.

Despite both the absence of explicit mention of persons with disabilities in the core human rights treaties and the failures to consider the just claims of persons with disabilities, some of the relevant treaty-monitoring bodies did seek to draw attention to the rights of persons with disabilities.[17] The United Nations Commission on Human Rights also urged the treaty-monitoring bodies to take due account

[13] Convention on the Elimination of All Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13.
[14] Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 44.
[15] International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (adopted 18 December 1990, entered into force 1 July 2003) 2220 UNTS 93.
[16] M.A. Stein and J.E. Lord, "Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities," in *The UN Convention on the Rights of Persons with Disabilities,* 20 footnote 20. See also T. Hammarberg, "The Rights of Disabled Children: The UN Convention on the Rights of the Child," in *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments*, edited by T. Degener and Y. Koster-Dreese, (Dordrecht: Kluwer Academic Publishers, 1995), 147-155.
[17] G. Quinn, "Resisting the Temptation of Elegance," in *The UN Convention on the Rights of Persons with Disabilities,* 217.

of persons with disabilities in various resolutions.[18] Each human rights Convention has a monitoring body, a committee charged with enforcing or monitoring the implementation of any given treaty. The States Parties are primarily responsible for the implementation of the treaty. The role of the monitoring committee is secondary and facilitates a constructive and open dialogue with States Parties.[19] It is an independent expert organ composed of members from various parts of the world, assigned to monitor states compliance with the treaty. The monitoring committees have three primary functions. First, each State Party is obliged to submit periodic reports on the implementation of the Convention. This procedure results in concluding observations in which the committee assesses the state-specific issues and provides recommendations explaining how compliance with the Convention should be improved. Concluding observations are the most authoritative since they reflect consensus across all members.[20] Second, the committees compose "General Comments" on issues of interpretation arising under a specific treaty provision, procedure or substance. The General Comments provide guidance to States Parties about what to include in their reports and have acquired the status of authoritative interpretations.[21] Third, five of the nine human rights treaty bodies[22] may, under specific circumstances, consider individual complaints or communications from individuals. This part of the work of the committees is

[18] T. Degener and G. Quinn, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, (New York and Geneva: United Nations, 2002), 47.

[19] G. Quinn, "Resisting the 'Temptation of Elegance': Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?" in *The UN Convention on the Rights of Persons with Disabilities*, 225.

[20] P.M. Taylor, *Freedom of Religion: UN and European Human Rights Law and Practice*, (Cambridge: Cambridge University Press, 2005), 12.

[21] I. Boerefijn and J. Oyediran, "Article 20 of the International Covenant on Civil and Political Rights," in *Striking a Balance: Hate Speech, Freedom of Expression and Non-Discrimination*, edited by S. Coliver, (Essex: Article 19 International Centre Against Censorship, Human Rights Centre University of Essex, 1992), 30.

[22] The ICCPR, ICERD, CAT, CEDAW and the CRPD. The ICPMW also contains provisions for allowing individual communications to be considered by the committee; these provisions will become operative when 10 States Parties have made the necessary declaration under Article 77.

closest to judicial decision-making. However, the monitoring body is not a court, and the cases are reviewed through written submissions. There is no provision regarding the binding nature of the final reviews of the committees. The findings of the committees constitute legal interpretations by the expert body and are not mere recommendations. The views adopted are important in developing the interpretation and understanding of the legal obligations stemming from the Conventions.[23] Hence, the composition and the jurisdiction of the treaty monitoring bodies are universal in character, applying one set of standards to a wide range of circumstances, and thereby protecting human rights through two or three different procedures. Most individual complaints addressing disability issues were considered inadmissible and few General Comments about this topic have been adopted. The relevant General Comments, individual complaints and recommendations are addressed subsequently.[24]

Of the General Comments that mention disability, fewer than twenty either address disability-based discrimination or point out that persons with disability require special attention and protection. Only three General Comments specifically address the human rights of persons with disabilities. General Comment 5 of the committee on Economic, Social and Cultural Rights defines how the ICESCR should be interpreted and implemented concerning persons with disabilities. It was the first UN legal document to define disability-based discrimination:[25]

> For the purposes of the Covenant, "disability-based discrimination" may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing

[23] M. Scheinin, "The Human Rights Committee and Freedom of Religion or Belief," in *Freedom of Religion or Belief: A Deskbook,* edited by L. Tore, W. Cole Durham, B. G. Tahzib-Lie, (Leiden: Martin Nijhoff Publishers, 2004), 192.

[24] For a more elaborate analysis see Degener and Quinn, *Human Rights and Disability*, especially part 2.

[25] T. Degener, "International Disability Law – A New Legal Subject on the Rise: The Interregional Experts' Meeting in Hong Kong, December 13-17, 1999," *Berkeley Journal of International Law* 18(2000): 190.

> the recognition, enjoyment or exercise of economic, social or cultural rights.[26]

It requires states to adopt legislation because to "deter future discrimination, comprehensive anti-discrimination legislation in relation to disability would seem to be indispensable in virtually all States Parties".[27] Furthermore, states are obliged to promote progressive realization of the relevant rights to the maximum of their available resources and this implies the following:

> The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.[28]

States should hence also provide the means to people with disabilities to take advantage of the rights and freedoms provided by the Covenant. The Covenant provides the means of empowering people with disabilities to live independently and support for a life of active participation in society. However, States Parties do usually not connect ICESCR rights with the achievement of autonomy and participation. Nevertheless, General Comment 5 and the ICESCR are still important in allocating appropriate support that enables people with disabilities.

As has been discussed previously, the CRC is the only human rights treaty that contains a specific article on disabilities (Article 23). The Committee on the Rights of the Child is highly aware of

[26] General Comment 5, *Persons with Disabilities,* Committee on Economic, Social and Cultural Rights (1994), paragraph 15.
[27] Ibidem, paragraph 16.
[28] Ibidem, paragraph 9.

disability issues[29] and adopted the comprehensive General Comment 9 on the rights of children with disabilities. The Committee notes that children with disabilities experience difficulties and barriers to the full enjoyment of the rights enshrined in the Convention and that these barriers should be removed.[30] The Comment provides guidance to States Parties on how to implement the rights of children with disabilities in relation to all the provisions of the Convention.

The Committee on the Elimination of Discrimination against Women adopted General Recommendation 18 on women with disabilities which requests States Parties to include information on women with disabilities in their periodic reports with respect to their exercise of several rights contained in the Convention. Furthermore, the Committee addressed the issue of disability in other thematic recommendations.[31] In the periodic reports there was little consistent reporting on the double discrimination experienced by women with disabilities.[32]

The freedom and participation protected by the ICCPR play an important role for people with disabilities, since they aspire to have access to the same rights and civic responsibilities in society as others. Respect for the civil and political rights of people with disabilities would not only protect them against abuses, but also remove obstacles to their inclusion and participation in society.[33] However, many States' reports treat disability as a welfare issue and not as a rights issue under the ICCPR. Most of the individual complaints addressing disability issues submitted to the Human Rights Committee were found to be inadmissible. One of the admissible indi-

[29] Degener and Quinn, *Human Rights and Disability*, 6.
[30] General Comment 9, *The Rights of Children with Disabilities,* Committee on the Rights of the Child (2006), paragraph 5.
[31] General Comment 24, *Women and Health*, Committee on the Elimination of Discrimination against Women (1999), General Comment 25, *Temporary Special Measures* (2004).
[32] Degener and Quinn, *Human Rights and Disability*, 6.
[33] Ibidem, 4.

vidual complaints, *Hamilton v. Jamaica,*[34] concerned the application of Article 10 of the Covenant (treatment of detained persons with humanity) to prisoners with disabilities. The Committee found a violation and held that States Parties have the duty to provide reasonable accommodation for prisoners with special needs. This indicates that it may be necessary to take additional measures to ensure the human rights of people with disabilities. The case *Corey Brough v. Australia* also concerned a detained person with a disability. The complainant is a juvenile Aboriginal who suffers from a mild mental disability. The Committee held that his

> extended confinement to an isolated cell without any possibility of communication, combined with his exposure to artificial light for prolonged periods and the removal of his clothes and blanket, was not commensurate with his status as a juvenile person in a particularly vulnerable position because of his disability and his status as an Aboriginal.[35]

The hardship of the imprisonment was therefore found to be incompatible with his condition and the Committee found a violation of Article 10(1) (treatment of detained persons with humanity) and Article 3 (juvenile offenders shall be accorded treatment appropriate to their age and legal status) of the ICCPR. In another disability case, *Clement Francis v. Jamaica*,[36] the complainant held among other things that the stress of waiting for the execution of the death penalty in the absence of appropriate psychiatric attention substantially damaged his mental health. In summary, the complaint was that the conditions of imprisonment caused the onset of a disability. The Committee found, inter alia, violations of the prohibition to torture (Article 7) and the complainant's right to be treated with

---

[34] *Hamilton v. Jamaica,* communication No. 616/ 1995, Views adopted by the Committee on 28 July 1999 (CCPR/C/66/D/616/1995).
[35] *Corey Brough v. Australia,* communication No. 1184/2003, Views adopted by the Committee on 17 March 2006, paragraph 9.4.
[36] *Francis v. Jamaica*, Communication No. 606/1994, Views adopted by the Committee on 3 August 1995 (CCPR/C/54/D/606/1994).

dignity (Article 10(1)). These cases indicate that the Committee is aware of how poor conditions of imprisonment can lead to disability and it is also watchful over incarcerated persons with disability. This is a welcome development because many prisoners have physical or mental disabilities.[37]

Although people with disabilities who live in residential care are especially vulnerable to abuse, States Parties do not include disability issues significantly in their reports to the Committee against Torture.[38] States Parties do, on the other hand, include information on discrimination on the ground of disability in their periodic reports to the Committee on the Elimination of Racial Discrimination.[39] Persons with disabilities who also belong to a racial or other minority group may face double discrimination on account of their race and disability as was also acknowledged at the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance.[40] When the CRPD entered into force on 3 May 2008 the Committee on Migrant Workers only relatively recent started functioning. The CPED entered into force on 23 December 2010 and hence the Committee on Enforced Disappearance could not include disability in its work before 2008 either.

3 Non-Binding Documents on Persons with Disabilities and the Shift towards the Social Model

In addition to the legally binding human rights treaties, there are various non-legally binding General Assembly declarations and resolutions that consider disability. The limitation of these "soft laws" is that they are not enforceable by individuals on the basis of disability. These non-legally binding instruments indicate the shift that has taken place from an approach motivated by charity towards the per-

[37] Degener and Quinn, *Human Rights and Disability*, 76.
[38] Ibidem, 6.
[39] Idem.
[40] Organised by the United Nations in Durban, South Africa, 31 Augustus – 7 September 2001.

son with a disability to one based on viewing persons with disabilities as holders of human rights. The human rights perspective on disability means viewing people with disabilities as *subjects* and not as *objects*. It locates the problems outside the person with a disability and addresses the manner in which society does or does not address the difference of disability. Theresia Degener distinguishes four periods of the position of persons with disabilities in de UN human rights system: persons with disabilities as invisible citizens (1945-1970); persons with disabilities as subjects of rehabilitation (1970-1980); persons with disabilities as objects of human rights (1980-2000); and persons with disabilities as human rights subjects (since 2000).[41] In what follows, each period will be discussed, as well as the declarations and resolutions adopted, to illustrate the trend in that period.[42]

3.1 The Period 1945-1970: Persons with Disabilities as Invisible Citizens

In the period of 1945-1970, persons with disabilities were invisible in the UN charter, human rights treaties and in the work of the UN Human Rights Commission. The General Assembly and the Economic and Social Council did adopt a number of resolutions from the 1950s onwards dealing mainly with prevention and rehabilitation. The Economic and Social Council seems to have been very active. It adopted a major resolution in 1950 dealing with "Social Rehabilitation of the Physically Handicapped".[43]

---

[41] T. Degener, "Die UN-Konvention: Menschenrechtsschutz für behinderte Menschen," held at the Fachtagung NW Art. 3 / DGRW / IMEW, Berlin, January 14 (2010).

[42] For a more comprehensive analysis see Degener and Quinn, *Human Rights and Disability*, especially part 1, and for more information and documentation see the website of the Secretariat for the CRPD and the Optional Protocol, <www.un.org/disabilities>. See also, the chapter by Harnacke and Graumann in this volume.

[43] U.N. Economic and Social Council [ECOSOC], *Social Rehabilitation of the Physically Handicapped: Report of the Social Commission*, 6th Sess., U.N. Doc. No. E/AC.7./L.24 (July 13, 1950).

3.2 The Period 1970-1980: Persons with Disabilities as Subjects of Rehabilitation

Although the UN World Health Organization focused on the prevention and rehabilitation of disability,[44] the General Assembly adopted two significant resolutions in the 1970s that illustrate a small shift towards a rights-based approach. In 1971 the General Assembly adopted a resolution entitled "Declaration on the Rights of Mentally Retarded Persons".[45] Article 1 of the resolution recognizes that persons with disabilities enjoy the same human rights as all other human beings. Furthermore, it affirms rights that are especially important to persons with disabilities, namely the right to proper medical care, training and rehabilitation (Article 2); to a decent standard of living and to engage in any meaningful occupation to the fullest possible extent of their capabilities (Article 3); to a qualified guardian (Article 5); and to protection from abuse and human rights violations (Article 6 and 7).

In 1975 the "Declaration on the Rights of Disabled Persons"[46] was adopted by the General Assembly. Remarkable is its recognition that persons with disabilities are entitled to the measures designed to enable them to become as self-reliant as possible (paragraph 5). This also indicates another step towards the social model. Furthermore, the Declaration recognized the civil and political rights (paragraph 4) and economic and social rights that are so important for the development of capacities and social integration (paragraph 6). Moreover, it was stated that organizations of persons with disabilities should be "usefully consulted in all matters regarding the rights of disabled persons" (paragraph 12).

---

[44] Degener, "Die UN-Konvention".
[45] General Assembly resolution 2856 (XXV1) of 20 December 1971.
[46] General Assembly resolution 3447 (XXX) of 9 December 1975.

3.3 The Period 1980-2000: Persons with Disabilities as Objects of Human Rights

During this period, a paradigm shift from the "charity" model to the "rights" model took place. The year 1981 was proclaimed the International Year of the Disabled (IYDP)[47] by the United Nations General Assembly with the theme "Full Participation and Equality". The resolution called for a World Programme of Action with an emphasis on equalization of opportunities, rehabilitation and prevention of disabilities (paragraph 3). It also defined it as the right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equal to those of other citizens, and have an equal share in improved conditions resulting from socio-economic development. The IYDP was followed by the International Decade of Disabled Persons from 1983 to 1992.

In 1982 the General Assembly adopted the "World Programme of Action concerning Disabled Persons" (WPA).[48] The WPA is a global strategy to enhance disability prevention, rehabilitation and equalization of opportunities, which pertains to full participation of persons with disabilities in social life and national development. The WPA also emphasizes the need to approach disability from a human rights perspective which indicates a shift towards the rights based approach. The aims of disability prevention and rehabilitation are the traditional ones found in the "caring" model.

In three chapters, the WPA provides objectives, background and concepts (paragraphs 1 to 36); the current situation (paragraphs 37 to 81); and proposals for the implementation of the WPA (paragraphs 82 to 200). The WPA requires periodic monitoring at the domestic, regional and international levels and is reviewed every five years. Two influential United Nations studies carried out in the 1980s have led to two key resolutions. Erica-Irene A. Daes, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, wrote *Principles, Guidelines and*

[47] General Assembly resolution 36/77 of 8 December 1981.
[48] General Assembly resolution 37/52 of 3 December 1982.

Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder (1986).[49] Consequently the General Assembly adopted a key resolution entitled "Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care",[50] known as the MI Principles. The MI Principles established standards and procedural guarantees and provided protection against the most serious human rights abuses that might occur in institutional settings, such as misuse or inappropriate use of physical restraint or involuntary seclusion, sterilization, psycho-surgery, and other intrusive and irreversible treatment for mental disability. The principles were innovative at the time, also because they emphasized both the quality of treatment and traditional values such as the right to liberty.[51] Today the value of the MI Principles is disputed.[52] The report by Leandro Despouy, also Special Rapporteur of the Sub-Commission, entitled *Human Rights and Disabled Persons* (1993)[53] reported widespread human rights abuses in the area of disability. He commented that persons with disabilities, unlike other vulnerable groups, had no protection under a thematic human rights convention. Nor did they have an international control body to provide them with particular and specific protection. He therefore recommended that all treaty monitoring bodies should take the human rights of persons with disabilities into account with a leading role for the Committee on Economic, Social and Cultural Rights. His report is highly authoritative and was endorsed by the United Nations Commission on Human Rights and the General Assembly.[54]

In 1990 the General Assembly adopted a resolution endorsing the "Tallinn Guidelines for Action on Human Resources Development in

---

[49] E.-I. A. Daes, *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder*, (New York: United Nations Publications, Sales No. E.85 XIV.9, 1986).
[50] General Assembly resolution 46/119 of 17 December 1991.
[51] Degener and Quinn, *Human Rights and Disability*, 33.
[52] United Nations, *Handbook for Parliamentarians,* 10.
[53] L. Despouy, *Human Rights and Disabled Persons*, (New York: United Nations Economic and Social Council, Commission on Human Rights, 1993).
[54] Degener and Quinn, *Human Rights and Disability*, 33.

the Field of Disability".[55] The guiding philosophy of the guidelines is that through human resources development, persons with disabilities are able to exercise their rights of full citizenship effectively (paragraph 7). Human resources development is a process centered on the human person that seeks to realize the full potential and capabilities of human beings (paragraph 6). The guidelines provide various strategies for human resources development including participation of persons with disabilities in society (A), strengthening of grassroots and self-help efforts (B), and promotion of education and training (D), employment (E), community awareness (G), and regional and international cooperation (I).

The United Nations General Assembly adopted a landmark resolution in 1993 entitled "Standard Rules on the Equalization of Opportunities for Persons with Disabilities" (Standard Rules).[56] The Standard Rules are the main United Nations rules guiding action in this area. As the title indicates, the shift from prevention and rehabilitation has been made to the rights perspective. The Rules consist of four parts: preconditions for equal participation (1); target areas for equal participation (2); implementation measures (3); and a monitoring mechanism (4). Section four appoints a Special Rapporteur to monitor the implementation of the Rules, this is currently Mr Shuaib Chalklen.

In the Vienna Declaration and Programme of Action adopted by the World Conference on Human Rights on 25 June 1993, the universality of human rights was reaffirmed. Paragraphs 63 and 64 of section IIB mention persons with disability, explicitly reaffirming that persons with disabilities are entitled to all the human rights enjoyed by others and that

> [t]he place of disabled persons is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, finan-

[55] General Assembly resolution 44/70 of 15 March 1990, annex.

[56] General Assembly resolution 48/96 of 20 December 1993. See generally B. Lindqvist, "Standard Rules in the Disability Field: A United Nations Instrument," in *Human Rights and Disabled Persons*, 63.

cial, social or psychological, which exclude or restrict full participation in society.

Since 1994 the Commission on Human Rights, replaced by the Human Right Council in 2006, adopts a resolution on human rights and disability. They used to focus on the United Nations system and the Standard Rules but towards the end of the 1990s the links between disability and the United Nations human rights machinery became closer.

3.4 The Period Since 2000: Persons with Disabilities as Human Rights Subjects

Despite the soft-law instruments discussed, the lacuna in the human rights protection of people with disabilities remained. Therefore the Ad Hoc Committee of the General Assembly negotiated during eight sessions from 2002 to 2006 about the CRPD. The Convention marks a paradigm shift towards the social model. Within this model, persons with disabilities are considered human rights subjects or rights holders instead of invisible, a rehabilitation subject or an object of human rights. The next section is devoted to detailing the defining event of this period, the CRPD.

4 The CRPD

The term "disability" in the CRPD remains undefined for political reasons but the definition of for instance discrimination indicates a significant shift in how the international community views human rights.[57] The Convention transcends the social model and adopts a "human right to development" approach, integrating first- and second-generation rights,[58] as was also done in the CRC. It marks a

[57] M.A. Stein, "Disability Human Rights," *California Law Review* 95(2007): 85.
[58] Stein, "Disability Human Rights," 91.

paradigm shift in attitudes and approaches to persons with disabilities, viewing them as "subjects" with rights rather than as "objects" of charity.[59] The articles in the Convention include both first- and second generation rights and expressly call attention to their indivisibility, interdependence and interrelatedness.[60] Disability–based human rights necessarily invoke civil and political rights and economic, social and cultural rights.[61] Some argue that the difference between the two sets of rights is significantly overestimated in any case.[62] Civil and political rights are usually understood as promoting equal treatment among individuals and include prohibitions against state interference. These first generation rights are usually called "negative rights" (or "liberty-rights"), because they require the state to abstain from interference. Economic, social and cultural rights are second generation rights. They are also called "positive rights" (or "claim-rights"), because they require the state to provide an adequate standard of living. In the case of disability rights, however, this distinction between positive and negative rights is often not sharp, since positive action is often required in order for persons with disabilities to enjoy civil and political rights on a par with others. Persons with disabilities are seen as entitled to claim essential support that will enable them to live a dignified life and to maximize their autonomy as a matter of positive right.[63] The same model was used for the CRC where a comprehensive register of human rights was applied to the circumstances of a particular group.

As the analysis in section 2 and 3 has shown, the core human rights instruments and soft law instruments do not provide sufficient protection to the human rights of people with disabilities. Most of the disability human rights claims were declared inadmissible; disability is only mentioned in the CRC; and the soft-law instru-

[59] United Nations Enable, *Convention on the Rights of Persons with Disabilities,* available at <www.un.org/disabilities> accessed 4 October 2010.
[60] Preamble of the CRPD, paragraph c.
[61] Stein, "Disability Human Rights," 78.
[62] Koch, "From Invisibility to Indivisibility," 67.
[63] C. O'Cinneide, "Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and Possibilities," in *The UN Convention on the Rights of Persons with Disabilities*, 166.

ments that exist are non-legally binding and can therefore not be invoked in legal proceedings. Because the core human rights treaties and soft-law instruments appeared insufficient to address the specific needs of persons with disabilities, the CRPD has been adopted. Criticism of the CRPD as "superfluous" parallels similar charges made about CEDAW. Time has shown CEDAW to be anything but redundant, and the same may be expected for the CRPD.[64] In part, this is because law can influence behaviour and alter broader social perceptions and practices.[65] Moreover, even without establishing new rights, the Convention articulates existing human rights within specific contexts of disability. For example, the articles on living independently (Article 20), personal mobility (Article 20) and habilitation and rehabilitation (Article 26) are intrinsic to the attainment of historically recognized human rights.[66]

One final point to note about the CRPD is that it is the first United Nations human rights treaty that is open for signature (Article 42) or accession (Article 43) by any regional integration organization. A regional integration organization is "an organization constituted by sovereign States of a given region, to which its Member States have transferred competence in respect of matters governed by the present Convention" (Article 44(1)). This definition is included for the European Union that decided to ratify the CRPD on 26 November 2009.[67] In its decision, the Council of the European Union held the ratification conditional upon the adoption of a Code of Conduct by

[64] C. Flinterman at the Conference "The UN Convention on the Rights of Persons with Disabilities: A European Perspective," Maastricht University, 8 November 2010.
[65] M.A. Stein and J.E. Lord, "Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities," in *The UN Convention on the Rights of Persons with Disabilities*, 32.
[66] Stein and Lord, "Future Prospects," 30.
[67] The European Community formally signed and decided to ratify the CRPD. The treaty of Lisbon entered into force afterwards, on 1 December 2009. However, this chapter will for the sake of clarity refer to the European Union and not to the European Community. For more information on the European Union as a party to the CRPD see L.R.L. Poffé, "De EU Partij bij het VN-Verdrag inzake de Rechten van Personen met een Handicap," *NJCM-Bulletin,* 36(2011): 63-74.

the Council, the Commission and the Member States.[68] This Code of Conduct has been adopted on 2 December 2010[69] and the ratification followed on 23 December 2010.[70] Because, under Article 44(1), member States of an international organization are also expected to be party to the Convention, they must provide a declaration clarifying the extent of their competence with respect to matters governed by the Convention. This declaration must also be provided by the international organizations and the Council itself.

5 Monitoring the Implementation of the CRPD

Like other core Conventions, the CRPD also established a treaty body to monitor its implementation. At many points during the drafting process it was unclear, because of the shortcomings of the existing monitoring process, whether there would even be a monitoring mechanism.[71] States parties often fail to meet their periodic reporting obligations and the volume of work overburdens the treaty bodies. During the negotiations, States challenged civil society and National Human Rights Institutions to think of an innovative system to ensure that the Convention becomes embedded domestically. Despite some innovative ideas by civil society and National Human Rights Institutions,[72] the drafters opted for a rather traditional mon-

[68] "Council Decision of 26 November 2009 Concerning the Conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities," 27 January 2010, Brussels, document number 2010/48/EC of the Council of the European Union, *Official Journal of the European Union*, L23/35-L23-61 .

[69] "Code of Conduct between the Council, the Member States and the Commission Setting Out Internal Arrangements for the Implementation by and Representation of the European Union Relating to the United Nations Convention on the Rights of Persons with Disabilities," 15 December 2010, Brussels, document number 16237/10 of the Council of the European Union, *Official Journal of the European Union,* C340/08.

[70] United Nations Enable, *Ratifications and Signatories of the Convention and Its Optional Protocol,* available at <www.un.org/disabilities> accessed 18 September 2011.

[71] Quinn, "Resisting the Temptation of Elegance," 227.

[72] The various proposals were presented in a so-called "non-paper" by Mexico during the 8th Session of the Ad Hoc Committee. *Non-paper on Monitoring: Draft Elements for a Monitoring Mechanism of the International Convention on the Rights of Persons with Disabilities*, 15 June 2006, available at

itoring mechanism.[73] The treaty establishes a treaty monitoring body (Articles 34-39) that should consult with other monitoring bodies (Article 38(b)).[74] The Committee on the Rights of Persons with Disabilities is in many ways similar to the other Committees. It is composed of twelve members with a possibility to increase depending on the number of States that ratify the CRPD. States Parties can only nominate candidates from their own nationals. Every State party is obliged to submit a report about the measures taken to give effect to its obligations under the Convention within two years after the entry into force of the Convention (Article 35(1)). Thereafter, States have to submit periodic reports at least every four years and whenever the Committee requests (Article 36). States that ratified the Optional Protocol recognize the competence of the Committee to receive individual or group complaints. The criteria for admissibility are the same as for other Committees (Article 2).

A Conference of States Parties (Article 40) is new in human rights treaties, and its role is to consider the implementation of the Convention. Even more innovative is the requirement of the creation of an effective institutional architecture for change at the domestic level (Article 33). It requires a focal point within national governments and the consideration of a coordination mechanism (Article 33(1)); an independent mechanism for the national implementation and monitoring (Article 33(2)) and active consultation with persons with disabilities and their representatives in the monitoring process (Article 33(3)).[75] The focal points must be organizations within the government that are charged with the creation and implementation of national disability policy in line with the CRPD. It should provide

---

<www.un.org/esa/socdev/enable/rights/ahc8documents.htm> (accessed 23 December 2010).

[73] Quinn, "Resisting the Temptation of Elegance," 225.

[74] This was also proposed by the Office of the High Commissioner of Human Rights in response to the shortcomings of the international monitoring system. See: Harmonized Guidelines on Reporting under the International Human Rights Treaties, Including Guidelines on a Common Core Document and Treaty Specific Targeted Documents, HRI/MC/2005/3, 1 June 2005.

[75] For more information about the implementation of the requirements in Article 33 see United Nations, *Handbook for Parliamentarians*, chapter 7.

a useful correction of the tendency in all governments to fragment disability policy depending on departmental priorities.[76] Some other international instruments, including the WPA and the Standard Rules have also called for the establishment of similar entities hence various countries have already established focal points or coordination mechanisms. The independent mechanism should take the "principles relating to the status and functioning of national institutions for the protection and promotion of human rights", known as the Paris Principles[77], into account. Given that these guidelines also hold for other monitoring obligations, a national human rights institute is the most likely rubric within which to provide such an independent framework for ensuring compliance with the national monitoring provisions under the Convention,[78] but the determination must be made on a case by case basis.[79] The independent mechanism must be functionally and personally independent as well as pluralistic in its representation of civil society. Its main functions are promotion, protection and monitoring of the rights in the CRPD.

6 Conclusion

As we have seen, previously existing human rights treaties and non-legally binding instruments proved inadequate to meet the specific needs of persons with disabilities and protect their human rights. The human rights treaties do not, with exception of the CRC, even mention disability rights, and the committees have not been able to comprehensively address disability rights in their work. Although significant soft-law instruments have been adopted, these do not

[76] Quinn, "Resisting the Temptation of Elegance," 254.
[77] General Assembly resolution 48/134 of 20 December, 1993.
[78] United Nations, *Handbook for Parliamentarians*, 108.
[79] *The UN Convention on the Rights of Persons with Disabilities: An Integral and Integrated Approach to the Implementation of Disability Rights, Background Document*, Study Commissioned by the Belgian Federal Public Service Social Security, Work Forum for the Implementation of the UN Convention on the Rights of Persons with Disabilities, 18-19 November 2010.

suffice because of their non-legally binding status. It was consequently necessary to adopt the CRPD. Although the Convention does not include new human rights, it does articulate existing human rights within the specific context of disability which was lacking. It marks a paradigm shift in attitudes and approaches to persons with disabilities and views persons with disabilities as "subjects" with rights instead of "objects" of charity. Moreover, the articles in the Convention include civil and political as well as economic, social and cultural rights and the Convention stresses the importance of their indivisibility, especially concerning disability-based human rights. Lastly, the CRPD calls for a focal point within national governments and an independent mechanism for the national implementation and monitoring of the Convention to strengthen the national reform process. The combination of innovation both at the international level and also with respect to the domestic level should pave the way for a successful shift to the social model at both levels.

2 Core Principles of the UN Convention on the Rights of Persons with Disabilities: An Overview

Caroline Harnacke and Sigrid Graumann

In December 2006 the UN General Assembly adopted the UN Convention on the Rights of Persons with Disabilities (hereinafter the CRPD). The Convention came into force in May 2008 after being ratified by a sufficient number of states. It grants persons with disabilities a number of civil and political, but also economic, social and cultural rights. It is widely agreed that this is a ground-breaking agreement for all persons with an impairment. In the following, we will provide an overview of the core, underlying principles operative in the Convention, many of which are taken up in other chapters of this SIM Special.

1 The Spirit of the Convention

As a successor to its two main non-legally binding antecedents, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1994) and World Programme of Action concerning Disabled Persons (1982), the Convention is a legally binding international agreement.[1] How did it come to the negotiations? And what preceded their development?

1.1 Historical Development

The beginning of the idea of the Convention is marked by the 1993 report of Leandro Despouy, UN Special Rapporteur on disabled

[1] United Nations, "Convention on the Rights of Persons with Disabilities and its Optional Protocol: Power Point Presentation," 2007, available at <www.un.org/disabilities>.

persons and human rights.[2] He made it clear that disability is a human rights concern for the United Nations and that the existing soft laws are not sufficient:

> (...) there is no specific body in charge of monitoring respect for the human rights of disabled persons and acting (...) It can be said that persons with disabilities are equally as protected as others by general norms, international covenants, regional conventions, etc. But although this is true, it is also true that unlike the other vulnerable groups, they do not have an international control body to provide them with particular and specific protection.[3]

Eight years later the development of a disability human rights convention was proposed in the UN General Assembly by the Government of Mexico. A publication by Theresia Degener and Gerard Quinn[4] also influenced the birth of the Convention.[5] They argue for a disability human rights convention because

> [i]t would enable attention to be focused on disability and would tailor general human rights norms to meet the particular circumstances of persons with disabilities. It would add visibility to the disability issue within the human rights system.[6]

In the same year of that publication, in 2002, the first session of the established UN Ad Hoc Committee took place.[7] During the negotia-

---

[2] L. Despouy, *Human Rights and Disabled Persons*, (New York: United Nations Economic and Social Council, Commission on Human Rights, 1993).
[3] Ibid., 73.
[4] T. Degener and G. Quinn, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, (New York and Geneva: United Nations, 2002).
[5] J. von Bernstorff, "Menschenrechte und Betroffenenrepräsentation: Entstehung und Inhalt eines UN-Antidiskriminierungsübereinkommens über die Rechte von behinderten Menschen," *Zeitschrift für ausländisches öffentliches Recht und Völkerrecht*, 67(2007): 1040.
[6] Degener and Quinn, *Human Rights and Disability*, 9.
[7] United Nations, "UN Enable: Promoting the Rights of Persons with Disabilities," 2010, available at <www.un.org/disabilities>.

tions, the participation of civil society was extraordinarily high.[8] The Convention is the most rapidly negotiated human rights treaty ever and got the highest number of opening signatures recorded for any human rights treaty.[9] What is so remarkable about it?

1.2 Paradigm Shift

It is widely agreed that the Convention constitutes a paradigm shift. It turns its back on a disability policy as a social welfare response and acknowledges that a disability policy needs to be based on rights.[10] Persons with disabilities are first and foremost seen as persons, as subjects, who have rights like everyone else – even though they might have special needs – and not anymore as objects that receive society's well-meant care. It means that a disability policy is no longer seen only as a issue of social welfare, but first of all as a matter of human rights.[11] Disabled persons do not receive care out of a meritorious attitude of charity, but states have the duty to make sure that human rights of persons with disabilities are respected, protected and fulfilled.

As Degener correctly analyzed: human rights do not presume non-disability.[12] Accordingly, the Convention does not create new or exclusive rights for disabled people. This would also not be in accordance with the whole idea of human rights.[13] As explained by Jack Donnelly:

---

[8] R. Kayess and P. French, "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities," *Human Rights Law Review* 8(2008): 14.
[9] Ibid., 2.
[10] Degener and Quinn, *Human Rights and Disability*, 1; Kayess and French, "Out of Darkness into Light?," 3.
[11] V. Aichele, "Die UN-Behindertenrechtskonvention und ihr Fakultativprotokoll: Ein Beitrag zur Ratifikationsdebatte" (Deutsches Institut für Menschenrechte, Policy Paper Nr. 9, August 2008), 4.
[12] T. Degener, "Die UN-Konvention: Menschenrechtsschutz für behinderte Menschen," (presented at Fachtagung NW Art. 3 / DGRW / IMEW, Berlin, Januar 14, 2010), 14.
[13] Aichele, "Die UN-Behindertenrechtskonvention und ihr Fakultativprotokoll," 4; S. Graumann, *Assistierte Freiheit: Von einer Behindertenpolitik der Wohltätigkeit zu einer*

> Human rights are, literally, the rights that one has simply because one is a human being. (...) Human rights are equal rights: one either is or is not a human being, and therefore has the same human rights as everyone else (or none at all).[14]

Thus, the idea of human rights obviously also applies to people with disabilities. The justification of human rights is often based on human dignity.[15] Therefore, we would like to draw attention to the fact that respect for dignity is mentioned among the general principles of the Convention.[16]

Yet the conclusion that human rights necessarily also apply to people with disabilities seems to question the necessity of a special human rights convention for disabled people. If everyone, including disabled persons, is protected by other human rights instruments, why then is the Convention needed? The reason is that some humans seem to be insufficiently protected by the general human rights legislation.[17] This holds not only for disabled people, but also for children or women. Therefore, they require tailoring of the general rights regime to their needs. This is exactly what is done by special conventions like the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). The same holds for the CRPD. As Frédéric Mégret ascertains:

> The Convention is testimony to the significant need for specific human rights instruments when it comes to certain categories of

---

Politik der Menschenrechte, (Utrecht: Publications of the Department of Philosophy Utrecht University, 2009), 58. Revised version: Frankfurt a.M.: Campus, 2011.

[14] J. Donnelly, *Universal Human Rights in Theory and Practice*, (New York: Cornell University Press, 2003), 10.

[15] D. Beyleveld and R. Brownsword, *Human Dignity in Bioethics and Biolaw*, (Oxford: Oxford University Press, 2001). This understanding needs of course further elaboration, yet it should not be done at this place.

[16] CRPD, Article 3(a).

[17] See E. van Weele, "The UN Convention on the Rights of Persons with Disabilities in the Context of Human Rights Law," in this volume.

> humanity whose condition has made them uniquely vulnerable to human rights violations (...)[18].

Disability rights are still human rights – "specific to persons with disabilities, yet rooted in the universality of rights".[19] Thus, the main problem is not that human rights excluded persons with disabilities, but that persons with disabilities were not visible within the existing human rights instruments because their specific needs were neglected.[20] Hence, "accommodating the difference of disability and making people with disabilities visible within the treaty system" was the challenge the development of the Convention was facing.[21] This idea was the "raison d'être" of the Convention from the very beginning of the negotiations[22] and herein lays the great innovative potential of the Convention. To understand the Convention as it is, it is important to understand the idea of disability that it uses.

1.3 The Social Model of Disability

Interestingly, even though the Convention contains a section on definitions, it does not have a definition of disability. Typically, a great deal of attention is devoted to defining disability in the proper way. In effect, however, definitions of disability run the risk of being stigmatising. The Convention only indicates that persons with disability 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."[23] Two points are notable here.

---

[18] F. Mégret, "The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?" *Human Rights Quarterly* 30(2008): 515.
[19] Ibid., 516.
[20] Kayess and French, "Out of Darkness into Light?," 12.
[21] Degener and Quinn, *Human Rights and Disability*, 4.
[22] Von Bernstorff, "Menschenrechte und Betroffenenrepräsentation: Entstehung und Inhalt eines UN-Antidiskriminierungsübereinkommens über die Rechte von behinderten Menschen," 1042.
[23] CRPD, Article 1.

First, the Convention refrains from giving an exact definition of disability and only gives an indication. Thus, the understanding of disability is not fixed. It is an evolving rather than a static concept.[24] Society and opinions within society might change and the Convention leaves room for this. For example, it is possible to include not only long-term, but also short-term impairments within the Convention's understanding of disability.

Second and more importantly, disability is a result of the interaction between an environment and a person rather than an inherent attribute of an individual.[25] A person is not disabled per se, rather disability results from an interaction between the individual and society.[26] This takes leave of the medical concept of disability which presumes that disability lies only within an individual. The social model used here acknowledges that disability also has its roots in discrimination that hinders full participation in society on an equal basis with others. This view can be summarized as follows:

> People are impaired by physical, mental or psychological damage, but they are disabled by social barriers, a lack of support and negative stereotypes.[27]

One of the most important defenders of the social model of disability is Anita Silvers. She argues that being biologically anomalous is only viewed as abnormal due to unjust social arrangements, most notably the environment.[28] Being normal or not is thus determined

[24] United Nations, "Convention on the Rights of Persons with Disabilities and its Optional Protocol. Power Point Presentation," Preamble.
[25] United Nations, "UN Enable: Promoting the Rights of Persons with Disabilities".
[26] World Health Organization, *World Report on Disability* (2011), 4.
[27] Graumann, *Assistierte Freiheit*, 34-35. Own translation. In the original: "Beeinträchtigt [impaired] sind Menschen durch körperliche, geistige oder psychische Schädigungen, behindert [disabled] aber werden sie durch gesellschaftliche Barrieren, fehlende Unterstützung und negative Stereotypen".
[28] A. Silvers, D. Wasserman, and M. Mahowald, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, (Lanham etc.: Rowman & Littlefield, 1998), 75.

by the surroundings; it has its source in the environment, not in the person that is labelled "disabled".

From this perspective, one main aim of the Convention, as stated in the general principles, can be understood much more clearly: the "full and effective participation and inclusion in society".[29] This needs to be seen against the background of the social model of disability. Only with this understanding of disability can one conceive of the empowerment and enablement of individuals with impairments, leading to their full inclusion in society.

In sum, disability is caused by interaction with a disabling environment – which of course can and also should be changed to an enabling environment. The "deficit approach" to understanding disability is consistently replaced by a "diversity approach". While the specialness of each individual deserves recognition, social circumstances must be regarded as the real problem.

2 Content of the Convention

Having analyzed the spirit of the Convention, let us now look at its actual content. The structure of the Convention follows the typical structure of similar Conventions. In addition to the specific rights it also contains a preamble, definitions, general principles and final clauses. In the following, we do not aim to provide a comprehensive overview of the document, but we will instead only focus on those parts that are important for the discussion in the remainder of this book.

2.1 General Principles

Article 3 of the Convention outlines its general principles. They are governed by an understanding of the entire Convention as a shift – in the light of the social model of disability as analyzed above – to a

[29] CRPD, Article 3(c).

human rights perspective. Accordingly, the general principles encompass: respect for dignity; non-discrimination; inclusion; diversity; equality of opportunity; and accessibility – as well as two paragraphs on multiple discrimination of women and children.[30]

These statements of principles at the beginning of the Convention make clear that the subsequent rights will embody far-reaching ideas. The first principle, the principle of respect for dignity, goes back to the roots of the idea of human rights. It already shows that disability policy is understood as a matter of human rights, not as a matter of charity. Hence, disabled people need to be empowered and enabled to lead an independent life, included in society. Therefore, equality of opportunity instead of discrimination, accessibility, and a positive perception of people with disability in society are basic but essential demands.

Those general principles are the guidelines for the design and refinement of the specific rights, which will now be discussed in greater detail.

2.2 Specific Rights

As already analyzed, the Convention is "an implementation convention [that] sets out a detailed code [for how existing rights] should be put into practice".[31] Accordingly, different familiar civil and political rights, but also economic, social and cultural rights have a place in the Convention. In general, those rights were already established by the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The specific rights and their listing make the connection to the exist-

[30] CRPD, Article 3.
[31] Chairman of the negotiating Committee quoted by Kayess and French, "Out of Darkness into Light?," 20.

ing human rights clear.[32] The Convention encompasses the following rights:[33]

Equality before the law without dis-crimination (Article 5)	Freedom of expression and opinion (Article 21)
Right to life, liberty and security of the person (Article 10, 14)	Respect for privacy (Article 22)
Equal recognition before the law and legal capacity (Article 12)	Respect for home and the family (Article 23)
Freedom from torture (Article 15)	Right to education (Article 24)
Freedom from exploitation, violence and abuse (Article 16)	Right to health (Article 25)
Right to respect for physical and mental integrity (Article 17)	Right to work (Article 27) Right to an adequate standard of living (Article 28)
Freedom of movement and nationality (Article 18)	Right to participate in political and public life (Article 29)
Right to live in the community (Article 19)	Right to participate in cultural life (Article 30)

[32] Aichele, "Die UN-Behindertenrechtskonvention und ihr Fakultativprotokoll," 7.
[33] United Nations, "Convention on the Rights of Persons with Disabilities and its Optional Protocol: Power Point Presentation"; United Nations, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention of the Rights of Persons with Disabilities and its Optional Protocol*, (New York/ Geneva: United Nations, 2007), 15-16.

These human rights are all well-known. The Convention focuses now on the actions that states must take to ensure that persons with disabilities enjoy those human rights on an equal basis with others. It obliges states to provide the appropriate enabling environment. Yet what does that mean? As completeness is not possible, it will in the following be exemplified by means of two articles, freedom of expression and opinion and access to information (Article 21) and respect for home and the family (Article 23).

Freedom of Expression, Opinion and Access to Information

Freedom of opinion and expression is already well-known from the Universal Declaration of Human Rights.[34] There, it is assured that

> [e]veryone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Thus, the right established here appears to be only a negative right. The state is not asked to enable anyone to anything, but only has to secure that no one interferes with the freedom of opinion and expression of its citizens. This exclusive emphasis on non-interference makes this right a negative right.[35] In contrast, the Convention turns this negative right into a positive one. The state has to actively enable someone to exercise the right. Here, the state does not only have to acknowledge the right to freedom of opinion and expression of disabled persons, the state must also take measures to ensure that

[34] The Universal Declaration of Human Rights (adopted 10 December 1948 by the United Nations General Assembly, Resolution 217 A(III)).

[35] Here, it is suggested that the state should not merely refrain from interfering itself, but should also stop interference by third parties. This might make the right closer to a positive right. However, the exact distinction between positive and negative rights in general can be disputed.

persons with disabilities can actually exercise this right. This is because having a right without being able to exercise it makes a right obviously meaningless. Therefore, all information that is intended for the public must be accessible for persons with various disabilities. Access to electronic communication and use of special means of communication like Braille and sign language for blind and deaf people is demanded. This includes information on the internet, radio, television as well as hardcopy information and public speeches. This information needs to be available for disabled people without additional costs. The Convention addresses not only the public sector, but the private sector as well. Private entities need to be urged to provide access and the mass media must be encouraged to make their services available. Yet the use of the words "encourage" and "urge" makes clear that these are not absolute obligations. Nevertheless, this right is currently far from being comprehensively implemented. Given the information flood we are facing day by day, its realization will be challenging.

Respect for Home and the Family

The article on respect for home and the family also has its roots in the familiar human rights. There, respect for privacy, home and a family is realized as the right to marry and to found a family, and in the statement that the family is entitled to the "widest possible protection and assistance".[36] The Convention clarifies what this means in reference to disabled persons. The positive duty of the state, which is left implicit in the other human rights declarations, is specified here.

The corresponding article of the Convention aims to eliminate discrimination against persons with disabilities in the family domain. First of all, this means that the widely known practice of forced sterilization, solely on the basis of disability, represents a

[36] International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171.

human rights violation.[37] Relatedly, the Convention states that disabled persons have the right to decide freely and responsibly on the number and spacing of their children.[38] At least in the public perception, this is far from self-evident. So far, this is again only a negative right. Yet its positive character also comes into play in the Convention. States Parties are said to have the duty "to render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities."[39] Furthermore, children should not be separated from their parents on the basis of a disability both in the case of a disability of the child or a parent except when all opportunities to support the family are exhausted and a separation is necessary for the best interests of the child. Thus, the claim for support and assistance of a family is very demanding. Parents with disabilities have various needs, extending from daily help with basic childcare in an assisted living environment and psychological support to only sporadic aid in e.g. filling out official forms or partial guardianship. All contract states are now obliged to provide information, support and assistance for that purpose. Therefore, this right is posing one of the greatest challenges following from ratifying the Convention.[40] But if states fulfil their duties so that disabled parents get all this support, they are far better able to rear their children than it is commonly assumed.[41]

2.3 State Obligations

A similar analysis could be provided with regard to the other rights, but this is not the place for it. Instead, we would like to draw attention to a more fundamental fact: if a person has a right, someone has the obligation to grant that right. Here, these are state obligations. By analyzing the different articles of the Convention and how

[37] Graumann, *Assistierte Freiheit*, 47; CRPD, Article 23(1c).
[38] CRPD, Article 23(1b).
[39] CRPD, Article 23(2).
[40] Graumann, *Assistierte Freiheit*, 48.
[41] Idem. Compare for a more detailed elaboration ibidem, 46ff.

they differ from formulations in other human rights instruments, it becomes clear that the special public obligations can be summarized under the three headings of awareness rising (see Article 8), accessibility (see also Article 3 and also Article 9) and habilitation/rehabilitation (see Article 26).[42] We will elaborate on these three aspects now.

Raising Awareness

The obligation of the state to undertake measures to raise awareness and foster respect regarding persons with disabilities is included in Article 8. The aim is that persons with disabilities and those without, understand their rights and responsibilities.[43] Measures should include public campaigns, building up an attitude of respect within the education system, encouraging the media to portray persons with disabilities in a manner consistent with the idea of the Convention and promoting awareness-raising programs.[44] The wording does not mention anything more concrete such as the frequency or extent of those measures, but one can imagine that a tremendous effort is needed to actually change the public perception of persons with disabilities, for instance towards the fact that disabled parents can be good parents, and to raise awareness of their contributions to society.

Accessibility

Accessibility is both a general principle of the Convention (Article 4) as well as the topic of a stand-alone article (Article 9). As a general principle it is essential to the enjoyment of all other rights and thus

[42] Summary of the state obligations similar to United Nations, *From Exclusion to Equality*, 16-18.
[43] United Nations, *Handbook for Parliamentarians*, 16.
[44] CRPD, Article 8. See also J. L. Scully, "The Convention on the Rights of Persons with Disabilities and Cultural Understandings of Disability," in the present book.

relevant to all areas of implementation.[45] Without being able to move around freely or having access to information in an appropriate format, many other rights become meaningless. Hence, accessibility fully embraces the spirit of the Convention "to live independently and participate fully in all aspects of life" (Article 9). Thereby, accessibility not only refers to the physical environment and demands the building of ramps and elevators, but as already analyzed above it includes access to information e.g. in Braille or in easy-to-read-and-understand forms. This right also encompasses assistance like guides, guide dogs or professional sign language interpreters. Again, those requirements do not only hold for public entities, but also need to be ensured for private sector entities that are open to the public.

The requirements following from this general principle can be found continuously throughout the Convention. Hence, accessibility is also positioned in:

- *access to justice (Article 13)*: The state has to facilitate the role of disabled persons as participants in legal proceedings and provide training in this regard for those working in the administration of justice.
- *living independently and being included in the community (Article 19)*: Disabled persons do not have an obligation to live in a particular living arrangement. They need to have access to community support services including personal assistance.
- *access to information and communication services (Article 21)*: information that is intended for the general public must be provided in accessible formats. The use of accessible language formats in official interactions must be facilitated.
- *access to education (Article 24)*: The state has to ensure an inclusive education system at all levels and facilitate the learning of Braille and sign language.
- *access to health (Article 25):* Disabled persons have the right to the highest attainable standard of health.

[45] United Nations, *Handbook for Parliamentarians*, 16 and 79.

- *access to work and employment (Article 27):* Disabled people have the right to work in an inclusive environment. The state must ensure their opportunity to gain a living by work and promote employment opportunities and career advancements.
- *adequate standard of living and social protection (Article 28*): The state has the duty to provide access to social protection for disabled people including assistance for disability-related needs. Their living conditions must be continuously improved.
- *participation in political and social life (Article 29):* Through accessible voting procedures and participation in the conduct of public affairs an effective and full participation of people with disabilities in society has to be possible.
- *participation in cultural life, recreation, leisure and sport (Article 30):* Disabled people must have access to culture and to mainstream sporting activities as well as disability-specific sporting. Their creative potential must be enabled and their cultural identity has to be supported.

This provides only a broad overview of the various rights where accessibility plays a role. Yet it certainly makes clear that the Convention poses great demands on its signatory states. States are obliged to fulfil the Convention and if this does not happen, it can – and should – be prosecuted. Thus, its implementation needs to be brought forward. It remains to be seen how states will handle this challenge.

Habilitation and Rehabilitation

The third aspect we would like to focus on is habilitation and rehabilitation. Whereas rehabilitation aims at people who acquired an impairment, habilitation aims at those who are born with an impairment. In all other aspects, rehabilitation and habilitation means the same, that is, enablement of disabled persons to attain and/or

maintain maximum independence as an active member of society.[46] Those programs are the crucial first steps to acquire the necessary skills to develop that capacity. Without it, disabled persons are unlikely to realize their other rights. The programs are usually time-limited and encompass "particularly (...) areas of health, employment, education and social services."[47] The use of assistive technologies is explicitly included.

Thus, habilitation and rehabilitation programs are far reaching and cover various aspects of life. The development and distribution of assistive technologies, from wheelchairs and handbikes to cochlear implants and brainwave-guided prosthetic hands, can also be extremely costly. Yet the Convention acknowledges that disabled persons have a positive right to be enabled by the state. Therefore, the state has the duty to provide habilitation and rehabilitation programs.

3 The Indivisibility of Human Rights

As was established above, the Convention has its roots in widely accepted human rights, referring to civil and political rights as well as economic, social and cultural rights; to negative rights as well as positive ones. Negative and positive rights are seen as belonging together. Civil and political rights on the one hand and economic, social and cultural rights on the other hand are often described as two generations of rights.[48] The distinction of the two generations of rights goes back to the decision made by the UN General Assembly in the 1960s to create two separate covenants, the Covenant on Civil

[46] Ibid., 17-18 and 77.
[47] CRPD, Article 26.
[48] B. Flóvenz, "The Implementation of the UN Convention and the Development of Economical and Social Rights as Human Rights," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, edited by O.M. Arnardóttir and G. Quinn, (Leiden: Martinus Nijhoff, 2009), 257; H. Kallehauge, "General Themes Relevant to the Implementation of the UN Disability Convention into Domestic Law: Who Is Responsible for the Implementation and How Should It Be Performed?," in *The UN Convention on the Rights of Persons with Disabilities*, 204.

and Political Rights and the Covenant on Economical, Social and Cultural Rights.[49] Yet this distinction was and is highly disputed. Many authors argue that economic, social and cultural rights simply underpin the system of basic freedoms promoted by civil and political rights.[50] Hence, the two generations of rights are seen as interdependent and interrelated. The Convention does not take up this distinction, but integrates the two forms of rights, as analyzed above. Thereby, each article is in need of an interpretation as to the kinds of right it refers to.[51] In implementing the Convention, some rights are subject to immediate fulfilment whereas others are subject to progressive realization.[52] This means that a state must take measures to realize the latter rights step by step, "to the maximum of its available resources and, where needed, within the framework of international cooperation,"[53] but it takes into account that it might take time until the implementation of those rights is complete. However, those rights still need to be realized. Thereby, the Convention constitutes a right to enablement for the "world's largest minority".[54]

[49] Flóvenz, "The Implementation of the UN Convention," 257. Other scholars also distinguish between civil and political rights so that they argue for three generations of rights (e.g. Degener and Quinn, *Human Rights and Disability,* 17-19). Referring to two instead of three different Covenants, we will in the following stick to the definition of two generations of rights.

[50] Degener und Quinn, *Human Rights and Disability*, 19.

[51] Kallehauge, "General Themes Relevant to the Implementation of the UN Disability Convention," 205.

[52] United Nations, *Handbook for Parliamentarians*, 19-20.

[53] CRPD, Article 4(2).

[54] United Nations, *Handbook for Parliamentarians*, III.

II

Transformative Dimensions of the CRPD

3 Shifting the Burden of Proof: How the CRPD is Transforming Our Understanding of Discrimination, Intersectionality, and Priorities[1]

Jenny Goldschmidt

Interviewed by Joel Anderson and Jos Philips

1 The Transformative Aspects of the Convention

Joel Anderson (JA): We have several topics we'd like to discuss, but perhaps we could begin by asking you what, from your perspective, is most distinctive about the Convention on the Rights of Persons with Disabilities.

Jenny Goldschmidt (JG): What's special about it can be seen at two levels. At the level of international standard-setting, the Convention is about increasing inclusiveness and about understanding in a concrete way the importance of accommodating difference. The second level concerns more pragmatic points about the way in which, at the national level, the burden of proof has shifted. You cannot simply take measures that affect disabled people in a negative way without due justification.

At the level of international standard-setting I think the Convention is a major advance, as Bielefeldt has explained in an important working paper.[2] We started with the Convention on Racial Discrimination,[3] which focused on non-discrimination in the way of not treating people differently. The Women's Convention[4] went one step

[1] The interview was conducted in the city of Leiden (Netherlands) on September 5, 2011.
[2] H. Bielefeldt, "Zum Innovationspotential der UN-Behindertenrechtskonvention," (Berlin: Deutsches Institut für Menschenrechte, 2009).
[3] International Convention on the Elimination of All Forms of Racial Discrimination (adopted 7 March 1966, entered into force 4 January 1969) 660 UNTS 195.
[4] Convention on the Elimination of All Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13.

further – in particular by including Article 5, which urges states to end stereotypes in traditional practices.[5] The Disability Convention goes further still. As the Preamble already makes clear, the CRPD regards disability as an emerging concept, which depends not only on the characteristics of the disabled person but also on the barriers that exist in society and in people's behaviour. So discrimination is increasingly being seen as a bilateral phenomenon. Whether I'm different depends not only on whether I have some different characteristics but also on how you perceive me. So there are significant obligations regarding the social climate and attitudes. This is a more complex and less clear-cut understanding of discrimination, which invites more creative thinking. That may be why lawyers sometimes seem to be afraid of it – and also the governments that have to pay for the necessary provisions.

However, these provisions and reasonable accommodations need not be regarded as costs only; they may lead to profit as well. A clear example comes from the Americans with Disabilities Act. The Metropolitan Transport Agency in Washington, DC was required to make the public transport system (including platforms, exits and trains) accessible for people with disabilities. They subsequently noticed that the metro was used much more by fathers and mothers with prams, and this led to far more profit than expected. So if you take measures that are inclusive it can also be quite profitable.

JA: Reasonable accommodations can be seen as investments in infrastructure that allows more people to be productive and to participate fully in society?

---

[5] CEDAW, Article 5: "States Parties shall take all appropriate measures: (a) 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; (b) to ensure that family education includes a proper understanding of maternity as a social function and the recognition of the common responsibility of men and women in the upbringing and development of their children, it being understood that the interest of the children is the primordial consideration in all cases".

JG: Of course the profits won't happen immediately: you have to make the investments before you reap the benefits. Also, from a fundamental point of view it's risky exclusively to emphasize the potential profit. For regardless of the profit, measures aimed at inclusiveness are often justified simply as a matter of justice and of human dignity.

JA: So pointing to profits is mainly important for countering objections based on cost, rather than as a justification for accommodations?

JG: It's not black or white. By showing that accommodations will not always be costly, the Convention can make people aware of their one-sided perspective. And it can make people aware that our society continues to be structured in ways so as to exclude people, and perhaps also to exclude themselves in the future, as they age and lose certain capacities.

JA: This seems to be a very important point. Within contemporary culture it is generally assumed that disability is a marginal phenomenon, and political and economic decisions tend to be made as if the world had relatively little disability in it. Part of the what the Convention is forcing people to do is to make these decisions on the basis of seeing the world realistically, as a world filled with a wide variety and varying degrees of impairments, compromised functioning, reliance on assistive devices, and so on – as much more normal. How do you see this impact of culture on the law and on political decision-making? And do you see prospects for the CRPD changing that?

JG: That's a difficult question. Disabled people have been called "the world's largest minority".[6] I agree with you that the Convention challenges us in area of culture; that's really the essence of the Convention. It challenges the assumption that the norms are neutral.

[6] See the "UN Enable" website at http://www.un.org/disabilities/.

Jos Philips (JP): Part of the difficulty seems to be that, at the point in time when economic and political decisions are made, the people making them do not have a need for accommodations themselves.
JG: Exactly. In China you see that the debate has been much advanced by the fact that a leading member of the party has a disabled child. Or think of the Vietnam veterans: there, disability became part of the experience of people. Imagine if politicians had to walk around with crutches in the city. They would quickly see how difficult it is to get around. That's the sort of experience that can make people aware of what they have been assuming.

JA: You're pointing to a distinctive characteristic of the Disability Convention, namely, that it provides protection for forms of vulnerability that will apply to the majority of humans (as they become old), but do not apply to them for most of their lives. What is the relevance of this fact – that anyone could end up being a member of the group covered by the Disability Convention?

JG: I don't think it played any role in the drafting process of the Convention, where the current position of disabled persons was more important. The focus was on addressing problems that were not adequately addressed by existing human rights law. But I think that as we move into the next stage, of implementing the Convention and securing adherence, it will be important to use the fact you mention when discussing disability.

JA: The fact that anyone can end up a member of the target group is arguably even more clearly the case with the possible convention on the rights of elderly persons. I know that there are different attitudes within the disability movement towards such a convention. Could you comment on the topic?

JG: I have not studied the arguments for that proposed convention, but I'm somewhat sceptical about everything that has to do with promoting age discrimination to an equal level with other forms of discrimination, such as discrimination on the basis of gender or race

or sexual orientation or disability. Without denying the impact and injustice of age discrimination, it is not in the same way about a specific group of people during all stages of life, every activity, in every social sphere. Moreover, from a legal point of view it is a very slippery concept as almost every measure or act can disproportionally affect a possible category of people older or younger than any given age threshold, so it is not clear what the distinctive feature is that identifies the group deserving protection.

JA: But the same applies to children, and we do have a Convention on the rights of the child. And the Disability Convention is not limited to people who have a congenital condition or a condition that never goes away.

JG: Yet there is a difference with age, when it comes to elderly people. Childhood is a different category: they need special protection and their needs have to be taken seriously. But other aspects of age are different. Everyone knows that they will age; that is a constant. Still I think it's not so all-inclusive, affecting all aspects of one's involvement in society. I recognize that there's a lot of discrimination against elderly people, but I don't see it as a reason to have a separate convention. If there is a need for another Convention, it's for "sexual orientation" or gender identity, which is much more tightly associated with deeply rooted negative assumptions, with stereotypes, and so on; and precisely because this is such a sensitive issue, with huge differences in different cultures.

JA: Allow me to make the standard philosophical move of introducing a thought experiment. Suppose that we lived in a society in which people over a certain age were generally treated as useless dead weight in society, as simply taking up space and consuming scarce resources. And suppose further that in this society there were widespread negative attitudes about persons above a certain age, why wouldn't that fit the same model?

JG: From a human rights perspective, I do not see what would need to be added to protect this specific group. The principle of reasona-

ble accommodation highlights that it should be part of normal practice to take differences into account. And the situation you describe is a flagrant violation of the principle of human dignity underlying all human rights conventions, of the right to life, etc. I don't see what an elderly convention would add to that. I see that elderly people are being treated as useless and are being excluded, but I think the existing human rights documents offer enough resources to protect the elderly – especially now that we have the resources of the Disability Convention. Now you can say that there are elderly people without any disabilities who are still being discriminated against. So maybe we should use the Disability Convention to open up a conception of equality in other contexts, but we also have the Covenant on Economic and Social Rights[7] for that. In addition, age is included everywhere in the text of other human rights conventions.

JP: Are you also saying that the philosophical thought experiment is not the appropriate way to think about human rights? That there is a different logic to human rights, as bound to the actual situation? That, as long as the existing instruments are good enough, you're not going to think about very hypothetical cases that might come up?

JG: I can't think of a case where if we had the proposed new convention on the rights of the elderly, things would change for the elderly – a case which wouldn't already be covered by the present conventions.

JA: Could you give some examples of where that is *the case for disability? Of how the establishment of the Disability Convention changes things, relative to the conventions that were already there?*

[7] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3.

JG: Considering the fact that the Convention creates no new rights, you might think that the Convention actually didn't change things so much, if you see it as an isolated event. But I see it as part of a larger set of conventions and precedents. If you look at the history, you see for example that the European Union already has a directive on equality in the workplace where disability is included. And at the international level, the different systems influence each other. But the Convention identifies the duties vis-a-vis disabled people at a certain level and makes it impossible to deny the obligations to protect the rights of disabled. Thus, the concept of reasonable accommodation – which had been included in the earlier directive – is the fundamental one because it is recognized as part of the principle of equal treatment. You cannot legitimately deny a special provision or accommodation if it is reasonable. If you do so, you are discriminating. Making reasonable accommodations is thus part of the prohibition on discrimination, and not, as some might think, an exception to the principle of equal treatment.

The whole legal definition of the case is thereby transformed. You are not asked anymore whether it was possible to hire this person in a situation where necessary accommodations were not already available; on the contrary, you have to demonstrate that the accommodation was *not* possible. This is a fundamental shift. And when you look at European Union case law you see that the specification of definitions goes further. There's a very interesting case from the Court of Justice of the European Union on the mother of a disabled child who was fired from a law firm (of all places) because they feared that the disability of her child would have consequences for her presence at work, for example that she would have to take leave. The court had to answer the question whether her dismissal was on the basis of disability. This is a very interesting case, because she was not disabled, and the Court included "discrimination by association" in the concept of discrimination, and we see that this approach has been followed e.g. in the General Comments of the CESCR.

JA: How do you think that the Disability Convention alters our understanding of this case beyond what was already in the background in connection with the Women's Convention?

JG: In the field of accommodations it can be argued that "taking differences into account" is in a more implicit way part of the other Conventions as well. But the new Convention adds several aspects, and one way or another, these changes will affect the other Conventions as well. Essentially, what both Conventions do is compel society to accept differences and to accept that different measures have to be taken for different people. Even when provisions are neutral, they can have very different implications for different people. For example given that it's mostly women who take advantage of parental leave, you cannot treat these measures as merely neutral.

JP: Earlier you said that the Disability Convention sets a minimum standard below which one may not fall. But is that actually true? Aren't states able to get away with doing less? For you just said that the Convention changes the landscape, not so much that it introduces a minimum standard.

JG: Indeed, it changes the argument. That doesn't mean you can never go below a certain existing standard if circumstances change. Where there is nothing you cannot expect a disproportional increase of attributed budgets to be given to the disabled or other special groups at the cost of other (perhaps also vulnerable) groups in need. But it changes the argument, and shifts the burden of proof.

JA: One way of putting this is to say that, on the standard understanding of human rights, the prevention of discrimination is directed at behaviour driven by prejudice and ignorance, hate and fear. It was more of a psychological or attitudinal problem, and the antidiscrimination provisions were about making it clear that behaviour based on those attitudes was not going to be tolerated. The Disability Convention, by contrast, thinks of nondiscrimination as more strongly a matter of really accepting, in concrete ways, the normality of a variety of different forms of embodiment or levels of ability.

JG: That's why, from a legal perspective, I would say that it shifts the burden of proof.
You have to prove that no solution is possible that includes all people. Of course, at one level it will never be possible to include all people at all levels of functioning, so it may be justified in certain moments that a group of disabled people remains excluded, or, for example, restricted in the rights to live independently, because it's simply too expensive or disproportionately costly. But you cannot simply say, we don't do it anymore because it doesn't fit our policy towards this particular group or we have less money to spend: you have to show that there is a fair balance between equally fundamental interests.

2 Implementation and Priority-Setting

JA: Let's now make the transition to implementation of the Convention and what you see as the main challenges – in the Netherlands, in Europe, and internationally – to putting in place monitoring systems and so on to give this Convention some real force.

JG: It is interesting that the Convention has so many ratifications now, and that the Netherlands have still not ratified it. It's not merely a negative attitude, it's not merely the fear that it will end up costing a great deal. It's also the fact that the Netherlands has a tradition of ratifying Conventions only once they have a clear and specific view of how it will have to be implemented. And, perhaps even more than other conventions, the Disability Convention is full of challenges that nobody can exactly foresee. This makes the ratification for a country such as the Netherlands difficult. However, this is not merely negative, considering that so many countries have ratified that have no disability policy or no intention to develop a disability strategy. The problems there are perhaps even larger. This doesn't mean that I approve of the Dutch policy of not ratifying yet. And, I do think the Dutch government is too afraid of the costs. But firstly, and as we have already discussed, if the costs of accommodation are unreasonable or disproportionally costly, then the Convention does

not require that they be imposed. And secondly, it's most of all the way that you discuss policies which has to be justified. So I hope that in the not too distant future, the Dutch government can be convinced that they are not taking the risk of bankrupting the country when they ratify the Convention. Moreover, the obligation to maintain at least the existing protection of disabled people is already accepted by signing the Convention!

JP: Are you just saying that implementing the Convention is not only about costs? Or are you also saying that implementing it doesn't in the end cost that much?

JG: You cannot simply cut the budget for some specific accommodations or services for disabled people. For example, Lodewijk Asscher, an alderman in Amsterdam, recently said that once you add up the effects of all new policy measures that have been taken by the present Dutch government, then some specific groups in society are definitely worse off, and disabled people are at the core of these. And that shifts the burden of proof to the government. They will have to acknowledge how they are excluding people from society. If there is such overwhelming evidence that this group is excluded disproportionately, they must have very strong arguments why this was the only possible option in dividing up the budget.

JA: Is that actually a model for how to think about setting priorities among different measures which address the rights and needs of different groups? Very often priorities are set in terms of cost-benefit analysis. Is it correct that the Disability Convention takes a much larger view of what it means to be respected in one's human rights and to be a full participant?

JG: It takes a more holistic view. And this holds for other Conventions as well. For example, if you look at the Women's Convention and how the reports are discussed by the monitoring committee you will also see that the committee questions policies of specific countries with regard to their combined effects on women. And the Disability Convention will demand this approach too.

JA: But once you have a more holistic view, things may start to look impossible, it may start to look like there are too many factors involved. So the argument then is made that we can't provide 100% complete justice for everybody, and people start to think that everybody's human rights are being violated everywhere.

JG: It is a challenge for the disability movement how you can master this, and this is also a matter of setting priorities. Here in the city of Leiden, there's the case where there are two sisters in an apartment building who need 24-hour a day care. And there are currently protests about this, because the new proposed policies do not cover this kind of provision anymore. All kinds of pragmatic reasons given for why it is not possible, but there's no real balance of arguments.

JA: The many cases like this often take the following shape. Someone needs an accommodation and the party who is responsible for providing it (for example, an employer, or the Housing Authority) says, "We'll accommodate you – not the way you are requesting, but in this other way that we view as reasonable. In the end, much of the debate is about the extent to which the dignity of the individual is being violated if she is forced to be flexible about how the accommodation is going to happen. In a sense, the whole debate gets shifted to what makes a reasonable accommodation reasonable. How do you see what can count as a reasonable accommodation shifting in light of the Disability Convention?

JG: I think it's always the two aspects we started with. One is the more down-to-earth question of what can reasonably be expected of taxpayers and so on. And the other is a more fundamental question: even if it's not reasonable, can we say that human dignity demands that as a society we go beyond what is reasonable? In the end we are always talking about the responsibility of the state, a public responsibility, to protect the rights and dignity of people, and this responsibility includes the duty to ensure that private persons or organizations do not violate these rights.

JA: In terms of political philosophy this becomes very tricky in an international context: I can imagine many different ways of approaching the question of what is reasonable accommodation. To what extent do we expect people to be flexible with their requirements, and to what extent ought we to give primacy to the dignity of the individual...

JG: But who is to decide what counts as dignity?

JA: One approach is to say that that is to be decided in the context of a national debate, in which a lot of very deeply held cultural, religious, historical views play a role. The contrasting approach is to say that, in an international context, what we need is a single set of demands that all member states must implement; the monitoring would then have to be done in terms of a strict, uniform checklist. That is very different from what is now typically the case for social and economic human rights, where the first approach is followed and it is pretty much left to the discretion of countries to determine what the specific areas are in which they will try to make progress and how they will do that.

JG: But still they have to justify what they actually decide to do – and not to do. There is a fairly elaborate framework on how different countries, within their margin of appreciation, must justify how socio-economic rights are being implemented. International monitoring always is complementary. It's the national states that have to implement international standards. And I agree with you, what is most interesting is how international bodies can compare the different circumstances and the different solutions that are found, and that may in the course of time lead to some common criteria.

JA: And whenever somebody shows that you can accommodate people in a new and better way, that it again shifts the burden of proof and puts the justificatory pressure on people to explain why they aren't following the lead of others.

JG: It is also very important for implementation that you should not only look top-down but expect a lot from the power and tools that the Convention can give to all groups in society, such as the disabled movements, to challenge and to demand answers at least.

JA: The right to justification.

JG: Yes.

JA: Let's get back to the issue of priorities, which has been a focus in the discussions among jurists and philosophers from the very beginning of our interactions, and to which some of the other contributions to this volume are dedicated.

JP: Perhaps this is putting it too simply, but many philosophers think that if you don't have clear-cut rules for setting priorities between rights in a very principled way, priority-setting will be left to the political game, and that will be to the detriment of the groups who need the rights. I have the sense that lawyers don't feel the same need for general principles about setting priorities. Could you just lay out what position is typically taken in the human rights law discourse?

JG: Priority setting is not very popular in human rights discourse. The most common answer will be that there are no priorities, although some rights are more absolute than others. But that's a different way of discussing matters. "Absolute", here, means that there are no exceptions. Basically, this is true for the right to life and the right not to be submitted to torture or inhuman treatment. These two rights have no exceptions. But for the rest it's very difficult, because every example you give can be countered by another case which emphasizes the interrelationship of human rights. The right to food is sometimes put forward as the highest priority right, because if you have no food you die, you cannot go to school, you cannot work, and so on. But if you don't have freedom of speech, you cannot make known that you need food, as has been the case in Ghana in the past when the military regime didn't want people to

know about the famine in the North, because they feared damage to their international reputation. They were afraid they wouldn't get loans, so the press was not allowed to publish information about the famine, which means that no international organizations such as the Red Cross could come to provide assistance. So you need to have freedom of the press to realize the right to food. That's why human rights lawyers don't want to talk about priorities.

JP: So the problem is not so much that some rights couldn't, in the abstract, be more important than others. Rather, it's that, as a largely empirical matter of fact, even the most important ones will entail the less important ones.

JG: It will always be possible to deny all priorities, with the possible exception of the right to life: if I'm killed then I can't exercise any human rights anymore. But that's not a priority, that's an absolute right.

JA: One of the things that are distinctive about the Disability Convention is that it focuses not only on negative rights but also on positive rights. The positive points are no longer just gifts or charity, they are part of what is owed to people. But especially as you expand possibilities for people – and acknowledge the different ways in which people can participate in the workforce, in the political process, and so on – it complicates what we want to say people are entitled to. The Convention makes it clear there are lots of different ways to get from marginalization and repression to full participation, and what we expect from member states is that they come up with an effective way, however they do it. But don't you want to say that priority should be given to those strategies that emphasize the most central human rights?

JG: "The most central human rights"???

JA: I see the problem. But the intuition is that the more choices there are, the more we need a principled way of deciding among them.

JG: Perhaps what you are saying can be reformulated as a demand for consistent policies regarding the gradual and stepwise implementation of human rights guarantees. I think that would be more acceptable, not only from the standpoint of policy but also from a philosophical point of view. You could set a long-term strategy, and start with more measures in one area, and then take up another area more intensively. Of course you cannot do away with the others altogether, but you start with for example giving priority to accommodating all schools etc. because you think education is a precondition, and then you can use this experience in other areas. Or you start in the area of labour because paid labour is an entrance to important forms of participation in society – whatever you want. But you must, in justifying your choices, be able to point to something more than dollar signs. So it's still not about priorities, but rather about justifying how one implements in stages. The fact that you cannot set priorities, in my opinion, doesn't make things unworkable. It doesn't mean that you have to do everything at the same level at the same time. Different choices can be made. You can spend available resources on human rights across the full spectrum, or start with a specific right or group of rights and spend more resources on that right. That's not the same as setting priorities.

JP: Let's stick with those two options. How would you go about choosing between those two options?

JG: I don't know whether you can make this choice in the abstract: specific circumstances at a specific time and place may urge different choices. I can imagine that all choices are justifiable, above a certain level. There are minimum standards that have to be met. We cannot say we don't pay anything anymore for health care for disabled people, because we start with some other focus.

3 Intersectionality and Employment

JA: There are two topics that we haven't gotten to yet. One is intersectionality, and the other is the issue of employment discrimination in particular.

JG: In a sense we have been talking about the topic of intersectionality, with the case of the woman who was fired because she had a son with a disability. This is an especially interesting case because the Court of Justice of the European Union had to answer the question whether she was dismissed because of disability, although she herself was not disabled. And very briefly, the court said that the only reason why she was dismissed had to do with disability – whether it was her disability or the child's disability was not relevant. And this is now incorporated as "discrimination by association".[8] This case is also interesting from the perspective of intersectionality because it also has to do with gender stereotypes. This mother was expected to take care of a disabled child, and I think that for a father of a disabled child this won't come up in the same way, at least not in the UK.

So I think intersectionality is one of the challenges in the field of discrimination law, and it also shows that we have to put more emphasis on the substantive rights that we are talking about – the right to work, the right to education, to health, etc. It is getting more and more difficult to separate different aspects of identity in people. The Women's Convention was a start in trying to include some dimensions of intersectionality, and the Disability Convention clearly shows that the multiple levels of disability must be taken into account, not only for women but also for elderly people, for women, children etc. You see that this is important when you look at for example the principle of discrimination by association. Intersectionality expands the scope of human rights. In the case of disability the

[8] For example, in *Coleman v. Attridge Law* (July 2008) the European Court of Justice ruled that, under the EU's Framework Employment Directive, "discrimination by association" can be illegal in the workplace.

principle of association, for example, this is quite straightforward, but in the case of someone with, say, a specific religion, it can be very difficult to apply.

JA: I'd like to come back to the question of employment law and discuss this in this context. If you have a model of nondiscrimination that is formulated in terms of prohibiting differential treatment of people (on the basis of race or gender, say), then someone who has a mobility or sensory impairment is not an obvious target of discrimination in that sense, if they are not hired for a job, because, after all, they are *different in the relevant sense. As we've been discussing, the Convention on the Rights of Persons with Disability takes things in a different direction. It puts the focus more on inclusion and accommodating differences as a way of promoting full inclusion and participation. That seems to generate a real tension with our existing policy on selection and promotion in the workplace, where choices are supposed to be made on the basis of what that individual can do, how many widgets that individual can crank out on the assembly line. What is a better way of thinking about what the Disability Convention demands in terms of nondiscrimination? How does it move us beyond the old model, and why doesn't it generate all kinds of conflict with the liberties of employers to make decisions with regard to whom to put on their payroll?*

JG: I don't think I understand your point here. In my view, the Convention does not change anything. Of course everybody trying to fill a job vacancy wants to get the best possible person for the position. However, some ways of understanding who is the best person for the job are premised on performance in the presence of unnecessary practical barriers – barriers that handicap persons with specific disabilities – and that cannot legitimately be relevant for the hiring decision. You still are entitled to select the best person for the job. It just means that if you want to hire someone for, say, testing sports shoes and someone applies who says, "I can wear shoes but I cannot walk on them myself because I'm in a wheelchair," and you want someone to test the shoes while walking on the street or whatever, then there is a relevant qualification he simply doesn't have. But if

it's someone who can test the shoes but he has diabetes and needs some time to take injections or something, then you have to set aside that aspect in the selection process, because it is not relevant for the capacity to test the shoes.

JA: But if you're looking to hire a sales representative who's going to travel all over the country meeting lots of people and doing lots of presentations, it seems like very many characteristics could be relevant for selecting the best candidate. Some of those characteristics are going to be clear cases of what should be excluded from consideration in whether to offer someone a job; here we're talking about well-established views about certain impairments deserving protection. But there are less clear cases. Perhaps someone suffers from a mild depression that makes it difficult to handle the pressure of being a sales rep on the road, or he's so overweight that he is going to require two airplane seats when travelling. I think there's a really big gray zone that raises issues for how we can consistently and in a principled fashion apply the understanding of nondiscrimination as inclusion and enablement that is entailed in the Disability Convention.

JP: And if you are thinking about market transactions then an employer would also have to remain competitive enough…

JG: But the point is that there is an assumption that some people will be the best value for the money, and you never really know that in advance, but only afterwards. What the Convention does is to challenge these assumptions. How do you know that the person is not the best for the job? Or the best value for money? In some cases the Dutch Equal Treatment Commission ruled that you can at least offer a temporary position to find out how it works.

JP: So the Convention invites us to think twice about our assumptions regarding who is best qualified for a job…
JA: And it also places certain considerations off-limits, right?

JG: Sometimes you have to say, "Even if he brings in twice as many orders, we simply cannot afford to hire him, because we're a small company." The cases will differ. I think that one of the most difficult things is the prejudices and stereotyped images that people have. Employers should have the burden of proof to show that something is really a requirement for the job. On the other hand, there are some limits to what you can expect an employer to provide as a reasonable accommodation. I think that for all cases of discrimination, the attitude issues are the most difficult. So I think that in the long run you may still need some kind of very hard "positive action" or "affirmative action" and even quotas.

JA: That reminds me of an interesting article by Susan Sturm and Lani Guinier[9] about how to address racial imbalances through affirmative action. They argued that very often what minority job candidates need is a chance to prove themselves on the job. They suggest that a good policy would be to promote more entry-level positions, where people get the chance to show what they can actually do, and that the selection gets made only after they have had a real opportunity to do that.

JG: Yes, but even then, you have to create the conditions for truly capable candidates to prove themselves, because if you just have one token person in an organization which basically doesn't accept this type of person, it won't work. There are lots of examples from the women's movement. There are cases where, for example, they tried to increase the number of women firefighters and they employed one or two women. But that didn't work, because the whole atmosphere was such that women did not feel welcome. I've seen many cases when I sat on the Equal Treatment Commission where the employer said, "Well, I hired this woman, but she should have known that she was working in a man's world, where people make

[9] S. Sturm and L. Guinier, "The Future of Affirmative Action: Promoting Diversity in Education and Employment Requires Us to Rethink Testing and 'Meritocracy'," *Boston Review*, December 2000/January 2001.

sexist jokes. She should be able to accept that." And I said, "Did you talk to the male employees and tell them that there was a woman coming? Did you suggest to them that maybe they should change their behaviour making these jokes and so on?" Similarly for disability: it is not just a matter of giving an opportunity to a few disabled people, but it is also a matter of educating the organization. That's what the Convention is about.

JP: How do you think in these contexts about who the duty-bearers are? It is primarily a responsibility of governments, or of employers?

JG: In terms of the Convention, it is the government who is accountable, but governments also have to see to it that private parties are in compliance. But it's the government that has to develop policies and to educate and to provide facilities and so on.

JP: So it is not the case that an employer can be brought to court and charged under the Convention?

JG: Well, they can already be charged under the national law, which in turn has to meet the international standards. But on the basis of the Convention, I think it is first and foremost states that have the obligation to address these concerns. Under EU directives, private parties are accountable as well.

JA: Which I think is a good place to stop. We would like to thank you again for this interview!

4 The Convention on the Rights of Persons with Disabilities and Cultural Understandings of Disability

Jackie Leach Scully

1 Introduction

Disability is a profoundly complex human experience and social phenomenon, and it is only to be expected that cultural understandings of disability have changed, and continue to change, over time. The most recent shift in understanding, which has taken place over about the last 40 years, is a move away from the view of disability as a primarily *biomedical* problem located in the individual's deviation from norms of form and functioning, and towards a broader sense of the *disablement* caused by mismatches between non-standard bodily forms and social arrangements that were designed to suit the standard. This view is the basis of the social model of disability, and subsequently of various social-relational models developed as the limitations as well as the strengths of the original model have become clearer.[1] Although rooted in disabled people's dissatisfaction with the available theorization of their lives, the conceptual restructuring of disability as a relational concept has begun to inform the cultural conceptions of disability held by the nondisabled world as well. Some evidence of this can be seen in the way that the language of social models of disability is making its appearance in public discourse, and in equality and discrimination policy documents. For example, the UK government's Office for Disability Issues states on its website that

[1] C. Barnes, "The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists?" in *The Disability Reader: Social Science Perspectives*, edited by T. Shakespeare, (London: Cassell, 1998), 65-78; T. Shakespeare, *Disability Rights and Wrongs*, (Abingdon: Routledge, 2006); J.L. Scully, *Disability Bioethics: Moral Bodies, Moral Difference*, (Lanham: Rowman & Littlefield, 2008).

> [t]he social model is the preferred model for disabled people. It empowers disabled people and encourages society to be more inclusive. The Office for Disability Issues encourages all government departments to use this model when considering disability.[2]

The processes through which cultural transformations in thinking about disability take place are inevitably as complex as the phenomenon itself. By "cultural transformation" I mean a fundamental change in the "givens" that a culture holds to be true about something: the values, principles, roles, acts and practices that are taken to be *obviously* right or wrong, or that can be placed without having to think too hard about it within our imagining of what constitutes a good life. Although transformations of such a fundamental kind are far reaching and radical, they are not necessarily rapid or even very obvious while they are happening. Certain events along the way may be obviously revolutionary, but the groundswell of change tends to be only noticeable when we look back and compare where we are now to where we were before.

The actual processes of social transformation are likely to be interactive and iterative. For example, what people in general think about a subject will spotlight the elements that experts will consider important to analyse, while expert conceptual and technical advances ultimately filter back into the social realm to affect how people act and think. One important route for these interactions is the creation of new policy and legislation. Essentially, legal and policy documents are statements of how (someone thinks) things should be. At a minimum, human rights documents like the CRPD can act as a kind of check list of relevant rights and obligations. The check list is a kind of practical pointer towards the organization of some version of an ideal world: it cannot guarantee a good life, but can guarantee a minimum framework in which fundamental needs are met and values adhered to so that a person with disability has as much

[2] HM Government Office for Disability Issues, http://odi.dwp.gov.uk/about-the-odi/the-social-model.php; Guidance Note on Disability and Development for European Union Delegations and Services, European Commission 2004, p.3.

chance as a nondisabled person of achieving a good life. But beyond functioning either as a check list or a description, the CRPD can act as a tool for the transformation of how cultures think about disabled people. Through the public discussion that, ideally, takes place as new policy documents circulate and key pieces of legislation are reported in the media, new configurations of the social roles and practices associated with what is being regulated will emerge. And so legal and policy instruments, as well as *reflecting* current understanding of a topic, also have a potentially *transformative* effect.

I want to suggest that the UN Convention on the Rights of Persons with Disabilities could play such a potentially transformative role for our cultural-moral understanding of disability (and of associated ideas like normalcy and impairment). Although there are many aspects of the Convention that could feature here, in this chapter I focus quite narrowly on a single principle of the Convention. I examine how it may affect both interpretation of the Convention's terms and the ontological status of disabled people, and consider how a shift in the cultural understanding of disability could significantly alter the narrative about and moral evaluation of one particularly contentious case.

2 The Convention

Article 3 sets out the eight general principles that guided the thinking behind the Convention and should now guide how it is interpreted. The principles range from rather broad expressions of respect for human dignity and autonomy in general principle (a), to a very specific statement about the evolving capacities of children with disabilities in general principle (h). As one of the more general statements, principle (d) is given as *Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity*.

It is immediately obvious that the key terms in this principle are ambiguous (the Convention gives little guidance on definitions, leaving most of that to the work of subsequent commentators). What I want to point out here is that the phrase "acceptance of persons with

disabilities as part of human diversity and humanity" can be interpreted as saying something quite radical about disability itself. Because the principle quite carefully does not say that all disabilities are undesirable anomalies, it leaves open the possibility of a disability being a neutral or even, in some contexts, desirable aspect of diversity. This reading of the principle represents a clear step away from the understanding of disability as *necessarily* an undesirable anomaly in human life, and towards a picture in which *at least some forms* of disability must be accepted as human variations that in the right context may be neutral, or only trivially disadvantageous.

With this understanding of disability, the Convention repositions its interest group alongside the groups covered by other, analogous Conventions relating to race (International Convention on the Elimination of All Forms of Racial Discrimination), gender (Convention on the Elimination of Discrimination Against Women) and children (Convention on the Rights of the Child). All of these are, for different reasons, marginalized social groups; marginalization means their members are disproportionately vulnerable, discriminated against and often profoundly disadvantaged. But while the genuine social disadvantage of being a member of one of these categories is acknowledged, there is no suggestion, either in the relevant Conventions or in general cultural thinking, that the world would be a better place if racial differences, or women, or children, did not exist.

Opinion on the ontological and moral status of disabled people, I would argue, is much more ambivalent. While globally there is a growing sense of the importance of affording rights and particular protections to disabled people, this is accompanied by a baseline assumption that most physical and mental deviations from some accepted norm are disadvantageous and, because of that, disabling, and so in an ideal world they would not happen. The simple existence of the Convention as a parallel to analogous Conventions covering other socially marginalized groups implicitly means that these assumptions have to be re-examined. It is important to emphasise here that I don't intend to suggest (and neither I think does the Convention) that *all* impairment and disability can or should be considered like this: there are impairments that so badly compromise the possibility of a minimally satisfactory, let alone a good life, that rea-

sonable people could not possibly call them neutral. But it is possible to argue from a radical interpretation of general principle (d) that there are variations of form or function from the accepted norm that are not disadvantageous, and hence should be accepted as unremarkable manifestations of human diversity. Even if this radical reading is rejected, a less radical reading, taken in the context of the Convention as a whole, still says that disabled people are full members of every human community and full bearers of all the rights that nondisabled people enjoy; and this itself has far-reaching implications for the treatment of disabled people and the conceptualization of disability.

3 "Choosing Disability"

The example I want to consider now is where parents with a physical impairment express a wish to have a child with "their" impairment, and may also want to use assisted reproduction technologies (ART) to increase their chances of doing so. It is important to be clear at the outset that so-called "choosing disability" is very rare. It seems to be confined to a small number of impairments that have some heritable component and that are associated with a strong internal group or cultural identity. Notably, this covers deaf people who consider themselves members of the signing Deaf community rather than as disabled people; dwarfism; and most recently, people with forms of autistic spectrum disorder who are being to identify themselves as "neurodiverse". Selective reproductive technologies such as preimplantation genetic diagnosis (screening and selection of embryos created in vitro) can in principle be used to select for rather than against an impairment. "Choosing disability" has received an entirely disproportionate amount of both bioethical and popular attention, partly because of intense publicity around cases where regulated ART has been involved, but also because the wish to have a child with what is seen by most people as a disability is counterintuitive and often disturbing.

In fact majority opinion seems to be that such a choice is not only bizarre but unethical as well. The issue first made major headlines

with media reports in 2002 about a Deaf couple in the US with genetic deafness who had used donor insemination (DI) to become pregnant.[3] That the couple were two women is relevant, because it meant they needed to use ART to have children. Controversy arose because they openly expressed the desire to use a genetically deaf donor in order to increase their chances of having a deaf child, and were refused because commercial sperm banks do not accept donors with a genetic abnormality. As a result, the couple concerned found an "informal" donor, a male friend with genetic deafness, and ultimately had two children, both with an audiological (hearing) impairment. Since that case was first reported there have been further flurries of attention, often when a more or less related issue is in the news; a notable example was the discussion about the revision of the UK's Human Fertilisation and Embryology Act in 2008, which inserted a new clause specifically prohibiting PGD clinics from implanting embryos carrying "serious genetic conditions" if alternative "normal" embryos are available.[4]

4 The Ethics of Choosing Disability

Ethical discussion of "choosing disability" tends to be based on attempts to weigh up two different sets of rights.[5] On one side are the rights of parents to what has been termed "reproductive" or "procreative liberty"[6] or "procreative beneficence"[7], that is, the right of par-

[3] L. Mundy, "A World of Their Own," *Washington Post Magazine*, March 31, 2002.
[4] HFE Act 2008; S. Emery, T. Blankmeyer Burke, A. Middleton, R. Belk, G. Turner, "Clause 14(4)(9) of Embryo Bill Should be Amended or Deleted," *British Medical Journal* 336(2008): 976.
[5] There are other forms of argument, e.g. drawing on care ethics (see e.g. J.L. Scully, "Disabled Embodiment and an Ethic of Care," in *Bioethics in Cultural Contexts: Reflections on Methods and Finitude*, edited by C. Rehmann-Sutter, M. Düwell, and D. Mieth, (Dordrecht: Springer, 2006), 247-262), but I will not discuss these in detail here; they do not affect the main point of this chapter.
[6] J.A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton: Princeton University Press, 1996).
[7] J. Savulescu, "Procreative Beneficence: Why We Should Select the Best Children," *Bioethics* 15(2001): 413-26.

ents to determine the number and timing and (as some but not all bioethicists will argue) at least some of the characteristics of the children they have. Balanced against these are claims to i) the child's right to "an open future" (the obligation of the parents to constrain as little as possibility the options that will be open to the child's autonomous choice[8]), and/or ii) the child's right not to be harmed.[9]

Arguments against the liberty of parents to choose deafness as a characteristic of their child depend on deafness being seen as something that i) constrains the child's possibilities to an unacceptable degree (i.e. closes off its "open future") and/or ii) constitutes an active harm that infringes the child's welfare. And in turn, this means they are based on the premises that deafness as a characteristic is inevitably disabling, and that disability is something that the world would always be better off without.

5 "Choosing Disability" in the Light of the Convention

I want to consider now whether the Convention might have what I described earlier as a transformative effect on our understanding of these situations: that is, whether it might change our evaluation of the moral problem of choosing *for* rather than *against* disability. Article 23 of the Convention, *Respect for home and the family*, is the one that most directly addresses the issue of reproductive choice. Paragraph 1 states: "States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in *all matters* relating to marriage, *family, parenthood*, and relationships, on an *equal basis with others*…." (my emphases). This is a claim that relates to reproductive liberty: it says that disabled people should have an exactly equal kind and degree of reproductive liberty as anyone else. Paragraph 2 of Article 23

[8] J. Feinberg, "The Child's Right to an Open Future," in *Freedom and Fulfillment,* edited by J. Feinberg, (Princeton NJ: Princeton University Press, 1992), 76-97.

[9] For elaboration of these arguments see D. Davis, "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27(1997) 7-15; J.L. Scully, *Disability Bioethics*.

then goes on to state: "States Parties shall ensure the rights and responsibilities of persons with disabilities....(but) in all cases the *best interests of the child shall be paramount*." This is a claim about the welfare of the child, applying both to disabled children and to the disabled and nondisabled children of disabled adults.

On its own, then, Article 23 does nothing much to change the arguments about the ethics of "choosing disability" that I have outlined. For instance, one argument would be that if nondisabled people have the opportunity to use methods of reproductive control, including ART, to select the characteristics of their children (the assumption being that selection would be against having a child with a disability), then preventing disabled people from using the same technologies to choose the characteristics of their children is a form of discrimination, and as such rejected by Paragraph 1. However, the stipulation in Paragraph 2 about the primacy of the child's best interests acts as a counterbalance to the reproductive liberty/discrimination claim. If a child's best interests require that it has as open a future as possible, and that it is not harmed, then an impairment that closes off options or harms the child must be avoided if possible, and certainly must not be actively chosen. And if the child's best interests are paramount then they must always outweigh the potential for discrimination.

But if, as I suggested above, general principle (d) of the Convention weakens or removes the *necessary* link between disability and harm to life chances, this changes the overall moral balancing of any case that hinges on predictions of the harm caused by disability. I've already shown that, although the principle makes no overt judgement about exactly how undesirable or not disability is, by stating that persons with disabilities are *part of human diversity and humanity* it opens up the possibility that disability is part of the human condition, not because suffering is part of the human condition but because not every disability involves suffering. In that case, our vision of the ideal society *can* contain the possibility of impairment; and if we don't start from the unquestioned premise that an ideal society would always be better off in the absence of disability, then it is not self-evident that choosing disability is necessarily an act that limits the child's open future, or causes it harm. These might be the

consequences, but they would have to be argued for, and would be dependent on the impairment itself and the context within which it is lived. In at least some cases (for example, where families are closely identified with the Deaf community or the emergent neurodiversity movement), arguments about the best interests of the child would be then become less forceful when set against the arguments for nondiscrimination or reproductive liberty.

It's worth pointing out in passing that much of this argument relies on societies having already moved some way towards the ideal of acceptance of disability as diversity, in practice and in attitudes. If societies adhere to rigid norms of body form or function, or if they lack the resources to support disabled people and their families, then the level of disadvantage and hostility that a disabled person faces will almost inevitably mean that arguments based on the best interests of the child will favour "normality" over any non-standard bodily variation.

6 The Convention, Cultural Transformation, and Implementing Human Rights

In the early days of what we now call the human rights movement, the focus of attention was above all on state actors. These were considered to be the bodies with the authority and means to protect (and of course also to infringe) human rights. Increasingly, however, the role of non-state actors in the preservation of human rights is being highlighted, including the need for cultural transformations of various kinds if human rights are to become normative, that is, integrated to such an extent into our institutions and everyday social lives as to seem obvious. Because of this increasing awareness recent human rights instruments, including the CRPD, have begun to refer to the state duty to "promote" the values and norms embedded in each instrument. So far there has not been much attempt to lay out in detail exactly what promotion requires of a government, nor (and this may be a bigger gap) has there been any empirically based evaluation of what forms of "promotion" (advertising? education? severe punishment for infringements? tax benefits?) most effectively en-

courage the members of a society to adopt new ways of thinking about human rights. It is also worth pointing out that discussions linking human rights and the need for cultural change have a tendency to refer solely to "other" (i.e., non-western) cultures and their supposed resistance to western ethical standards, especially in terms of women, sexuality and the family. Although there is much to be debated here, all I want to do now is to note that western societies are not exempt from the need for a transformation in their thinking about human rights, including their beliefs about how and to what extent the rights of particular social minorities (such as disabled people) can be respected in increasingly diverse and often fragmented contemporary societies.

It is surprising (at least to this ethicist) that there seems to be very little empirically based literature on the processes through which change in cultural norms, in particular moral norms, takes place. Most of the work that directly tackles the question of cultural transformation has been done within cultural studies, and disciplinary barriers may have prevented much crossover between this work and more ethical-political analyses. The approaches of different schools of critical discourse analysis[10] for example indicate methods for examining how discourse – such as the discourse around a new Convention – reflects and shapes the meanings afforded to social practices and roles, and also reflect on the interaction of personal agency and social structure in the negotiation of meaning. The social anthropologist Pierre Bourdieu's notion of *doxa*[11] provides another perspective from which a community's practices can be related to how its members generate their sense of what is "obviously right". Still, the dynamic and socially embedded nature of normative change makes it hard to place what can be observed at any given time within a theoretical position. I am not aware of any published

[10] L. Chouliaraki and N. Fairclough, *Discourse in Late Modernity: Rethinking Critical Discourse Analysis*, (Edinburgh: Edinburgh University Press, 1999); E. Laclau and C. Mouffe, *Hegemony and Socialist Strategy*, (London: Verso, 1985); J. Torfing, *New Theories of Discourse: Laclau, Mouffe, and Zizek*, (Oxford: Blackwell, 1999).

[11] P. Bourdieu, *Outline of a Theory of Practice*, (Cambridge: Cambridge University Press, 1977).

work, for example of discourse or Bourdieusian analysis, or using some other approach, that tracks how new public policy or legislation, or instruments such as the CRPD, is taken up by the networks of related meanings and social practices so that they in turn feed back into how the text is interpreted and implemented.

To explore whether and how the Convention can effect cultural change means concentrating on the beliefs and practices of the various lay groups who make up the majority of the public realm, rather than only on the ethical or legal experts whose interest lies more in the fine detail of interpreting the Convention and then implementing it as policy. Given how recently the Convention was signed, and also acknowledging the depressingly low profile of disability issues, it seems likely that at the moment most people will not have heard much about the Convention. Even as (or if) knowledge of it becomes more widespread, many people's awareness will be no more than that a Convention on disabled people's rights exists. Nevertheless, I would suggest that even this is enough subtly to reshape the cluster of meanings associated with disability. The simple fact of the existence of the Convention sends out the message that disabled people are equal subjects of rights with nondisabled people, and that their particular vulnerabilities require the articulation of targeted measures to ensure that those fundamental rights and freedoms are protected. The type of obligations that are associated with protecting those rights are spelled out in the Convention, and in doing so it writes a description of the societal responses to disability that should be taken as normative. A step beyond this is the message that could be sent out by general principle (d): that disabled people are part of human diversity and humanity, and disability need not always be viewed as a deviation from the norms of a good life. Thus, irrespective of whether the more or the less radical version of general principle (d) is preferred, the Convention can express some fundamental modifications to societal expectations about the normative status of disability and/or the inclusion of disabled people in social organizations and practices.

By "sending out a message" to the public about how things should be, the Convention is serving an expressive or symbolic function. When human rights instruments are described as having a symbolic

value the sense is usually pejorative. It tends to mean that human rights instruments are solely for show and have no power in real life. But the expressive function of a piece of policy or legislation is an important, though under-researched, one. Within legal studies, the examination of "symbolic politics" or the expressive function of law has tended to focus on deterrence, or to place symbolic work in opposition to tangible benefits,[12] although some recent writers see legislation as inevitably both symbolic and instrumental.[13] That a legal statement has a large amount of symbolic value need not, however, mean that it is useless. The notion of a law "sending out a message" that some forms of behaviour will not be tolerated by a society has been invoked in debates about legislation covering hate crimes, blasphemy, domestic violence and so on, where it is seen as having an important function in mobilizing progressive opinion. The passage of a statute demonstrates the strength of social consensus, irrespective of whether the law is ever actually used in punishment.[14] But again, rather little is known about the social processes through which laws send out messages and those messages are read by the right audiences, although most writers acknowledge that in order for a law to influence social norms, information about the existence of the law is crucial. It would be useful to know more about this in order to predict what might happen with the CRPD, through which avenues, and on what sort of time scale. Clearly, empirical research is needed; indeed, it might be that the CRPD provides a useful case study for just such research.

I have suggested that the Convention has the potential for transforming the broad cultural understanding of disability, and furthermore that this will then change our evaluation of particular ethical dilemmas concerning disability – though the effects may be un-

[12] See e.g. M. Edelman, *The Symbolic Uses of Politics,* (University of Illinois Press, 1964 (second edition, 1985)).

[13] B.A. Stolz, "Interpreting the US Human Trafficking Debate through the Lens of Symbolic Politics," *Law and Policy* 29(2007): 311-338.

[14] R. McAdam, "The Origin, Development and Regulation of Norms," *Michigan Law Review* 96(1997): 338-433; Anderson, E. and R. Pildes, "Expressive Theories of Law: A General Statement," *University of Pennsylvania Law Review* 148(2000): 1503–1575.

expected, as I have tried to show in my example of the moral evaluation of choosing disability within the Deaf community. Equally, the direction of transformation will depend on factors that may be hard to predict, including which of several possible messages the Convention "sends out" into the public sphere. Understanding these processes will be challenging but vital if we feel that particular directions of cultural change – towards the recognition of disabled people as rights bearers, and their inclusion in society – are desirable, and we want to know how to increase the chances that the Convention promotes them.

5 Resolving the Tension between Equality and Difference: Towards a New Understanding of Discrimination

Sigrid Graumann

1 Introduction: Experiences of Misrecognition and the Changing Notion of Discrimination

Even though the Universal Declaration of Human Rights begins with the famous statement that "all human beings are born free and equal in dignity and rights", the historical experience has proven that, in reality, the protections provided by human rights do not apply to everyone equally. Many groups such as the poor, foreigners, women, children and persons with disabilities have for a long time not been equally protected by human rights. Obviously, there is a certain tension in human rights thinking between respecting rights equally and recognizing particular differences. And the growing insight into this problem has led to a remarkable extension of what can count as discrimination. My aim in this contribution is to analyse the extended notion of discrimination in current human rights thinking with regard to the new Convention on the Rights of Persons with Disabilities (CRPD) and to discuss whether this extension is well-grounded from a philosophical point of view. I start with the communitarian critique that human rights thinking neglects violations of personal identity that are caused by the experience of disregard of difference. I will discuss the relation between demands to respect the rights of all persons equally and demands for recognition of difference as formulated by social movements such as the independent living movement. Drawing on the work of Seyla Benhabib, I will argue that truly respecting the human rights of persons with disabilities on an equal basis with others requires a combination of both perspectives – in Benhabib's words, persons with disabilities should be recognized as both generalized others with equal rights *and* as concrete others with individual needs and particular living conditions. This leads me, finally, to the question of what obliga-

tions we have to reduce discrimination – according to its extended notion. My answer is that we should combat discrimination not only by preventing the arbitrary denial of equal rights but also by equalizing opportunities and by fostering social esteem concerning persons with disabilities. And that is exactly the intention of the CRPD.

2 Towards an Extended Notion of Discrimination

The CRPD follows the tradition of other human rights treaties, such as the Conventions on the rights of women and children, which focus on protecting members of particular societal groups from discrimination.[1] Generally, one of the main challenges for such group-based Conventions is to handle the tension between the demands for equal respect and the demands for recognition of differences. It has often been stated that, in coping with this challenge, the CRPD[2] – comparable to the CEDAW[3] or the CRC[4] – does not contain any "special rights" for people with disabilities but merely defines more precisely the general protection of human rights as they relate to the special risks to which people with disabilities are exposed. However, if there are no special new rights, the question is what is really new about the Convention. In order to answer this question it might help to have a closer look at the definition of "discrimination" in the CRPD:

> 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

[1] Generally, discrimination means any illegitimate unequal treatment.
[2] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 70.
[3] Convention on the Elimination of All Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13.
[4] Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 44.

> rights and fundamental freedoms in political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of reasonable accommodation.[5]

In human rights law, the notion of discrimination was originally restricted mainly to arbitrary denials of equal rights. However, the passage from the Convention just quoted mentions other structurally caused, direct and indirect forms of unequal treatment as forms of discrimination. This reflects a general tendency in the development of human rights thinking. This development is driven by the misrecognition experienced particularly by members of certain social groups. Such experiences have proven that traditional interpretations of what human rights demands are about could not protect their rights in an adequate way and thus has motivated societal conflicts.

The articulation of experiences of misrecognition in such societal conflicts has raised public awareness of particular human rights violations, which had previously been more or less invisible. Extending the notion of what counts as discrimination according to the human rights framework might be the consequence of these historical developments. The evolution of the definition of discrimination in the history of group conventions reflects this. Already in the CEDAW, which has been adopted 1979, the first sentence of the definition of discrimination is formulated in nearly the same way as in the CRPD. What is new is the second sentence labelling not only prejudices and negative stereotypes but also the lack of reasonable accommodations as discrimination. This means that the predominant concept of discrimination now includes not only the withholding of formally equal rights but also prejudices, negative stereotypes, diverse barriers and lack of support.

A further shift in human rights thinking is related to the formulations of the obligations of the state to prevent discrimination. This again becomes obvious if we compare the CEDAW and the CRPD. The CEDAW demands from the state "to modify the social and cul-

[5] CRPD, Article 2(3).

tural 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" (CEDAW Article 5). Despite the progressive force for the empowerment of women that it was at the time, this is a rather weak formulation of state obligations, compared with the CRPD. The CRPD instead demands even more from the state, namely concrete measures addressing prejudice and misrecognition.

To sum up, if we consider the notion of discrimination in the CRPD as the provisional end point of a historical process, it can be stated, first, that there is an extended notion of what counts as discrimination; second, there is an increasing awareness of indirect, structurally caused forms of discrimination; and third, there are growing demands regarding the responsibility of the state to prevent and defend against discrimination.[6] However, it is not clear yet whether these extensions of human rights thinking can be convincingly justified from a philosophical point of view.

3 The Tension between Respecting Rights Equally and Recognizing Difference

From an historical point of view, it was initially the white, male, economically independent members of the dominant culture in society who were the primary beneficiaries of human rights protections. For a long time, rights-violations experienced by members of other societal groups, such as women, children, cultural minorities and disabled people, remained largely invisible and unrecognized. This has been picked up by several authors from the communitarian camp who are defending communities based on common values against the liberal political individualism. The observation that misrecognition experienced by members of cultural minorities has not

[6] cf. H. Bielefeldt, "Diskriminierungsschutz als menschenrechtliche Verpflichtung," (Berlin: Deutsches Institut für Menschenrechte, 2005), 2–6.

been taken seriously in the liberal politics of modern western societies motivated Charles Taylor to formulate his fundamental critique of human rights and their underlying ideas of equal dignity and rights. Taylor defends the demands for recognition of a cultural identity which require the assertion of specific rights by cultural minorities against a strict policy of equal treatment. Taking a Hegelian perspective, he refers to the relationship between recognition and personal identity. His central thesis is that misrecognition or non-recognition does not merely show a lack of respect for a person or a group of people. In addition, a person or a group of people can suffer real damage to their identity because of misrecognition by others.[7]

Taylor argues that cultural minorities that are afflicted by misrecognition or non-recognition adopt a deprecatory view of themselves. As a result, he states, they are "incapable of taking advantage of new opportunities" and are "condemned to suffer the pain of low self-esteem".[8] However, it is his view that human rights thinking tends to neglect such violations of personal identity. He argues that human rights can be seen as universal and "difference-blind rules".[9] They are, as he points out, only apparently neutral because they are marked in reality by particularity due to the hegemonial culture. In his words, they are nothing else than "a particularism masquerading as the universal".[10] On these grounds Taylor tends to object to a human rights approach as such and argues it should be replaced with a policy of recognizing particular differences. In a similar way, Alasdair MacIntyre criticizes rights-based liberalism, focusing on the situation of persons with disabilities and the help, support and care they need. In order to ensure that fundamentally impaired persons are cared for in an adequate way, public policy should not be based on the ideal of independence but on the insight in the funda-

[7] C. Taylor, "The Politics of Recognition," in *Multiculturalism and 'The Politics of Recognition'*, edited by C. Taylor and A. Gutmann, (Princeton: Princeton University Press, 1992), 25–74, at 25.
[8] Ibid, 26.
[9] Taylor, "The Politics of Recognition," 40.
[10] Ibid, 44.

mental dependency on other persons that determines many periods of human life. We should foster the "virtues of acknowledged dependencies" in society instead of believing in rights.[11] That is also the reason why Hans Reinders advocates a "politics of culture" instead of a "politics of rights." He thinks that developing adequate strategy to ameliorate the societal position of disabled persons requires building caring relationships through character rather than through rights.[12]

However, despite the fact that these communitarian authors identify crucial problems in human rights thinking, I do not believe that the implications they think their critiques have are very helpful for disabled people. After all, during the last two or three decades, disabled people themselves have been lobbying for a policy of rights instead of a policy of charity. Concerning the fact that the CRPD is part of binding international law now, disability activists consider it a great achievement to be able to put their demands in the language of human rights.[13] That is why I would doubt that they are prepared to accept these communitarian ideas.

My own suggestion is to use a distinction drawn by Seyla Benhabib, which gives one the opportunity, on the one hand, to take the communitarian critique seriously and, on the other hand, to deal with it in a more constructive way. To resolve the problem that, by referring to modern political principles such as equality, one does often not do justice to people in more vulnerable situations, Benhabib distinguishes between the concept of the generalized other and the concept of the concrete other. When we adopt the perspective of the generalized other, she points out, we assume formal equality and reciprocity from a moral point of view. When we adopt the perspective of the concrete other, by contrast, we bracket our equality and regard each other as persons with individual and col-

---

[11] A. MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues*, (Chicago: Open Court, 1999), 119-128.
[12] J.S. Reinders, "The Good Life for Citizens with Intellectual Disability," *Journal of Intellectual Disability Research* 46(2002): 1-5.
[13] J. Campbell and M. Oliver, *Disability Politics: Understanding our Past, Changing our Future*, (London: Routledge, 1996), 72-74.

lective identities and particular needs. These different attributes and qualities are irrelevant with respect to the fact that we should recognize each other as general others with equal rights.[14] However, they are important if we want to determine what, exactly, it means to respect the rights of an other person and how we should recognize her individual needs and living conditions in a particular societal context. Further I suggest that we should understand the concepts of the generalized other and the concrete other as two complementary, equally necessary perspectives in order to determine exactly what equal respect for the rights of a particular persons demands. To give a rather simple example: if we want to guarantee freedom of movement for persons with disabilities on an equal basis with others we have to consider their particular impairments. A person who uses a wheelchair needs barrier-free constructed buildings and public transport; a person who is blind special aids to orientation.

4 Reducing Discrimination by Fostering Autonomy and Independent Living

Within the CRPD itself, we find rather compelling examples of how to cope with the tension between demands to respect equal rights and demands to recognize particular differences, such as the regulations with the aim to guarantee "independent living" for all persons with disabilities.

Among the general principles formulated in Article 3, we find the general demand to "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons".[15] This formulation contains two aspects of autonomy which have to be respected, protected and insured: *autonomy as independence* from persons and *autonomy as authority* to make one's own choices.

[14] S. Benhabib, "Ein anderer Universalismus: Einheit und Vielfalt der Menschenrechte, *Deutsche Zeitschrift für Philosophie* 55(2007): 501–519, at 509.
[15] CRPD, Article 3(a).

If the claims following from the right to autonomy shall be ensured for people with particular impairments, both aspects of autonomy have to be taken into account. This means first of all that barriers which hinder persons with disabilities to exercise their autonomy on an equal basis with non-disabled persons have to be abolished. This is reflected in Article 9 with the heading "accessibility" which says:

> To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas [...][16]

Obviously, this regulation is directed against environmental barriers and thus against *restrictions* on the capacity to exercise autonomy. To formulate this more concretely, the barriers mentioned in this Article are understood as *external restrictions* of the autonomy of persons with particular impairments. It goes along with obligations to abolish such restrictions in order to empower disabled people to exercise their autonomy on an equal basis with others. Since barriers are understood here as interfering with the autonomy of disabled persons, the obligations derived from this aspect of autonomy are mainly negative duties or duties of non-interference.

But this is not enough to ensure the right to autonomy to all people with disabilities: even if all the barriers mentioned here would have been abolished, not all people with disabilities could exercise their rights on an equal basis with others. However, it is important to notice that the meaning of "barriers" in the CRPD is much broader: The CRPD defines barriers not only as environmental, communicational and informational but also as social, economic and attitudinal barriers. This is particularly relevant for disabled persons with an

[16] CRPD, Article 9.

increased need for support and care. For them the provision of adequate help, assistance and care is necessary in order to enable them to enjoy their right to autonomy to the extent individually achievable for them. This means that the obligations related to guaranteeing autonomy are also directed at the compensation of *internal restrictions* on autonomy which are caused by individual impairments.

In Article 19 "Living independently and being included in the community", we find an interesting categorization of the aspects which have to be necessarily considered in order to ensure the right to autonomy for *all* disabled people without discrimination against them. The general statement at the beginning of Article 19 demands "to recognize the equal right of all persons with disabilities to live in the community, with choices equal to others". This means, first of all, that this regulation is directed against forced institutionalization, which disabled people have been and are still exposed to in different countries. The prohibition of forced institutionalization gives disabled people the authority back over their lives which they have lacked so far. However, the prohibition of forced institutionalization alone does not ensure the possibility to live independently if there are no other choices available. Thus, the general statement is being put in more concrete terms in the following sentence: "Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others."[17]

This means that the state has to take concrete measures to empower people with disabilities by making adequate choices available. It follows from this that the state has to ensure the availability of different living settings, such as accessible and affordable apartments for persons with physical impairments or assisted accommodation in individual and shared apartments for persons with higher demands for support and care. However, this is still not enough to ensure that *all* disabled people can live independently on an equal basis with others and can make their own choices according to their

[17] CRPD, Article 19.

own ideas. Evidently, at least some persons with disabilities need individual compensation for limitations which are related to their particular impairments. This insight is reflected in the next paragraph of Article 19, which claims that "persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in community, and to prevent isolation or segregation from the community". Only if such services are truly available will all persons with disabilities be able to exercise their right to autonomy on an equal basis with others.

The aforementioned regulations of the CRPD show what it means to determine exactly what is required in equally respecting the autonomy rights of a particular person with disability. Thus it was illustrated how the concepts of the generalized other and the concrete other have to be understood as two complementary, equally necessary perspectives in order to adequately prevent discrimination on the basis of disability. With regard to particular impairments, it might not be enough to prevent interference with the autonomy of a person; it might also be necessary to take measures to actively support or assist her in realizing her autonomy. Thus, when we are identifying what counts as a denial of individual autonomy and of equal rights to live independently and to be included in community, we should focus not only on forced institutionalization but also on various barriers, including a lack of choices and individual assistance.

5 Reducing Discrimination by Fostering Social Esteem

Because it includes differentiated regulations aimed at ensuring equal autonomy for persons with particular impairments, the CRPD can at least partially accommodate the communitarian critique of human rights. This convincingly demonstrates that it is possible to recognize individual needs and living conditions related to particular impairments within the human rights framework. However, Charles Taylor formulates his critique much more profoundly. According to him, the principles of liberal politics neglect individual

differences and thus cannot possibly prevent discrimination. On the contrary, as he points out, "difference-blind" political principles, such as human rights, are themselves discriminating and harmful because they oppress personal identities. Thus he states: "Non-recognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being."[18]

Employing Axel Honneth's concept of recognition, however, we can reconcile the demands for recognition of equal rights and of difference. For Honneth, the demand for recognition of difference formulated by social movements (such as the independent living movement) is just as reasonable as the demand for the recognition of equal rights, because it is the prerequisite for developing an intact personal identity. This could lead one to think that a universal right to esteem could be justified. However, both, Taylor and Honneth refrain from formulating universally binding duties in this context. Of course, they are totally right when they state that feelings or attitudes towards others – in our case towards disabled persons – cannot be enforced on an individual basis. Thus, the question is indeed whether it makes any sense to formulate a right to esteem. And if there were such a right, which duties of whom could be connected with it?

Without a doubt, these are difficult questions. However, the CRPD shows that it is possible to answer them. This becomes clear when one considers how the CRPD solves the problem raised by widespread definitions of disability that are based on individual functional defects and thereby support depreciating views of persons with disabilities. The CRPD avoids such discriminatory definitions of disability. First, the CRPD states in the Preamble that "disability" has to be seen as an "evolving concept". Second, instead of an exclusive definition, Article 1 describes to which persons the CRPD is to be applied:

[18] Taylor, "The Politics of Recognition," 25.

> 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.[19]

This instruction for the application of the CRPD adopts the so-called social model of disability and avoids the deficit-oriented medical model, which was the basis of definitions of disability in the past. It draws attention to the disabling societal circumstances and demands changes to them. One could argue, of course, that this might merely reflect the aim of avoiding discriminatory terms within human rights language. However, this is not all the CRPD demands. The CRPD also contains concrete duties to counter discriminating attitudes towards persons with disabilities in society. Article 8 (on awareness raising) formulates the obligation of states parties "to raise awareness throughout society, including at the family level, regarding persons with disabilities, to foster respect for the rights and dignity of persons with disabilities."[20]

Interestingly, this regulation provides a way of resolving complex issues regarding obligations arising from legitimate claims to esteem. The addressees of a corresponding "duty to esteem" are not individual citizens (since they cannot be *forced* to have particular feelings towards persons with disabilities) but rather the state, which is obliged to *foster* disability-friendly attitudes by raising awareness. Thus the main argument against an individual right to esteem does not apply. Individual citizens can be forced not to insult or offend persons because of their disability; but it is not their duty to have positive attitudes towards disabled persons. At the same time, it is a kind of collective duty, which has to be exercised by the state, to prevent prejudices and discriminating attitudes by creating appropriate societal conditions. Furthermore the CRPD gives directives for concrete measures, for example for public relations pro-

[19] CRPD, Article 1(2).

[20] CRPD Article 8(1). See also J.L. Scully, "The Convention on the Rights of Persons with Disabilities and Cultural Understandings of Disability," in this volume.

grams to foster the sensitivity for the "important contributions" made by disabled persons to their communities and for training programs for medical, educational and legal professionals dealing with sensitive human rights issues regarding the particular dangers disabled people are exposed to. Compared with anti-sexist or anti-racist obligations articulated in other human rights documents, these directives in the CRPD define much more precisely and concretely what the state has to do, not only to combat negative attitudes but also to facilitate positive attitudes towards disabled persons.

This shows that, despite all doubts concerning an individual right to esteem, the related obligations of the state can be formulated in an adequate way. Thus, with the CRPD a way has been found to successfully implement legitimate claims to social esteem within the human rights framework.

6 Conclusions

I hope that I have convincingly shown that the comprehensive notion of "discrimination" that is formulated in the CRPD can successfully be defended against popular objections. It represents a major step forward in human rights thinking to understand discrimination not only as the arbitrary denial of equal rights but also as the lack of support and care and the experience of nonrecognition and misrecognition due to individual differences. This is a specific example of how the concepts of the generalized other and the concrete other should be regarded as two complementary, equally necessary perspectives in order to determine exactly what equal respect for the rights of a particular person with disabilities demands. The real-world contribution of this further development of human rights thinking is to improve the living conditions of persons with disabilities but also of the members of other socially marginalized groups. More generally it has shown the communitarian critique of human rights politics to be only partially right. It is not that human rights, as general principles, are intrinsically blind to difference; the main problem arises from their being applied in difference-blind ways. That is not an entirely new insight, but it points to a more sophisticated understanding of what it means to treat equal cases equally

and unequal cases unequally. And it shows that it does not make much sense to regard the "politics of culture" and the "politics of rights" as opposing concepts. In order to truly ensure equal rights of all persons both kinds of politics are indispensable.

6 Intellectual Disability and the Human Right to Vote: Evolving Conceptions of the Universality of Suffrage[1]

Joel Anderson

One of the important contributions of the 2006 Convention on the Rights of Persons with Disabilities is to make clear that restricting voting rights on the basis of disability is a violation of human rights.[2] As in the case of women or racial minorities, the disenfranchisement of persons with disabilities is at odds with the principle of "universal and equal suffrage" articulated in the Universal Declaration of Human Rights.[3]

At the same time, the right to vote is standardly been taken to be a *qualified* right, permitting the exclusion of children, prisoners, non-citizen residents, and persons who lack mental capacity. Although these restrictions on voting rights are imposed by nearly all UN Member States, they have become topics of debate in recent years. In light of the CRPD, the disenfranchisement of persons with psychosocial or intellectual disabilities has come be seen as particularly problematic and for two reasons. First, many of the voting restrictions in question have tended to rely on overly broad classifications, for example, disenfranchising all individuals placed under guardianship. Inspired in some cases by the CRPD, human rights jurisprudence has identified a need for much more carefully tailored restrictions, such as the "*Doe* standard" of mental capacity," according to which individuals could not be disenfranchised unless it has

[1] Previous versions of this text were presented in the Practical Philosophy & Ethics Colloquium at Utrecht University and a conference organized by the Dutch Coalition on Disability and Development, on "The World Report on Disability and CBR Guidelines in Different National and Cultural Contexts". I would like to thanks especially Jos Philips, Thomas Fossen, Caroline Harnacke, Rob van Gerwen, and Pauline Kleingeld for feedback on earlier versions.

[2] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 70.

[3] The Universal Declaration of Human Rights (adopted 10 December 1948 by the United Nations General Assembly, Resolution 217 A(III)), Art. 21(3).

been demonstrated that they lack "the mental capacity to make their own decision by being able to understand the nature and effect of the voting act itself".[4]

Recently, however, a second critique has emerged regarding the disenfranchisement of persons with mental illness or cognitive impairments, one that challenges the very idea that voting restrictions should ever be based on mental capacity, no matter how carefully the lines are drawn. In December 2011, this challenge was articulated in the first official statement of the UN Committee on Human Rights regarding the implications of the CRPD for political rights. As I discuss below, this "Thematic Study on Participation in Political and Public Life by Persons with Disabilities"[5] argues that the CRPD, by classifying limited cognitive and psychosocial abilities as intellectual disabilities,[6] reframes capacity-based restrictions on voting rights as human rights violation.

This second challenge (against capacity-based voting restrictions) is controversial, however, and raises fundamental issues about the universality of voting rights. The tension is this. On the one hand, the notion of universality that is central to the human rights tradition suggests that suffrage should be unconditional. The CRPD can be seen as bringing out the sense in which universality is a matter of

---

[4] *Doe v. Rowe*, 156 F.Supp.2d 35 (U.S. District Court, Maine, 2001), 53. As I discuss below, several researchers have been working to develop precise protocols for fair and objective measures of mental capacity. For present purposes, the formulation just given for the "*Doe* standard" serves as a placeholder for the type of cognitive impairment that is frequently deemed to be a legitimate threshold for disqualifying individuals as voters.

[5] Thematic Study on Participation in Political and Public Life by Persons with Disabilities, by the UN Office of the High Commissioner for Human Rights (December 21, 2011) A/HRC/19/36. On March 22, 2012, the Human Rights Council adopted a resolution (A/HRC/19/L.9/Rev.1) broadly endorsing the Thematic Study.

[6] I will be using the term "intellectual disabilities" throughout as an umbrella term for a wide range of diminished abilities resulting from the interaction of broadly cognitive impairments and the (typical) environment. Although for some purposes it is important to distinguish intellectual disability from disability resulting from mental illness, that distinction is not central here. The term "mental capacity" refers to a particular threshold level of cognitive functioning, typically, the level required for individuals to make their own decision by being able to understand the nature and effect of the voting act itself. Thus, some persons with intellectual disabilities will still have mental capacity in this sense, depending on where that threshold is set.

"full inclusion" of "all members of the human family". On the other hand, Member States do seem to have a compelling interest in taking measures to increase the likelihood that votes cast in an election express the free and informed political views of citizens. The very point of democratic elections seems to be threatened by arbitrary and ignorant voting, and discouraging that might require setting minimal standards for voter competence.[7] Promoting democracy, after all, is not just about expanding the number of people casting ballots but about more fully realizing an ideal of self-governance, a goal that is advanced primarily by voters who can understand and care about the issues and how to address them effectively.

The issue, then, is whether capacity-based restrictions on the voting rights of persons with intellectual disabilities are fundamentally at odds with the letter and spirit of the CRPD or whether, if formulated and implemented in a precise and proportionate fashion, they are permissible exceptions to the principle of universal suffrage. My aim in this paper is not argue for one particular way of resolving this issue. Rather, my more modest aim to articulate the issue, the underlying jurisprudence (leading up to and in the wake of the CRPD), and the wider issues raised in the debate, so as to make clear that this is not an issue that can be avoided. What is at stake are fundamental principles that are in deep conflict.

I begin by recalling four central arguments for universal suffrage. I then summarize the central claims of the CRPD with regard to political rights (and especially the right to vote), highlighting its implications for various forms of passive discrimination and the importance of ensuring real accessibility. In section 3, I focus in on the disenfranchisement of persons who lack mental capacity, reviewing several of the human rights documents that have supported restrictions on "universal suffrage", before turning to the recent shift away from making suffrage conditional on capacity. I conclude by identifying some of the issues that must be addressed by critics of capacity-

[7] In *The Ethics of Voting* (Princeton: Princeton University Press, 2011), Jason Brennan argues that poorly informed and irrational voting is a form of reckless wrongdoing. Although he stops short of advocating capacity-based disenfranchisement, he clearly sees this as undermining the notion that expanding the number of voters is always a good idea.

based restrictions on the voting rights of persons with intellectual disabilities.

1 The Presumption of Universal Suffrage

The right to vote is clearly one of the most central political rights, particularly in light of the democratic principle that the exercise of state power over individuals is legitimate only with the consent of the people. As such, there is a strong presumption in favour of interpreting the reference to "universal and equal suffrage" strictly, as ruling out any restrictions or qualifications. As the European Court of Human Rights stated in *Hirst v. U.K. (No.2)*, in the context of challenging the disenfranchisement of prisoners, "...the right to vote is not a privilege. In the twenty- first century, the presumption in a democratic State must be in favour of inclusion... Universal suffrage has become the basic principle....Any departure from [this] principle risks undermining the democratic validity of the legislature thus elected and the laws it promulgates".[8] In particular, there are at least three reasons for thinking that universal suffrage is fundamentally important, based on concerns with self-determination, non-discrimination, and democracy.

The first reason for granting the right to vote unconditionally has to do with the connection between basic human dignity and having a say in what happens to one. To treat individuals as if they have no perspective that matters is to treat them as mere objects of manipulation. Having a vote may not actually give one significant power or influence, but it does mean that one counts as having a voice. Universal suffrage is a matter of categorical respect for rights to self-determination and decision-making authority, which is violated when one is denied an opportunity to express one's preferences in a way that is taken seriously. In this sense, the right to vote in elections is aligned with the same basic dignity that is violated when persons with disability have to deal with medical professionals or

[8] *Hirst v. U.K., No.2* (App no 74025/01) European Court of Human Rights (2005), 122.

caregivers manipulating their bodies or rearranging their furnishings as if they were not even there. Being disenfranchised does not merely eliminate a means for resisting domination (by voting against the government), it amounts to being told that one has no legitimate claim to do so. Respect for human worth rules this out. Put slightly different, restrictions in universal suffrage are fundamentally at odds with the principle of political autonomy, according to which one's individual liberty can be legitimately curtailed only by laws of which one is, ultimately, a co-legislator.[9] This idea is also captured in one of the guiding principles of the disability movement: "Nothing about us without us!"

Second, universal suffrage is a matter of equality and nondiscrimination. Not only is it fundamentally important that one have a voice but also that one's voice not be seen as of lesser worth than that of others. Individuals can be free and equal citizens only if the basis for their governing their affairs jointly is not marked by arbitrary exclusions or differences. In this sense, nondiscrimination is tied to respect, as it is expressed in the enforcement of equality: "State action must express 'equal concern and respect' for all persons (to cite Ronald Dworkin's well-known formulation). It also must express a collective understanding of all citizens as equal members of the State, all equally part of "us", notwithstanding their racial, ethnic, or religious differences."[10] Disenfranchisement of groups within society explicitly and directly accords them a unequal and subordinate status, but there are also many indirect and passive ways in which individuals are denied "participatory parity".[11] Differences in access to information and polling stations represent real forms of inequality, whether they result from living in a rural location, being illiterate, or having a visual impairment.

---

[9] J. Anderson, "Autonomy," in *The International Encyclopedia of Ethics*, edited by H. LaFollette, (Oxford: Blackwell, 2013).

[10] E.S. Anderson and R.H. Pildes, "Expressive Theories of Law: A General Restatement," *University of Pennsylvania Law Review* 148(2000): 1503-1575, here 1520.

[11] N. Fraser, "Social Justice in the Age of Identity Politics: Redistribution, Recognition, Participation," in N. Fraser and A. Honneth, *Redistribution or Recognition?: A Political-Philosophical Exchange*, (London: Verso, 2003), 7-109.

Finally, there is also a third consideration that is often raised in advocating the enfranchisement of previously excluded groups, namely, that inclusivity improves democracy. The key idea is that, when a society excludes voices from the democratic process, it thereby diminishes its ability to appreciate what is in the common good or what full justice requires. That is to say, because the democratic process has an important *epistemic* function in facilitating a better understanding of which course is best for a society to take (and, above all, which course would be wrong), it matters a great deal that the democratic process be maximally inclusive.[12] In trying to determine what laws would be just and how their implementation can be appropriate, democratic societies must ensure that the distinctive perspectives of those who are not average or "standard" citizens are included.

2 The CRPD and Political Rights – Negative and Positive Rights

Taken together, these principles would seem to ground a strong conception of the universality of voting rights, and the CRPD represents a consolidation of this vision with regard to the political rights of persons with disabilities. More specifically, the CRPD conceptualizes this universality of the voting rights of persons with disability in terms of both "negative" and "positive" understandings of these rights (discussed in the present section),[13] as well as conceptions oriented towards avoiding group-based discrimination and towards unconditional inclusion (discussed in subsequent sections).

---

[12] D. Estlund, "Beyond Fairness and Deliberation: The Epistemic Dimension of Democratic Authority," in *Deliberative Democracy: Essays on Reason and Politics,* edited by W. Rehg and J. Bohman, (Cambridge, MA: MIT Press, 1997), 173-204; and I.M. Young, *Inclusion and Democracy*, (New York: Oxford University Press, 2001).

[13] On the relation between "positive" and "negative" rights in the context of disability rights, see J. Philips, "Human Rights, the CRPD, and Priority-Setting" and C. Harnacke and S. Graumann, "Core Principles of the UN Convention on the Rights of Persons with Disabilities: An Overview," both in this volume.

It is useful, at this point, to quote the relevant text of Article 29 of the CRPD:

> *Participation in political and public life*: States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake: (a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by: (i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use; (ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate; (iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice.

As a statement of "negative rights" regarding voting,[14] the CRPD provides a forceful expression of the wrongness of disenfranchising people because they have a disability. This is vitally needed for combatting ordinary violations based on prejudice toward the differently bodied, as in cases where persons with intellectual disabilities are turned away at polling stations because of there disability. The CRPD makes clear that the fact that a person one uses a wheelchair or is blind ought not to count as grounds for restricting one's access to political participation. These prejudiced interferences with the exercise of individuals' voting rights was already a wrongful viola-

[14] The full text of the article has wide and important implications for other domains of political participation and inclusions – such as the right to be a candidate for office, to participate in political organizations, and so on – but I will focus throughout on voting rights.

tion of key political liberties, but at the end of the 20th century, a consensus emerged in the human rights community that persons with disabilities constituted a group whose human rights were in need of a distinct articulation of their right to inclusion and participation on a par with others, and human rights documents began emerging to protect these rights more generally.[15] In this regard, the CRPD and related documents reinforce the rights of persons with disabilities by making emphatically clear that these forms of interference are human rights violations.

Simply removing explicit forms of exclusion and interference is not enough, however, to guarantee full participation on a par with others. In part, this is a matter of power. As Gerard Quinn pointed out early on in the movement for disability rights, "…[I]t is arguable that the "voice" of the disabled community needs to be amplified somewhat as a corrective and as a way of ensuring effective political participation".[16] More concretely, as a statement of positive rights, the CRPD articulates the universal rights to political participation in a way that radicalizes the correlative duties of member states proactively to take all reasonable measures to *enable* full participation. It is particularly distinctive in emphasizing that universal protection of human rights entails a fundamental and urgent commitment to providing the assistance necessary for exercising the rights.[17] It is not enough for Member States to ensure that citizens are not disenfranchised directly; they are obliged to actively intervene in ensuring that individuals are included in society and have real, effective access to participation on a par with others.

---

[15] These documents include the World Programme of Action concerning Disabled Persons, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the International Covenant on Civil and Political Rights, the European Charter on Human Rights, and the Americans with Disabilities Act; see also E. van Weele, "The UN Convention on the Rights of Persons with Disabilities in the Context of Human Rights Law," in this volume.

[16] G. Quinn, "The International Covenant on Civil And Political Rights and Disability: A Conceptual Framework," in *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments,* edited by T. Degener and Y. Koster-Dreese, (Dordrecht: M. Nijhoff, 1995), 92.

[17] S. Graumann, *Assistierte Freiheit: Von einer Behindertenpolitik der Wohltätigkeit zu einer Politik der Menschenrechte*, (Frankfurt am Main: Campus, 2011).

In the case of voting rights, the commitment to including those of us with disabilities *as a matter of realizing genuine universality* means that there are obligations to provide ramps for wheelchair accessibility, Braille or other accessible versions of the electoral materials, and so on. In line with the insights of the social model of disability, the source of barriers is to be understood in a wider sense, as a way of providing access that accepts people as they are, in the diversity of modes of embodiment we have.[18]

In the case of voters with intellectual disabilities, this calls for presenting information in an "easy to read" format as well as finding ways of accommodating, for example, persons with severe anxieties about public voting areas or persons who need extra assistance in understanding voting procedures (such as touch screens or complex ballots). Note that, given the range of psychosocial or intellectual disabilities, this commitment to enabling political participation creates problems for the "pragmatic" approach to resolving the tension between unconditional inclusion and a "qualified" right to vote. That is, one might think that there is no need for capacity-based restrictions on suffrage, since persons who lack the capacity to vote will not notice what they are missing. They will tend not to find their way to the polling places or even request the opportunity to vote. However, one of the significant implications of the CRPD is that "natural barriers" to non-participation should not be assumed to be legitimate. Indeed, Member States are obliged to take an active role in enabling and facilitating participation. Seen from this perspective, neglecting individuals' lack of awareness could arguably be seen as a *de facto* exclusion on the basis of disability.

As this last point makes clear, realizing the ideal of enablement raises particularly complicated issues in the case of intellectual disability and voting, issues that I return to in section 5. But the more fundamental issue, in the case of voting rights, is whether the capacities being enabled and facilitated can also legitimately function as criteria for qualifying for suffrage.

---

[18] See C. Harnacke and S. Graumann, "Core Principles of the UN Convention of the Rights of Persons with Disabilities: An Overview," this volume.

3 Lack of Mental Capacity as a Non-Arbitrary Basis for Disenfranchisement

In the jurisprudence leading up to and directly after the adoption of the CRPD, the developments just discussed (regarding to positive and negative rights), have been complemented by a discussion of issues of group discrimination, to which I now turn. Particularly in the case of intellectual disabilities, mental health issues, and psychosocial impairments, the position that has emerged in the human rights jurisprudence permits disenfranchisement on the basis of incapacity but insists that it must be done in a way that does not amount to discrimination against persons with disability. It will be important to look closely at this approach, because it represents the main alternative to the emerging interpretation of the CRPD expressed in the 2011 "Thematic Study" that rejects capacity-based restrictions on voting rights. The approach incorporates three components: a stated presumption in favour of universality (discussed above), a practice of permitting restrictions on suffrage to specific groups (on various grounds of the "margin of appreciation" afforded Member States in how they go about meeting human rights obligations), and an emphasis on eliminating *arbitrary* implementations of restrictions on suffrage.

As we have seen, although there is a strong presumption, in both the letter and spirit of human rights law, in favour of the universal suffrage, human rights documents have *always* tended to treat it as a qualified right. It is not just that countries fall short of full compliance. Nor is this only a matter of the limits of what accommodations Member States can reasonably be expected to make, given limited resources. Rather, it is argued that some voters fail to qualify and therefore may legitimately be excluded. As a matter of fact, most Member States of the U.N. deny the right to vote to four groups: children, prisoners, non-citizen residents, and persons who lack mental capacity.

Although the 1948 Declaration does not mention any restrictions on universal suffrage (speaking in Art. 21 only of "universal and equal suffrage"), the 1966 International Covenant on Civil and Political Rights states that restrictions on universal suffrage are allowa-

ble, as long as they are not "unreasonable": "Every citizen shall have the right and the opportunity, without any of the distinctions mentioned in article 2 [race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status] and without unreasonable restrictions."[19] In 1996, the UN Human Rights Committee provided an interesting and influential elaboration of implications of this CCPR article in "General Comment No. 25":

> Any conditions which apply to the exercise of the rights protected by Article 25 should be based on objective and reasonable criteria. For example, it may be reasonable to require a higher age for election or appointment to particular offices than for exercising the right to vote, which should be available to every adult citizen. The exercise of these rights by citizens may not be suspended or excluded except on grounds which are established by law and which are objective and reasonable. For example, established mental incapacity may be a ground for denying a person the right to vote or to hold office.[20]

The document makes very clear that the disenfranchisement of some groups is not necessarily objectionable, as long as it is done in a way that is not arbitrary, gratuitous, or disproportionate. In the background is also the view that, given the variety of electoral approaches systems among democratic countries, Member States should be allowed some leeway (some "margin of appreciation", as the European Court of Human Rights puts it) in how they implement the restrictions.[21]

---

[19] Article 25 of the International Covenant on Civil and Political Rights (adopted 16 December 1966) 999 UNTS 171.

[20] General Comment No. 25 on the right to participate in public affairs, voting rights and the right of equal access to public service (Art. 25) CCPR/C/21/Rev.1/Add.7 (July 12, 1996), para. 4

[21] With regard to cognitive impairment, it is interesting to note further that the General Comment No. 25 adds that it is "unreasonable to restrict the right to vote on the ground of physical disability or to impose literacy, educational or property requirements" (ibid, para. 10). The formulations seems designed to allow room for excluding persons with

This general approach is further elaborated in the European context in the Venice Commission's 2002 "Code of Good Practice in Electoral Matters", which is particularly specific regarding when limitations on universal suffrage may be appropriate. It begins by enumerating the conditions to which the right to vote is subject — age (I.1.1.a), nationality (I.1.1.b), and residence (I.1.1.c) — and then addresses the "deprivation of the right to vote":

> (i) provision may be made for depriving individuals of their right to vote and to be elected, but only subject to the following cumulative conditions: (ii) it must be provided for by law; (iii) the proportionality principle must be observed; conditions for depriving individuals of the right to stand for election may be less strict than for disenfranchising them; (iv) the deprivation must be based on mental incapacity or a criminal conviction for a serious offence; (v) Furthermore, the withdrawal of political rights or finding of mental incapacity may only be imposed by express decision of a court of law.[22]

As of 2001, all but four UN Member States have exclusions from the vote based on mental capacity.[23]

The Venice Commission recommendations make no reference to the grounds on which these restrictions are justified, but the current jurisprudence seems to follow two tracks. Whereas a first set of restrictions — age, citizenship, and residency — are taken to apply

---

intellectual disabilities – as long as it is done, as it were, properly. But it is not obvious why literacy is automatically and categorically rejected, while other forms of capacity qualifications would be allowed.

[22] European Commission for Democracy through Law (Venice Commission), *Code of Good Practice in Electoral Matters: Guidelines and Explanatory Report*, Council of Europe, CDL-AD (2002) 23 rev., adopted 19 October 2002, at 1(1)d; cf. the appendix "Explanatory Report," at para. 6(d)).

[23] Blais, A., L. Massicotte, and A. Yoshinaka, "Deciding Who Has the Right to Vote: A Comparative Analysis of Election Laws," *Electoral Studies* 20(2001): 41–62, here, 51. The four countries at the time were Canada, Ireland, Italy and Sweden. For an overview of disenfranchisement on the basis of mental incapacity in various U.S. states see K. Schriner and L. Ochs, "'No Right Is More Precious': Voting Rights and People with Intellectual and Developmental Disabilities," *Policy Research Brief* 11(2000): 1–15.

categorically (with some allowances, e.g., for non-citizen voting in local elections), the second set of conditions — criminal offense and mental incapacity — as seen as requiring careful scrutiny and the avoidance of "blanket" exclusions. For example, in *Hirst vs. U.K.* (no. 2), the European Court of Human Rights ruled in 2005 that disenfranchising all prisoners failed to meet the proportionality test. Similarly, in the landmark 2010 case of *Alajos Kiss v Hungary*, the European Court of Human Rights made a decision with significant implications for persons with cognitive disabilities, drawing on the CRPD and emphasizing the problematic character of blanket disenfranchisement. The plaintiff in this case had been placed under partial guardianship as the result of a diagnosis of bipolar disorder — a cognitive impairment in the broad sense — and on this basis had been denied the right to vote. In this case the European Court of Human Rights ruled that "[t]he applicant in the present case lost his right to vote as the result of the imposition of an automatic, blanket restriction on the franchise of those under partial guardianship. He may therefore claim to be a victim of the measure".[24] In addition to affirming that discrimination on the basis of mental illness represents a human rights violation under CRPD, the decision is significant in arguing that automatic disenfranchisement on the basis of being under guardianship is insufficiently proportional. The position taken is clearly that judgements of mental incapacity may be permissible grounds for disenfranchisement but need to be more circumscribed in scope and careful in its administration. As the European Court of Human Rights concluded in *Kiss v. Hungary,* "an indiscriminate removal of voting rights, without an individualised judicial evaluation and solely based on a mental disability necessitating partial guardianship, cannot be considered compatible with the legitimate grounds for restricting the right to vote".[25]

In the disability rights community, the *Kiss v. Hungary* decision of the European Court of Human Rights has been widely hailed as a watershed in defending the voting rights of persons with intellectual

[24] *Alajos Kiss v Hungary* (App no. 38832/06) European Court of Human Rights (20 May 2010), §43.
[25] *Kiss v Hungary*, §44.

disabilities and mental illness, partly because it draws explicitly on the CRPD.[26] To the extent to which advocacy of the voting rights of persons with disability takes its cue from this *Kiss v. Hungary* decision, the key task lies in developing more narrowly tailored, objective, and specific criteria for capacity-based disenfranchisement, as well as fair procedures for applying those criteria (usually only by court judges). Particularly to the extent to which nursing home staff, officials at polling stations, and others routinely prevent persons with mental illness or cognitive impairments from voting, reducing discrimination involves developing and enforcing clear guidelines regarding when and by whom persons may be excluding from voting. Accordingly, in the words of the recent report of the Fundamental Rights Agency, the European Court of Human Rights is centrally concerned with "arbitrariness or a lack of proportionality in the restrictive measures introduced by national authorities".[27]

In the United States, recent efforts in this regard have centred on a U.S. District Court decision in the 2001 case of *Doe v. Rowe*. As in *Kiss v. Hungary*, this case involved the blanket disenfranchisement of persons placed under guardianship because of mental illness, as specified in the Constitutions of the state of Maine that had been endorsed in two state-wide referenda. The court focused on the unequal and disproportionate treatment involved in relying on being placed under guardianship for mental illness, "while permitting incapacitated persons diagnosed with mental retardation or senility to vote as they choose."[28]. The *Doe* court concurred with the parties in the case "that Maine has a compelling state interest in ensuring that 'those who cast a vote have the mental capacity to make their own decision by being able to understand the nature and effect of the voting act itself'". And, in line with this, that court argued that failure to meet what has become known as the "*Doe* standard" *does*

[26] See "Thematic Study" cited above and report of the European Union Agency for Fundamental Rights (F.R.A.) on "The Right To Political Participation of Persons with Mental Health Problems and Persons with Intellectual Disabilities" (October, 2010), <http://fra.europa.eu/fraWebsite/research/publications/publications_per_year/2010/pub-vote-disability_en.htm>.

[27] F.R.A. report, 10.

[28] *Doe v. Rowe*, 156 F.Supp.2d 52.

constitute legitimate grounds for disenfranchisement, as long as it is done in a precise and procedurally correct way. This has led to several efforts to develop scientifically rigorous tests for assessing whether individuals meet the *Doe* standard, as well as for new understanding of "mental capacity" that is based on individuals' actual ability to function.[29]

4 From "Non-Arbitrary" Exclusion to Full Inclusion

These efforts to develop fair and accurate measures of voting competence fit into a long history of expanding suffrage by eliminating false claims about the incompetence of groups of people. Suffrage movements have frequently focused on refuting myths about the purported incompetence members of some particular group – e.g., women or people of color – by showing that they are, in fact, at least as capable as established groups of contributing effectively and appropriately to the democratic process. Thus, in cases like *Kiss v. Hungary* and *Doe v. Rowe*, the courts were sharply critical of persons with a diagnosis of mental illness or with being placed under guardianship, but primarily because being placed under guardianship on grounds of mental illness is not a reliable proxy for voting competence.

The strategy for expanding suffrage does, however, assume that it is appropriate that meeting something like the *Doe* standard of mental capacity is a relevant criterion for suffrage. But what if disenfranchising prospective voters on the basis of lack of mental capacity is less like disqualifying prospective airplane pilots with visual impairments and more like barring racial minorities from public spaces, no matter how "scientific" the criteria for racial membership

[29] Appelbaum, P.S., R.J. Bonnie, and J.H. Karlawish, "The Capacity to Vote of Persons with Alzheimer's Disease," *American Journal of Psychiatry* 162(2005): 2094-2100; Karlawish, J.H., R.J. Bonnie, P.S. Appelbaum, C. Lyketsos, B. James, D. Knopman, C. Patusky, R.A. Kane, and P.S. Karlan, "Addressing the Ethical, Legal, and Social Issues Raised by Voting by Persons With Dementia," *Journal of the American Medical Association* 292(2004): 1345-1350; M. Redley, "Citizens with Learning Disabilities and the Right To Vote," *Disability & Society* 23(2008): 375–384.

might be? Indeed, there appears to be an emerging trend in human rights discussions of challenging the very idea of capacity-based restrictions. And the CRPD is playing an important role here, with its emphasis on inclusion of "all members of the human family" on a par with others, regardless of abilities.

The strongest official statement of this shift comes from the 2011 "Thematic Study" of the UN Human Rights Committee mentioned earlier. What is particularly striking about this document is the explicit distance taken from voting restrictions, even those that are based on objective and reasonable criteria. After acknowledging the fact, as we saw in the previous section, that human rights documents have explicitly permitted restrictions to voting rights in the case of mental incapacity, the "Thematic Study" asserts, "The legal landscape has changed dramatically", concurring with Manfred Nowak's statement that the majority of voting restrictions "are no longer compatible with the prohibition of discrimination in articles 2, para. 1, and 25 [of the Universal Declaration of Human Rights] or with the present-day understanding of democracy." Furthermore, "This holds true, in particular, with regard to limitations of the right to vote and stand for election on the basis of psychosocial or intellectual disabilities."[30] The "Thematic Study" adds that Article 29 of the CRPD "does not foresee any reasonable restriction, nor does it allow any exception for any group of persons with disabilities. Thus, any exclusion or restriction of the right to vote on the basis of a perceived or actual psychosocial or intellectual disability would constitute "discrimination on the basis of disability" within the meaning of article 2 of the Convention."[31] This is particularly

[30] United Nations Office of the High Commissioner for Human Rights, "Thematic Study," para. 26-28. See also the following statement from the November 2011, recommendation of the Committee of Ministers to member states on the participation of persons with disabilities in political and public life (adopted by the Council of Europe's Committee of Ministers on 16 November 2011): "All persons with disabilities, whether they have physical, sensory, or intellectual impairments, mental health problems or chronic illnesses, have the right to vote on the same basis as other citizens, and should not be deprived of this right by any law limiting their legal capacity, by any judicial or other decision or by any other measure based on their disability, cognitive functioning or perceived capacity".

[31] United Nations Office of the High Commissioner for Human Rights, "Thematic Study," para. 29. The report also refers directly to the earlier work of the Committee on the Rights

clear language. But if there was any room for doubt as to whether the Human Rights Committee is here arguing for a change of course, it was eliminated in the March 2012 remarks to the Human Rights Committee by Theresia Degener, Special Rapporteur for the Committee on the Rights of Persons with Disabilities:

> Many countries have laws that deny those disabled persons who are declared legally incapacitated, the right to vote and stand for elections. In reality these are persons with intellectual or psychosocial impairments. These laws are in violation with Art. 29 CRPD, according to which all disabled persons, no matter what their impairment is, have an equal right to participate in the electoral process. I know that this runs counter to many legal opinions on who should have the right to vote....[T]here is reason to believe that there is a growing readiness to revise the traditional understanding of voting capacity....The incapacity approach to disability is [being] challenged.[32]

This is articulation what genuinely *universal* suffrage looks like in the wake of the CRPD amounts to saying, in effect, that requirements of voter competence of the sort articulated in the "*Doe* standard" should be rejected the way in which literacy tests have been rejected.[33]

Although the position taken here by the Human Rights Committee has not yet, to my knowledge, been tested in the courts, there are a number of theorists who have been arguing along similar lines. One

---

of Persons with Disabilities, whose September 2011 monitoring report on Spain explicitly recommended that Spain amend legislation allowing "the denial of the right to vote based on individualized decisions taken by a judge", something previously taken to be the gold standard for legitimate restrictions on voting (Ibid, para. 48).

[32] T. Degener, "The Right to Political Participation in Context of Disability (Art. 29 CRPD)," opening statement to the Fourth Interactive Debate on the rights of persons with disabilities during the 19th Session of the Human Rights Council (March 1, 2012), https://extranet.ohchr.org/sites/hrc/HRCSessions/RegularSessions/19thSession/OralStatements/CRPD%20Committee.pdf, accessed on June 3, 2012 via the link from http://-www.ohchr.org/EN/Issues/Disability/Pages/politicalpubliclife.aspx.

[33] United Nations Office of the High Commissioner for Human Rights, "General Comment No. 25," para. 10.

important statement is found in a recent article by Martha Nussbaum, who makes very clear the indignity and inequality of the current failure to accommodate and enable the political participation of persons with intellectual disability.[34] For the current failure to implement such measures for all individuals means that "a large group of citizens are simply disqualified from the most essential functions of citizenship. They do not count. Their interests are not weighed in the balance".[35] Anticipating the difficulties many will have envisioning what such accommodation would involve, she argues for a set of proposals for how to move toward full political participation of persons with intellectual disabilities. She usefully distinguishes accommodations for those with relatively minor cognitive impairments (like easy-to-read instructions), decision-making assistance via a "buddy" in cases of more significant impairments, and surrogate-voting in case of individuals with profound impairments. This is an area where a great deal of work still needs to be done in finding feasible and effective strategies of inclusion.[36] As I discuss in the next section – and as Nussbaum readily acknowledges – there are complex details to work out, particularly of how to implement these accommodations while avoiding fraud and manipulation.

At the same time, not all of the remaining issues regarding the voting rights of persons with intellectual disabilities are matters of practical implementation. There are also deep issues about what considerations may actually weigh in favour of permitting some capacity-based voting restrictions. In my discussion here, I have focused on the emergence of a CRPD-influenced line of argument that rejects any such restrictions, but there is more that needs to be

---

[34] M. Nussbaum, "The Capabilities of People with Cognitive Disabilities," *Metaphilosophy* 40(2009): 331-351.

[35] Ibid, 347.

[36] Important work is already being done; see, for example, Redley, "Citizens with Learning Disabilities and the Right To Vote"; J. Vorhaus, "Citizenship, Competence and Profound Disability," *Journal of Philosophy of Education* 39(2005): 461–475; P.S. Karlan, "Framing the Voting Rights Claims of Cognitively Impaired Individuals," *McGeorge Law Review* 38(2007): 917-30; K. Schriner, L.A. Ochs, and T.G. Shields, "The Last Suffrage Movement: Voting Rights for Persons with Cognitive and Emotional Disabilities," *Publius: The Journal of Federalism* 27 (1997): 75-96.

said, particularly about the tension I mentioned at the outset. Without trying to actually adjudicate the disputes between defenders of unconditional suffrage and defenders of capacity-based restrictions, I will now try to identify some of the issues and concerns that still need to be addressed going forward.

5 Remaining Questions Regarding Unconditional Suffrage

In sharply criticizing capacity-based restrictions on suffrage, the UN Human Rights Committee's "Thematic Study" fundamentally challenges many existing electoral policies, policies that are not only firmly entrenched in the political culture of the vast majority of Member States but also explicitly supported by earlier human rights documents and a long tradition of jurisprudence regarding the restriction of the "qualified" right to vote. The interpretation of CRPD as incompatible with competence-based disenfranchisement represents a bold and radical departure from the standard understanding of voting rights as "qualified" rights reserved for citizens who meet certain levels of competence (or age). It is sure to be scrutinized closely, and appropriately so. Even those who fully endorse the CRPD's commitment to full inclusion of all persons in the political life of society, may well feel the force of certain principled objections to eliminating all capacity-based restrictions on voting rights, many of which go unmentioned in the "Thematic Study". In closing, I will mention several of them, in order to identify the issues that are likely to be central to the continuing discussion of how to interpret and implement Article 29 of the CRPD.

A first set of issues to be addressed has to do with the capacity-based disenfranchisement on the grounds that Member States have "compelling state interests" and "legitimate aims" that could justify restricting suffrage in the case of persons who are unable to meet the *Doe* standard. If the state has an interest in the electoral process being such that the votes cast reflect voters' informed choices about candidates and issues, is that interest a compelling basis for disenfranchising voters who are unable to understand the issues on the ballot? Would any restriction on the basis of voter competency vio-

late the human right to vote, or could restrictions be developed that represent a proportional response to a compelling social (in this case, electoral) interest? In this connection, opponents of capacity-based restrictions should be careful not to rely too heavily on the fact that the state does not restrict the voting opportunities of the numerous citizens *without* disabilities who have no clue what they are doing when they vote. For advocates of capacity-based restrictions could still argue that the right to vote is "qualified", but that it should be conditional upon actual capacities, rather than group membership. As we saw, this was the approach taken by the European Court of Human Rights in *Kiss v. Hungary*.

Second, there are complicated issues of as to the leeway or "margin of appreciation" that Member States have in meeting their obligations under Article 29 of the CRPD and other documents articulating universal political rights. Out of respect for "the diverse cultural and legal traditions embraced by each Member State" and in order to "avoid damaging confrontations between the Court and the Member States", the European Court of Human Rights has typically granted Member States wide discretion in determining how to organize electoral processes.[37] In line with this, Member States might argue that the margin of appreciation should permit them to restrict the suffrage of citizens who fail to meet *Doe*-type criteria for mental capacity (or political knowledge), for example as part of ensuring confidence in the integrity of elections, as expressions of the will of the people. Any such argument would be subject to close scrutiny, however, especially given the point made forcefully in *Kiss v. Hungary* that "if a restriction on fundamental rights applies to a particularly vulnerable group in society, who have suffered considerable discrimination in the past, such as the mentally disabled, then the State's margin of appreciation is substantially narrower and it must have very weighty reasons for the restrictions in question".[38]

---

[37] For an overview, see the Council of Europe's Lisbon Network briefing, "Margin of Appreciation,"http://www.coe.int/t/dghl/cooperation/lisbonnetwork/themis/echr/-paper2_en.asp (last consulted on July 8, 2012).

[38] *Kiss v Hungary*, §42.

Third, if the CRPD is read as forbidding capacity-based disenfranchisement and as obligating Member States to guarantee political participation regardless of intellectual disability, this has significant implications for proxy voting or voting by guardians. Member States' discretionary leeway is likely to be deemed particularly significant with regard to specifying the most appropriate ways to facilitate surrogate-voting and assistance in decision-making for persons with profound intellectual disability. Given the concerns expressed about the permissibility of "family voting" and postal voting,[39] this is a subject that calls for careful and creative exploration of possibilities, involving persons with disabilities to the extent possible. Some of the issues raised relate to compelling state interests in avoiding voter fraud, but they also engage fundamental concerns about the guaranteeing rights of self-determination. Indeed the entire issue of "assisted decision-making" and its relation to political participation by persons with intellectual disabilities is a particularly complex issue that must be addressed in developing a comprehensive human rights framework for securing and promoting the political rights of persons with intellectual disabilities.

Fourth, given the importance of the disability movement's forceful arguments against conceptualizations of persons with disability as passive patients in need of charity, there are sensitive issues that arise in connection with the form of political "participation" that is possible for persons with profound intellectual disabilities. Particularly in cases in which the scope of individual agency and political will is very limited, the appropriate model of political rights may need to shift from a focus on participation to a focus on the protection of interests and advocacy for well-being, raising further complications regarding the relationship between will-based and interest-based conceptions of political rights.

Fifth and finally, there are also important issues that need to be addressed regarding the wider implications of rejecting competence-based suffrage restrictions. In combination with the principled rea-

[39] See, respectively, the Venice Commission, "Guidelines on Elections," Art. 4(b) and United Nations Office of the High Commissioner for Human Rights, "Thematic Study," para. 57-8.

sons for universal suffrage outlined in section 1 above, the emerging rejection of competence-based restrictions also challenges one of the other standard exclusions on suffrage, children. Insofar as minimum-age restrictions are defended on the basis of an inability to appreciate what is at stake when they cast their vote, they too are implicitly challenged by the CRPD-inspired shift away from capacity-based voting restrictions. For once surrogate-voting, assisted decision-making, and easy-to-read electoral materials are mandated as accommodations for adults with intellectual disabilities, it becomes much more difficult to argue that 10-year-olds ought not to have a voice in elections or that the interests of infants ought not to be represented in the political process. Indeed, this starts to look like a violation of the principle of equal treatment. In this context, it is particularly striking that, even as she emphasizes the importance of universal suffrage and the outdated character of previous jurisprudence in her remarks to the Human Rights Committee, Special Rapporteur Degener nonetheless treats the ongoing disenfranchisement of children as obviously appropriate: "We all know the right to vote is not an absolute right and can be restricted for various reasons, such as age."[40] And, indeed, given the likely opposition among Member States to eliminating age-based disenfranchisement, the issue of "margin of appreciation" is sure to arise here again, along with political considerations as to how hard to push for further expansion of suffrage in the face of resistance from Member States and the potential for an anti-CRPD backlash.

These are complicated issues, but a sustained engagement with them is long overdue. To this day, most UN Member States take their commitments to "universal suffrage" to permit the disenfranchisement of persons who lack a certain level of mental capacity. The emerging understanding of the human rights of persons with disabilities challenges this assumption and has put these issues of voting rights on the human rights agenda. The most recent interpre-

[40] Degener, "The Right to Political Participation in Context of Disability," 2012, p. 1. For a discussion of capacity-based conceptions of the threshold between childhood and adulthood, see J. Anderson and R. Claassen, "Sailing Alone: Teenage Autonomy, Parental Supervision, and Regimes of Childhood," *Law and Philosophy*, 31(2012): 495-522.

tations of the CRPD from the Office of the High Commissioner for Human Rights, make a shift with profound and controversial implications for the relationships between individual capacities, political inclusion, the universality of rights, and the very nature of democratic self-governance. In this regard, there is much more theoretical and jurisprudential work to be done in investigating these issues and articulating the relevant principles. And this is work that is well worth doing, for what is ultimately at stake in these debates is the dignity and self-determination of persons with intellectual disabilities, and their right to political participation on an equal basis with others.

7 Disability, Handicaps, and the Nature of Sports

Jan Vorstenbosch

1 Introduction

Although organized sport, as we know it today, is a relatively recent social practice, it has acquired a central place in modern societies. Indeed, for some critics, the attention paid to sports is disproportionate and has become more of a moral problem than an asset. The neutral starting-point taken in the present chapter is that the fascination with sports has to be explained in terms of how the nature of sports, its competitive logic, and the emotional resources it engages capture something that is typical of modern societies. Of particular interest to the subject of this chapter: the rights of the disabled in the context of sports, is the dynamic and dialectical relationship between equality and difference. Arguably, the tension between equality and differences or "inequality", is central to the self-reflexive societal structure of modern western liberal societies. In sports practices this tension between equality and difference is premised on its competitive or agonistic nature. Sports practice is also characterized by striving for perfection. This originally stems from the classical, especially Greek culture, and it takes on new proportions and means in the modern scientific and technological era.[1]

A complication that in some sense lies at the heart of the issues of this chapter, is that the United Nations Convention on the Rights of

[1] Much could be learned about the interpretation of equality and difference by studying the history of a sport such as cycling, especially in response to scientific and technological advances. At the start of the 20th century, when the first Tour de France was organized by a French newspaper, the cyclists were each day sent on their way without any support, carrying a reserve tyre around their own neck. Nobody bothered about performance-enhancing substances, many a cyclist dropped into a local pub and drank a few beers. After 25 stages, the time gaps between the first-place and second-place participant regularly amounted to several hours. In 1988, the difference between the winner (Lemond) and second-placed (Fignon) was eight seconds, and this helps explain why debates about doping were mounting and dietary rules for the cyclists were strictly observed.

Persons with Disabilities (CRPD), which is central to this book, is addressed to state or public authorities. Civil society authorities such as the authorities of sports organizations have to move within the legal framework of nation states. However, they have a lot of leeway to issue their own rules and considerable discretion as how to interpret these rules and how to organize competition on the basis of particular criteria. The way this organization materializes is closely connected to the essentials of sport. Sport is a physical and competitive endeavour that builds on biological differences in capacities and talents. Sport aims also to bring out several other differences between individuals, in such respects as training and effort, in realizing these capacities in functionings and performances. I mention just one example of the way these differences set limits to general moral ideals and principles of equality. Article 3(g) of the CRPD includes under "general principles" the "equality between men and women", but this is at odds with separation of men and women in competition, which is almost universal in sport.[2] I cannot go into the complex relation between the authority of the state and the autonomy of civil society organizations such as sports clubs. This matter will, of course, turn up in the cases that I discuss in this chapter, but my aim here is not to provide an interpretation, let alone application, of the rules and rights of the CRPD. Rather, my aim is to call attention to the difficulties involved in applying the general rules and rights mentioned in the CRPD in the context of social practices that have a meaning and dynamics of their own. My aim in this chapter is, accordingly, to inspire some interest in the prospect of furthering our insights into disability by discussing some of the conceptual and normative themes that surface in sport, especially when persons with disabilities and those without disabilities do not strive for excellence in separate contexts (such as the Olympics and the Paralympics) but compete with each other in the same

[2] There are, however, philosophers of sport who argue for an abolition of this "sexist" categorization, which in their view we can remedy thanks to genetic technology and the possibilities of "equality" that it promises for "future mankind", see *Genetic Technology and Sport*, edited by T. Tännsjö and C.M. Tamburrini, (London and New York: Routledge, 2005).

race or match, something made increasingly possible by advanced technologies such as prostheses.

The structure of this chapter is straightforward. I will first describe (and sparingly comment on) two legal cases that illustrate the kind of issues at stake in the application of rights theory to the social practice of sports in the case of persons with disability. Both cases involved the position of disabled athletes in professional or elite sport.[3] The two cases are ten years apart and situated in different institutional and legal frameworks. They elicited much interesting and heated debate as well as diverging legal judgments. In the discussion section I will expand on some underlying themes, without trying to solve any problems in any deeper ethical sense.

2 The Case of PGA Tour, Inc. vs. Martin

In 1998, golfer Casey Martin qualified for the Professional Golf Association (PGA) Tour of the USA. Because of a leg-related syndrome he was unable to walk the golf court and he requested to round the golf circuit by golf cart. However, PGA rules stipulate that competitors *walk* the course, so his request was rejected. Martin filed a lawsuit against PGA. The 9th US Circuit Court of Appeals ruled in his favour, basing its judgment on the Americans with Disabilities Act (ADA) which became federal law in the USA in 1990. "All the cart does is permit Martin access to a type of competition in which he otherwise could not engage because of his disability."[4] The Supreme Court upheld this ruling, arguing that "the use of carts is not inconsistent with the fundamental character of golf, the essence of which has always been shot-making".[5] Many stakeholders in golf, however, did not agree. The fact that shot-making is the essence of golf (as

[3] In bracketing cases of amateur sport, I am unfortunately setting aside important issues regarding rights of social inclusion. But the case of amateur sport is distinct in many ways, since many of the legal and procedural matters that, as we will see, play an important role in the dealings with athletes with professional ambitions, are generally not available and/or followed by people in amateur or recreational sports.

[4] Cited in J. Bowen, "The Americans With Disabilities Act and Its Application to Sport," *Journal of the Philosophy of Sport* 29(2002): 66–74.

[5] PGA Tour, Inc. vs Casey Martin. 121 Ct. 1879. May 29, 2001.

scoring goals is for football) does not mean that all other demands, factors and abilities are insignificant. The resulting debate raised empirical, conceptual-normative and principled issues. According to some experts, a professional golfer uses 25% of his energy in walking a regulation tour. Others claimed that riding in a cart was actually a disadvantage for Martin, because he would not have the "feel" of the course, and the relaxing effect on muscles of walking. Both claims are based on the, perhaps trivial, suspicion of an unfair difference between Martin and his opponents, which conflicts with a general principle of a "level playing-field" that informs sports practices. Several principled solutions to this problem were considered, such as allowing or requiring all golfers in the tournament to ride in a cart from hole to hole. It was even claimed that riding the players in a cart, would enable the competition to be more focused on "shot-making", according to the Supreme Court "the essence of golf".

Martin's request did elicit some philosophical reflection on the essence of sport, particularly golf. It forced some of the stakeholders to reconsider their intuitions and face the fact that the legal judgments seemed to enforce a break with the traditional way of playing golf. We will return to this friction between principled ruling and the tradition of a sport in the discussion. Another procedural aspect that surfaced in the debate is whether judges may determine authoritatively the essential features of a sporting practice and rule on the implications of this determination. Should this authority not belong to the governing bodies of sport? Isn't it the case that the unique history, conventions and disputes within a particular sport are or should in some sense be "impervious" to the "outsider", even if this is a legally appointed judge?[6] And, indeed, in a case quite similar to that of Martin, the 7th U.S. Circuit Court ruled differently from the 9th, declaring that "[t]he decision on whether the rules of the game should be adjusted to accommodate him (i.e. the suitor) is best left to those who hold the future of golf in trust".[7]

---

[6] Bowen, "The Americans With Disabilities Act and Its Application to Sport," 69.

[7] R.S. Brown and D.J. O'Rourke, editors, *Case Studies in Sport Communication*, (Westport Conn.: Praeger, 2000).

3 The case of IAAF vs. Pistorius

Anita Silvers notes with respect to the case of Martin that the Americans with Disabilities Act must be interpreted as "requiring evidence that skill or talent in distance walking either is a criterion of excellence in tournament golf or directly affects satisfying such a criterion".[8] Particularly important in this regard is the *kind* of evidence that is relevant to these matters. The judges of 9th U.S. Circuit Court in the case of Martin, did not make use of any scientific evidence, for instance as brought forward by some in the resulting debate, while those of the 7th U.S. Circuit Court took the stakeholders in sports to be authoritative. But the appeal to scientific evidence *did* figure prominently in the second case that I have selected for discussion: the case of the International Association of Athletics Federations (authorized by the International Olympic Committee) against the South-African runner Oscar Pistorius who requested to be admitted to the 400 meter sprint in the 2008 Olympic Games. Pistorius was born with both of his legs missing the fibula – the long, thin outer bone between the knee and ankle. At eleven months old, his legs were amputated below the knee and he was fitted with two artificial prosthetic blades. He turned to athletics as a teenager, and thanks to his talents, passion and tenacity, he succeeded in running the 400 metres faster and faster, eventually having no other disabled athletes who were a serious match for him in competitions such as the Paralympics. As his times approached the qualifying times that IAAF had set for admittance to the 400 metre sprint in the regular Olympic Games, he submitted an official request to be allowed to compete. The IAAF, which amended its rules in 2007 to ban the use of "any technical device that incorporates springs, wheels or any other element that provides a user with an advantage over another athlete not using such a device", rejected the request. But Pistorius went to the Court of Appeal of the Games, which ruled against the

[8] A. Silvers, "Formal Justice," in *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, edited by A. Silvers, D. Wasserman and M. Mahowald, (Lanham MD/Oxford: Rowman, 1998), 131-146, at 124.

IAAF in May 2008, saying the sprinter's carbon-fiber blades did not provide unfair advantage against athletes with intact legs.

This last consideration concerning "unfair advantage" is one of the differences with the first case, in which the judges confined themselves to the argument from the essence of sport. In contrast to the case of PGA Tour, Inc. vs. Martin, there seems less room for doubt what the essence of running 400 metres is: it is running the 400 metres faster than your rivals in the race. There are few circumstantial or additional aspects that define the sport. But whether there is an advantage for one of the competing athletes in running it, and what it is, is a question which led to a vigorous debate about the problem whether the prostheses of Pistorius and the way they enable him to propel himself forward, can be shown to give him an edge over athletes who run the distance with their normal legs. Below, I will set out the particularities and debates about the role of scientific evidence in sport. To complete the description of the case: Pistorius participated in the pre-Olympic South-African run-offs to be part of the South-African relay team (4 x 400) and only missed qualification for the team by 0,75 seconds. In this national competition, he was treated no differently from his rivals. After a renewed effort, he eventually succeeded in qualifying for the London Games in 2012, running in both the semi-finals of the 400 metre race and the finals of the 4 X 400 relay race.[9]

4 Discussion

I will now draw out of these two cases a series of principled and conceptual issues that are of larger interest to the disability debate as it is canvassed by the relevant Declarations such as the CRPD. Specifically, I will comment on:

[9] There was also a debate about the safety of other athletes in a relay race, in case Pistorius should have a fall, because the relay race is not run in separate lanes, but I will not go into this issue.

1 The nature of justice, and the role of a theory of justice;
2 The concept of a handicap;
3 The essential-accidental distinction as it applies to sports and is used by judges to decide on discriminatory treatment;
4 The role of science in decision-making on unfairness in sport;
5 The problem of who is in charge to decide on rule changes in sports competitions;
6 The relation between social practices and rights theory.

4.1 Distributive Justice, Formal Justice and Stigmatization

Anita Silvers protests against what she calls a "distributive" approach to the unequal treatment of disabled persons.[10] The distributive approach allocates resources towards disabled individuals so as to provide them with the financial or other means to compensate for their disadvantages. According to Silvers, this approach perpetuates the stigma associated with disability. One of the reasons why this happens is that there has to be an objective criterion to identify the rights-holders. According to Silvers, this effect augments the problems of the disabled. She proposes as an alternative a "formal justice" approach that targets not the individual but the obstacles in the environment that disadvantage individuals with specific impairments. The Americans with Disabilities Act and the CRPD is informed by this "social model" approach.[11] I am not convinced by Silver's arguments, which I cannot treat here at any length.[12] I only will comment on the argument of stigmatization as it works out in the particular context of the case of golfer Martin.

I want to generalize this conceptual issue a bit and point out the following. First, the notion of "formal justice" is an unfortunate misnomer, especially when it is understood as opposed to "distributive justice", which is certainly not equivalent to "material justice". As Rawls has pointed out, formal rights belong to the most im-

[10] Ibidem.
[11] On the "social model", see the chapter in this volume by C. Harnacke and S. Graumann.
[12] For a discussion see Bowen, "The Americans With Disabilities Act and Its Application to Sport".

portant "primary goods" that are distributed equally by a just society. Second, the argument of stigma does not seem to be particularly linked to the individual-environment distinction, even if one concedes that this distinction is tenable, which is by no means evident. As a matter of fact, the assignment of formal means such as a personal budget to disabled persons often stigmatizes them far less (as it remains in the background of the bureaucracy) than changing the rules, such as golf rules, which precisely singles out a particular individual as the person for whom the entire environment has to be altered. This singling-out threatens to lay the blame of having to change a presumably smooth practice of sport on the particular individual.

Silvers, who, to be sure, points out some real problems with distributive models and stigmatization, underestimates the extent to which doing justice to persons with disabilities is bound up with the manifold of injustices and inequalities that variously relate to primary goods, concrete goods, public environments and specific concrete contexts such as those created by sports practices. We had better start any analysis of a specific problem of justice with the question(s): who is to act regarding to which goods or environments, with respect to which reference group and on what grounds? If the state is the agent, as it will be in many disability cases, it is hard to see how Silvers could avoid establishing a criterion for eligibility, which she thinks dispensable in the case of environmental changes. The next golfer with difficulty walking may still have to prove that the rule that Martin's case elicited, applies to his or her case. Nobody will be allowed to travel the golf course in a cart who hasn't given proof of being unable to do this on foot.[13]

[13] Martha Walters, former attorney for Martin, acknowledged the legal arguments on both sides, but said the tour's conclusions were specious. "You don't change the rules," Walters said, "you write down Casey's condition and limitations and agree to accommodate his limitations. The [ADA-mandated] individual assessment [of a disability] is only to enable that person to participate". (cited on: http://www.ada.gov/fmartin.htm, accessed June 10, 2012). In the 10 years since the Supreme Court decision, however, the tour has reviewed only a few applications for golf carts, almost exclusively in qualifying competitions. Other than Casey Martin, only Erik Compton – twice a heart transplant recipient – has used a cart in an actual PGA Tour or Nationwide Tour event. He was granted the use

4.2 The Concept of a Handicap and the Constitutive Role of Obstacles in Sports Practices

The cases of Martin and Pistorius are interesting because the context of sports suggests an intriguing dialectic with regard to the conceptualization of what a handicap is. It is a commonplace of disability studies that the concept of a handicap is a social construct. This general idea finds an interesting confirmation in the concept being used in golf for indicating the playing level of a golfer, namely, his or her "handicap". The lower the handicap – that is the number of shots beyond "par", the average number of shots needed to complete the circuit – the better the player.[14] It is clear that the rules of golf are a contingent historical-social construct, as are the rules of every sports practice which regularly are changed in response to changing circumstances such as technological innovations and other factors. The notion of a handicap in golf is also a construct that is premised on the relation with the particular sport as a much more complex construct – a bad golfer with a large handicap might well be an excellent football player.[15] Of course, handicaps in golf can be overcome, as golfer Martin showed, and this is not the case with all disabilities that strike persons. But nevertheless, it puts the concept of a handicap into a particular perspective, to wit, the dependency of handicaps on social context. For in these cases, one of the issues is some kind of reversal of handicaps: the "normal" athletes (actually they are not "normal" golfers, they are professionals) claim that *they* are disadvantaged in the competition relative to the conditions un-

---

of a cart for a six-month period during his recovery phase. He now plays without one. (http://sports.espn.go.com/espn/otl/news/story?id=6561119, accessed June 10, 2012). Which does not make Martin's case less interesting from a theoretical point of view.

[14] The actual system to determine the exact handicap of a golfer, is a bit too complex to explain here, and it differs per country. For purposes of this chapter, a golfer's "handicap" can be said to indicate his or her *potential* not average score. In this sense, Casey Martin had the potential to play golf at a professional level, if allowed the use of a cart.

[15] This point is particularly clear in the Pistorius case, since even those who argue that his prostheses give him an unfair advantage in running the 400 metre readily agree that he is exceptionally skilled in handling them, in much the way a tennis player such as Roger Federer is skilful in handling his tennis racquet.

der which Martin or Pistorius compete. This dialectic is predicated on the specific character of a sports contest which presupposes *both* equality of conditions (or chances to win), to make it fair, *and* diversity – of style, of tactics, of luck, of competence, and of course of results – to make it interesting. The essence of many debates in sports is actually to strike the balance between these two dimensions – by argument, evidence, negotiation, and so on. The concepts of "obstacle", "handicap" or "disadvantage", "fairness", and "the point of the game" have to be interpreted within the specific rule-governed context of each particular sport. Both the morality of equality and the interest in and importance of diversity, excitement and meaning have to be taken into account in developing this interpretation.

This is just the general background of an intriguing problem that Bowen puts up for discussion.[16] In general, the justified complaint of the movement for rights of disabled persons is that society historically has either intentionally or by dint of neglect caused obstacles for their functionings. Buildings that are not accessible for wheelchairs are an example. These situations should be redressed on grounds of justice. But in the area of sports, obstacles are actually and intentionally *created* for potential competitors. In this, Bowen claims, sports practice is perhaps unique: in sport, the rules make action possible and meaningful in the first place, they not just regulate actions, but *define* them. High jumping *is* only high jumping in sports when the bar is crossed in the way the rules describe. These rules define the specific capacities that the sport puts to the test. This testing is reinforced by the competitive nature of the game. So elite sport does not discriminate specifically against persons with disabilities, it "discriminates" against *all* people who lack the talent, discipline or whatever else is needed to compete for the prizes. We will see in the next section that this truth does not solve the problems at hand. Here I want to round off this point with an argument that puts Bowen's claim that sport is unique, into perspective.

Perhaps sports and games are the only practices that deliberately introduce relatively arbitrary obstacles such as hurdles and rules

[16] Ibid.

such as a particular distance to cross these hurdles, to create a human practice. But perfectionism, excellence and competition are by no means unique to sport. In fact, they are an important element of many other practices. In many important social domains, the differences in ranking order between below-average and above-average ability or those with and without impairments cannot be eliminated by any structure of individual rights. The different groups will have to put up with it and mostly they succeed in doing that by adapting their choices to their possibilities. However, the question remains: ought they? Or perhaps: when, at what point, ought they to resign themselves to their limited natural capacities or context-bound opportunities, and on what points are they permitted (or even obliged) to dispute these limits, on grounds of discrimination? And ought the political or human community as a whole to stand *with* them in those cases? Bowen ends his discussion with the remark: "if one (i.e. Martin) cannot successfully accept the challenges prescribed by the sport, then, like many others, they simply cannot compete".[17] This "simply", however, seems to me too simple, and also too hasty.

4.3 The Essential-Accidental Distinction in Sports

In the rulings of the courts we can see that the fundamental axis that informs the judges' judgments is that between essential and accidental elements of the game. This raises issues of demarcating and defining sports, as well as ontological problems. There is no space to treat these problems at any length here.[18] I will only make two remarks that may be relevant for the purposes of this chapter. First, it

[17] Although Bowen qualifies this conclusion by admitting "that from a utilitarian stance that relativizes the sport activity to the greater good of other systems and the morality of the encompassing society, it may be more profitable to argue for the feasibility or the necessity of allowing Martin to play". But I am not so sure about that claim. It depends on the kind of utilitarian (value-)theory that one invokes to decide on the issue of rule-changes.

[18] See for an introduction: J.W. Morgan and K.V. Meier, editors, *Philosophic Inquiry in Sport*, (Champaign: Human Kinetics, 1988), esp. the article by B. Suits, "The Elements of Sport," 39-48.

is clear that the distinction between the conditions for participating in a sporting event and the conditions for gaining *access* to the event, may help to deal with some problems that clearly and correctly count as discrimination.[19] To mention just one: in order to create equal access, a court ordered a redesign of the available restroom space in a proposed athletic complex that would prevent wheelchair owners from accessing the restrooms.[20] The new situation evidently decreased the social isolation of individuals with disabilities. Analogously, if talented chess-players in a wheelchair would have severe problems with access to the place where matches are played, then this would be discriminatory and ought in principle to be redressed.[21]

Second, taking the match as the unity of action and meaning of sport, we could try to take leave of the rather rough scheme of essential and accidental or peripheral, by switching to a conceptual (or rather phenomenological – I will explain shortly the meaning of this term) approach in terms of foreground and background. There are, first, clearly elements that can be put in the background and that give no good reason to discriminate. There are, second, elements

[19] See CRPD, Article 9: Accessibility.

[20] See Chris McKinny, Sports Facilities and the American Disabilities Act, https://law.marquette.edu/national-sports-law-institute/sports-facilities-and-ada. However, McKinny concludes on the basis of an overview of application of accessibility rules in the ADA: "If any one principle can be deduced from the aforementioned case summaries, it is that ADA law is quite unpredictable. Determinations of compliance are quite subjective due to their fact intensive nature, thus, case outcomes are difficult to predict".

[21] "In principle", because I am not sure whether the principled moral justification in terms of rights and equality can by itself shoulder the political and legal argument that in every and any case things should be redressed. That it would hold good in any case, seems uncertain in view of the budgetary constraints and general principles of justice that actual policies in a polity have to deal with. Rawls gives this uncertainty as a reason to shrink back from treating the problem of redress at any length in *A Theory of Justice*, (Cambridge, MA: Harvard University Press, 1971), and even then, he restricts redress to the social lottery. Nor will an appeal to the distinction between negative and positive rights resolve issues of cost. As Holmes and Sunstein convincingly argue, negative rights are by no means without costs and their protection sometimes demand extensive and costly state action. See S. Holmes and C. Sunstein, *The Costs of Rights: Why Liberty Depends on Taxes*, (New York: Norton, 1999). In any case, taking budgetary constraints into account might alter the normative issues and, in any case, force the relevant agents to set priorities in a principled manner.

that are central to the principle of fairness and equal chances. And then there are, third, contested elements in the game, such as traversing the golf course on foot. This conceptual ordering is just a start, because in many cases there is an interplay between different elements, even in the foreground. This might require a holistic approach to the matter. I will come back to this holistic nature in section 4.4 below. Here I confine myself to the following suggestion. The case for the non-essential character of a specific feature of a sport, and the case for the applicability to rules in sports of the principle of social inclusion as stated by the CRPD, could be framed in terms of the relatively background (or foreground) character of the capacity, property or rule in the specific case of a sport. Take again chess as an example. The fact that nowadays female chess players are joining their male colleagues in tournaments, shows that gender is a background element in chess; or – perhaps a better example for this occasion – in many sports, such as running the hundred meter, impaired vision ought not to be a barrier to competing on equal footing with seeing athletes, just as hearing impairments need not represent a ground for competing in athletics with hearing athletes, since alternatives to a starting gunshot are easy to arrange.[22]

4.4 The Role of Science in the Debate on Fairness in Sports

This conceptual differentiation between essential and accidental will, however, take us only so far. It will serve to justify only those disability accommodations that are relatively uncontroversial in affecting capacities that are not seen as essential or central to what the sport is about. Although distinctions solve no problems by themselves, they do help to articulate what the problem is and to direct the debate to the real issues.

---

[22] To illustrate once again the particularities and surprising inversions in the area of handicaps and sport: blind chess and chequers are considered to constitute extra challenges for non-blind players!

In the end, there is no alternative for taking the bull by the horns and confronting the question by whom and on what principles the appropriate form of participation, in regular competitions, by disabled athletes, should be decided, whether the compensatory devices are acceptable or they are allowed to operate under modified rules. We already saw that procedural and substantial answers have been offered to these questions. Procedurally – regarding the question of who has the authority to decide – the alternative answers seem to be: either the impartial judge in a democratically established system of law, or the authorities and/or stakeholders in the relevant sport. But we also saw that the judges differ in opinion, with some making an authoritative and substantial judgment of their own regarding the issue of what is essential and what is peripheral in a particular sport, and others deferring to the decisional authority of the stakeholders ("those who hold the future of the sport in trust"). Moreover, the substantial judgment what is essential to the sport is contested and there is controversy whether the rights of individuals such as Martin and Pistorius should override the equality of conditions or chances between competitors that seems central to the idea of sports. Both cases turned out, on closer examination, to involve a principled question concerning fairness, although Martin's case is complicated by the fact that issues surrounding the "essence of golf" are involved. In Martin's case both the fundamental issue of the essence of golf, or which challenges are central to golf, and the question of application played a role. The question of application is whether in Martin's case he really did derive an advantage from not having to walk the course, or, alternatively, was handicapped by the fact that there are also disadvantages in not having to be able to walk, such as the inability to warm your leg muscles. It is the question of application which is central to the fairness argument. In the Pistorius case the second issue was central.

Once we agree on the essential physical and mental challenges that must be confronted as a constitutive aspect of excelling in a sport – challenges that ground and inform the sport as a meaningful meritocratic practice – we have to ensure that the conditions under which rivals compete for winning the game, are fair. These conditions must conform to a principle of equality of conditions that are

relevant for winning the competition. Any major external asset – such as a technological device or a performance-enhancing substance – that some rivals (may) use, but others, for various reasons, may not or won't, will violate this principle. Both the question whether something is "major" or "substantial" asset, and the question whether an asset is "external" or alien to the game as such have been the subject of long-standing debate and controversy in sport in all kinds of cases.

The question whether a particular technique or preparation constitutes an unfair advantage has largely been taken to be resolvable by only taking recourse to an evidence-based, scientific approach, assuming that science would come up with consensual, authoritative answers. Let's see what evidence this scientific approach has brought in the case of Pistorius, which arguably will be the more influential, precedent-provoking case, and which involves scientifically complex questions.

An important article to broach this debate, was written by two South-African scientists on a Sports and Science Internet site.[23] The authors identify three key issues in the debate.

First, they point out that the case is in need of some "incentive clarification" because a number of opinions and interpretations on scientific issues are closely connected to vested interests of a commercial nature. This holds for instance for the company that developed the Cheetahs (the prostheses used by Pistorius). This company is still working on the perfection of the device, a point I will come back to below. The authors do not mention the "ideological interest" on the part of disabled athletes that is invested in the case. However, this interest is clear in the opinion of Troy Engle, coach of the US Paralympic track and field team, who said in response to the fact that Pistorius was not initially selected for the Games: "There's not another story that has brought more attention to the Paralympic movement than Oscar Pistorius. He's been a wonderful ambassador

[23] R. Tucker & J. Dugas, "Oscar Pistorius – Science and Engineering vs. Training: An Evaluation of All the Evidence," to be found on the Internet site "The Science of Sport" http://www.sportsscientists.com/2007/07/oscar-pistorius-science-and-engineering.html, accessed April 27, 2012.

for our movement, and I'm obviously disappointed for him." Of course, this interest as such is completely justified. However, it should not bias the collection, assessment or acceptance of the evidence concerning the question of whether Pistorius' prostheses given him a relative advantage in track events.

Second, Tucker and Dugas describe the delicate position of the IAAF. This Federation is responsible for the fairness of rules in international athletics, taking into account the possible precedence-effect that the Pistorius case may have for the future of sports. In these days of technology, there is a considerable risk of opening a Pandora's Box by allowing technological devices to be introduced in sports competition. Control of the criteria by which to discriminate between acceptable and unacceptable devices is easily lost, and the means, for instance the financial means to evaluate the differences caused by using performance-enhancing substances scientifically, and establish controls, are limited. The IAAF will have to face the implications for the future of sports of allowing this particular technology. One of the problems is that allowing the technology will make it more difficult to determine by what means and in which proportions improvements in sports are achieved. Pistorius's equipment is something that can be worked on by engineers. The contribution of training (or of talent, or of mentality, I would add) will increasingly be more difficult to determine in relation to the added value of the improved prostheses. As a matter of fact, the only way to control these differences will be either to force Pistorius to keep running on the same prostheses and not to use a new "generation" of Cheetahs, or to test thoroughly whether each alteration to their design changes the situation in a relevant way.[24]

The authors also indicate that Pistorius is a rather unique case, not only as far as his impairment is concerned but also in so far as his financial means are concerned. Each of the prostheses costs 18,000

[24] It should be said that Pistorius has claimed that he did not change his prosthetics for the last seven years, but this claim also is disputed by Tucker in his extensive latest contribution to the debate: Revealing the Pistorius Science part 3, dated August 25, 2011. See http://www.sportsscientists.com/2011/08/pistorius-12-sec-advantage-and.html, accessed on June 13, 2012)

US dollars. From a principled point of view this financial element seems irrelevant, but the importance of money again shows that physical disability is only one dimension of relevance that cannot as such be abstracted from a complex pattern of practical, axiological and moral differences and considerations that may count in establishing a theory of fairness for sports practices.

Third, the authors examine exhaustively the scientific evidence as to whether the Cheetahs give Pistorius a major advantage. There is no space to treat these arguments at any length here. They are rather technical and relate for instance to the spring mechanism of the prostheses, the reduced limb mass that Pistorius has to transport and the length and frequency of Pistorius' strides. But the conclusion of these authors is clear: the prostheses definitely confer an advantage. The authors admit that Pistorius has a disadvantage too, which has to do with the coming off of the starting blocks due to the fact that his balance in this position is compromised, but the longer the distance, the less relevant this disadvantage becomes.[25]

4.5 The Relation between Social Practices and the Theory of Rights

In many concrete cases, there is an intricate and complex relation between rights theory and its translation into practice on the one hand, and the issues relating to scientific evidence that I just surveyed on the other hand. To begin with, the correctness of an appeal to a right has to be established, for instance by making sure that the individual making the appeal in fact meets the conditions for belonging to the legally protected group in question. Often, this correctness has to be established by an objective test that is informed by politically negotiated criteria and effectuated by science and ex-

[25] Tucker recently reviewed new evidence from tests carried out at Pistorius's request (evidence which, much to Tucker's dissatisfaction, was not peer-reviewed) and also examined the heated debate on the issue between the leading physiologists on sprint mechanics. He sees his early conclusion confirmed, stating that, with regard to Pistorius, "every line of evidence – the metabolic, the mechanical, the physiological, the pacing – points to one thing – substantial advantage". Ibid., see note 24.

perts. Whether science is up to this task, is not the issue here. But it might be that the stigmatization that Silvers mentioned in her article as an implication of formal justice, derives to a considerable extent from this process of applying abstract rights to concrete situations of individuals. When invoking a rule, a person with a disability will first have to justify the claim of a right to being accommodated, relative to "the normal cases" for whom the conditions of admittance and functioning are taken for granted and where no accommodation is necessary. Second, this individual will have to prove that he or she really belongs to the class circumscribed by that rule. In the case of Pistorius it is also clear that this dialectical process of rule and application will be particularly difficult, because "science likes numbers" and Pistorius is a single case until now. In his case it might be very difficult to interpret the available physiological parameters in view of the necessary comparisons between Pistorius and his rivals.

It seems to me that this interplay between science and rights, illustrated here by the relation between science and sports, directs us also to a general and deeper problem that specifically concerns the relation between abstract or formal rights and equality and social practices of which sport is an interesting example. The competitive, public, tradition-bound, meritocratic and perfectionist nature of sport – articulating each of these adjectives would require a separate article[26] – is largely based on quite different schemes and assumptions than the theory of general rights on which a legal and moral system of law and rights is based. Rights discourse is applicable to a certain extent insofar as issues of access and opportunities are relevant. There should be no discrimination on non-relevant grounds. But the class of relevant grounds for exclusion in sports is broad, prominent and obvious. Few individuals shorter than 185cm are found in sports such as basketball and volleyball, except when they have special talents that are useful for the game. The cases of Martin and Pistorius are unsettling for the practices of golf and athletics because they challenge received opinions about the essence of the

[26] See S. Loland, "Normative Theories of Sport: A Critical Review," *Journal of the Philosophy of Sport*, 31(2004): 111-121.

game and the way it should be played. They force the parties involved to explicate the underlying assumptions of the actual sports practices and to think through its foundations. There is a tension or conflict between the postulates of modernity, such as equality of rights and the historical and tradition-based rule-systems of sports. It is revealing that tradition is often precisely what the disability rights advocates aim to overcome. Whether intended or unintended, many societal barriers to access and participation of persons with disabilities are unjustified and ought to be eliminated. But the core of traditional, relatively stable rules by which many sports practices are defined and constituted, seem essential to their existence as a recognizable phenomenon that people can identify with. Even if according to scientific measures the prostheses of Pistorius would not give him an unfair advantage, the fact that the race is run by people who have a very different appearance, might be relevant for the trust and interest that the spectators (can bring themselves to) have in the game. If, under the influence of developments driven by the tandem of law/morality and technology, this stable and recognizable base of rules is challenged, the future of many sports might be jeopardized.[27] Technological accommodations for people with disabilities are sure to continue, as long as technology advances and individuals using assistive technologies claim access to sports practices on grounds of disability. This claim to access in sports might be supported by a moral principle based on equality of rights, but also be further strengthened by increasing doubts of the possibility and legitimacy of *any* demarcation between natural and artificial in a technological age. For applied and philosophical ethics, as well as for the philosophy of sport, cases such as Martin's and Pistorius', however incidental they might be, will retain their value as important references for debates that will be with us for a long time.

[27] A far more influential issue in the rights-practices-conflict is the fact that the policy against doping, which for many is central to the future of sports, is in danger of conflicting with privacy and liberty rights, as 24-hour controls are at the order of the day. If a court would uphold these rights in a case against a doping authority, it would be very hard to sustain the credibility of many sports.

5 Conclusion

This chapter has mainly raised questions and doubts and does not allow for a definite conclusion concerning the cases from which it started. I only want to add three methodological points that it may be worthwhile to pursue further.

First, the arguments mounted by Tucker and Dugas in their articles on Pistorius' use of prostheses in competition, consist largely of science-based, physiological data. The debate might get an interesting turn if a phenomenological, "holistic" account of the functioning of the body, for instance along the lines of Merleau-Ponty's work, is (also) taken into account.[28] This might give an interesting new take on the issue of sports and disabilities. Interestingly, Merleau-Ponty suggests that the functioning of the "abnormal" body often gives us a better understanding of the human body than the conduct of the "normally" abled. He was not referring to "excellence", which basically is equal to reaching a higher standard on the same measure, but about people who really seem "wired" in a different way. But whether this theoretical understanding translates on the practical level into the idea that the 'abnormal' bodied competing with the help of technology would heighten our appreciation of athletic competition, seems doubtful.[29]

---

[28] M. Merleau-Ponty, *Phenomenology of Perception*, (London: Routledge, 2002, originally 1945); M. Merleau-Ponty, *The Structure of Behaviour*, (Boston, MA: Beacon Press, 1967, originally 1942).

[29] The phenomenological approach might also have some new arguments in store for the discussion about whether certain changes in sport are for the better. It seems plausible that sport, certainly elite sport, is essentially a public event played out in the open and visibly. The public arguably has an important role to play in rule-changes and the future of sport. The normative and moral implications of this role are as yet not very well articulated (has "the public" a moral right not to be deceived by athletes, and if so, on what grounds?), although elite sport presupposes massive public attention for its economic conditions of existence. But if the events and processes in sport can no longer be followed or shared by the public and one can no longer identify with what is happening, because the participating athletes have a quite different bodily make-up than they themselves, then the public might lose its interest. The public might get interested in the carnivalesque attraction of exposing unusual bodily figures and movements – but that would be a different thing from sport, and it would raise different moral questions.

Second, I have tried to argue for the thesis that there is a deep tension and possibly a deep conflict between politically generated general rights and the rules of a social practice such as sport. This debate will be with us for many years to come. Philosophers will have a significant role to play in articulating the concepts, evaluating the arguments and suggesting "best practices" taking into account substantial as well as procedural considerations. It might be worthwhile to start a comparative debate about how and to what extent this same conflict between rights and practices occurs in other practices, for example in the professions or science, and how persons with disability are accommodated in those contexts.

Third, the importance of technological advances for the functioning and emancipation of the (physically) disabled is generally obvious, well-documented and widely acclaimed.[30] But there may be a downside to this acceptance, although this downside is very difficult and delicate to articulate and discuss. The opportunities and facilities that advanced technology affords those with impairments are often considered to be an unmixed blessing, further strengthening the case for the benefits that technology brings to humankind. It is also used to justify research and development of technologies which in the longer run might have far-reaching consequences for society in general, because they open up new, controversial and problematic opportunities for the "abled" as well. There is a commercial, rhetorical and ideological side to the role of this "for the benefit of the disabled"-argument because it is hard to challenge, given the historical social morality in many countries that cherish the rights and care for the "least advantaged" as an important principle. It is very hard to spell out how to deal with the Janus-faced character of the argument; it may even be impossible to deal with in any rational way given the dynamics of general and applied scientific and technological developments. But the fact that many sports practices have refused to allow advanced technological devices for the sake of other

[30] "Generally", because cases such as the use of cochlear implants for those with hearing impairments suggests that assistive technology is often controversial, even among those with disabilities.

values and meanings that are inherent to sports, may be an interesting, although perhaps exceptional, case of canvassing this intriguing connection between the future of people with disabilities and the general future of humankind in the technological era. Perhaps the very idea of normalcy will eventually die out, once technology, which was initially developed to help people with disabilities to function better, comes to be upgraded and used to enable people in general to choose their own bodily and perhaps mental make-up for purposes that they have set themselves. But for the moment we are stuck with the problems of defining or re-defining the meanings and limits of sports, two examples of which I have presented and discussed in this chapter.

Part III

Setting Priorities

8 Human Rights, the CRPD, and Priority-Setting

Jos Philips[1]

1 Introduction: On Human Rights and Prioritization

The UN Convention on the Rights of Persons with Disabilities (CRPD) reads like a very ambitious document. Many philosophers therefore stress the importance of having prominent and principled guidelines for priority setting in the implementation of this Convention. Many think that without such guidelines, priority setting risks becoming an ad-hoc exercise, which may harm the cause of disabled persons as well as the cause of human rights. However, human rights lawyers are often wary of principled approaches to priority-setting, and oppose to their having a prominent place in the emerging practice of human rights. Examples of principled approaches include those that give priority to some human rights or general principles over others (e.g. to non-discrimination over inclusion[2]) and those that identify a core of certain human rights (e.g., the most important part of the right to accessibility), and say that this core ought to get precedence in implementation. Human rights lawyers do recognize that one sometimes has to make choices about which, or whose, human rights to protect or realize. But they often think that such choices are better left to the specific contexts at hand, and not dealt with by specifying a general hierarchy of human rights.[3] Philosophers, on the other hand, are often in favour of giving principled priority to, for example, some rights – or values or general

[1] For their comments on earlier versions of the present essay, I would like to thank Joel Anderson, Marcus Düwell, Jenny Goldschmidt, Caroline Harnacke, Roland Kipke, Titia Loenen, Fernando Sancen, Esther van Weele, and colloquium and working-group members at Utrecht University and Eberhard-Karls University Tübingen. Of course the present text is entirely my own responsibility.

[2] Cf. CRPD, Article 3.

[3] Relatedly, many lawyers also reject the terminology of "priority-setting" and prefer to speak of "balancing human rights". I will, however, stick to the former terminology.

principles etc. – over others,[4] and suggest that it would be good if the human rights practice would develop prominent guidelines specifying such priorities. Similarly many they do seem to favour identifying, as a prominent part of the human rights practice, the most urgent parts of a right.[5]

In this chapter, I will argue that both positions – the one that many human-rights lawyers endorse and the one more common among philosophers – have significant strengths and significant drawbacks, with the result that in practice one might equally well go with either approach. However, it is noteworthy that generally human-rights lawyers and philosophers agree on one point: that human rights *as a whole* are to receive significant priority over other policy considerations. This, I will argue, is the most important consideration from which one ought to approach issues of prioritization that arise in implementing the CRPD.

The chapter is structured as follows. The remainder of this introduction will explain how the concept of human rights will be understood in what follows. Then I will (in Section 2) identify various important questions that come up when we think about priority-setting in implementing the CRPD. In Section 3, it will be argued that the most important sources in the human rights practice take the view that one should, in at least two ways, refrain from setting principled and prominent priorities within human rights; and we will see three reasons that support this position. Subsequently we will, in Section 4, evaluate these reasons, contrasting them with positions that many philosophers hold. This will show that both the views that lawyers frequently hold and those which many philosophers take, are problematic. I will go on to note, in Section 5, a major point of convergence between human rights lawyers and philosophers, and it will be argued that this point should be our key to approaching issues of

[4] Cf. H. Shue, *Basic Rights*, (Princeton: Princeton University Press, 1996, 2nd ed.); A. Gewirth, "Duties to Fulfill the Human Rights of the Poor," in *Freedom from Poverty as a Human* Right, edited by T. Pogge, (Oxford: Oxford University Press, 2007); J. Griffin, *On Human Rights*, (Oxford: Oxford University Press, 2008).

[5] See previous footnote.

priority-setting. To conclude, I consider an important objection against this position (Section 6).

To start, then, let me explain the concept of human rights as I will use it. I will follow Charles Beitz in regarding human rights as an (emerging) practice. According to Beitz, human rights are defined by their roles in a modern world, that is, a world one of whose most important characteristics is its being organized in distinct states. Human rights say that certain important individual interests ought to be protected against threats that are common in such a world. Human rights are primarily addressed to states as dutybearers and secondarily also to other agents, and these rights are emphatically a matter of international concern, meaning that underfulfilment of human rights in some state provides outside parties with pro-tanto reasons of various kinds for doing something.[6]

As such, human rights provide the current world order with on the one hand some kind of ideal – namely, that at least everyone's human rights should be fulfilled in this world order. On the other hand, human rights also give guidelines for non-ideal situations – namely, they provide various parties with reasons for action where human rights are underfulfilled. Beitz regards human rights (or as he puts it, the human rights practice) as providing reasons that are justice-related, but he explicitly rejects considering human rights practice as a complete account of justice or as an account of "basic justice", in some sense of that expression. Yet human rights do, according to Beitz, form a subset of all considerations of justice, a subset whose contents are shaped by the roles that human rights play in the modern world order.[7] The account that Beitz gives of human rights is intended for the tradition that has emerged since World War II and whose most important documents are generally held to be the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights (ICCPR), the Inter-

[6] Cf. C. Beitz, *The Idea of Human Rights*, (Oxford: Oxford University Press, 2009), 109. On this understanding of the (emerging) practice of human rights, the practice will have – and at certain points even *has* to have – numerous juridical expressions, but important aspects of it will be non-legal.

[7] Ibidem, 143–144.

national Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of all Forms of Racial Discrimination (CERD), the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), and the Convention on the Rights of the Child (CRC);[8] and to this we can add the Convention on the Rights of Persons with Disabilities (CRPD), which is the focus of our attention in the present chapter.

2 Some Questions of Prioritization

We will now discuss three questions concerning priority setting that arise in the implementation of the CRPD and that deserve prominence from a philosophical point of view. All these questions also contain suggestions as to how priority setting could be dealt with.

A first question is whether principled priority should be given to *certain human rights*, or general principles, over others. For example, is non-discrimination, as such, more important than participation?[9] (This may be the case because, say, it is more closely linked to human dignity, understood as a justifying basis for human rights.) Or is the right to liberty and security of the person more important than the right to live independently[10] (e.g. because it is more of a precondition for enjoying any rights at all?[11])? Some may think that such a principled priority of certain rights or principles over others is unacceptable or impossible; but this is not immediately clear and needs to be argued for. If it should turn out that certain rights or general principles are, as such, to get priority over others, that result would certainly be important for the implementation of the Convention.

[8] Cf. ibidem, 25-26, and E. van Weele's contribution in the present book.
[9] See CRPD, Article 3.
[10] CRPD, Articles 14, 19.
[11] Cf. Shue, *Basic Rights*.

A second question is whether one should try to provide *second-best specifications* of certain rights. Take, for example, what the Convention says about accessibility:

> States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.[12]

Would it be (possible and) acceptable, say in situations of extreme resource limitations, to single out certain forms of communication and information, access to which is to receive priority? Put more generally, could, and above all should, a second-best threshold be specified that tells us when a certain right is to count as minimally fulfilled?[13] If the answer is affirmative, this would certainly be helpful in implementing the Convention.

A third question about priority-setting, and a third way to identify priorities in implementation, concerns not the priorities within human rights, but the priority that human rights *as a whole* ought to receive vis-a-vis other policy goals that a state may have. As we shall see below, this turns out to be a particularly important way to deal with priority-setting.

In short, some important questions concerning prioritization in implementing the CRPD are (1) whether certain general principles or rights deserve priority in applying the Convention; (2) whether

---

[12] CRPD, Article 9.

[13] This suggests two further questions, and correspondingly two further approaches to priority-setting in implementing the Convention. Although these are outside the scope of the present chapter, they deserve mentioning. The first question is whether one could and should give further specifications of the contents of rights, that is to say, not second-best specifications but simply more concrete specifications of the contents of certain rights – which may also help in getting clarity concerning how to implement the Convention. And the second question is whether it would be possible and acceptable to give priority to certain groups of beneficiaries (e.g. larger groups, groups of persons who are worse-off compared with others), when not everyone's rights can be realized.

second-best specifications of particular rights should be given; and (3) what prominence human rights, as specified in the CRPD and other documents, ought *as a whole* to get vis-à-vis various other policy goals of states.

We should add that what concerns us in this chapter is whether certain rights should get *principled* priority over others (to take the first question just mentioned), and whether this principled priority should be a *prominent* part of the human rights practice. Here, principled priority refers to priority across many contexts and usually based on a general argument or account. This can be opposed to priority that is context-specific and typically based on context-specific arguments or judgments. Furthermore, what interests us is whether such principled priority should be a prominent part of the human rights practice, more specifically: whether it should be affirmed in important human rights documents.

3 Human Rights Documents and Doubts about Priority-Setting

I will now consider the first two questions just indicated (we will later on return to the third). I will argue that the main human rights documents are silent on which rights should, as a matter of principle, receive priority over others (they do not specify a hierarchy among human rights), and that they do not generally provide second-best specifications of rights. And not only that, they also seem to *oppose* a hierarchical ordering of rights and the construction of second-best specifications. I will discuss three reasons for not seeking to set priorities within human rights, or even opposing them. These reasons concern a lack of relevant agreement; the interrelatedness of human rights; and the risk of hampering the realization of human rights. They will be evaluated in Section 4.

Concerning the question of whether certain rights or general principles deserve principled priority over others, the answer implicit in the main human rights documents is: no. A first observation is that the CRPD, for example, does not mention a principled priority among rights, nor does the Universal Declaration. Concerning gen-

eral principles, for example, inclusion is not said to be more important than diversity.[14] Regarding rights, freedom of movement and nationality is not said to be more important than the right to participate in the political and public life.[15] Secondly, there are some widely accepted ideas in the human rights tradition to the effect that we *should not* adopt a principled priority between rights: the ideas of indivisibility, interdependence, and interrelatedness of human rights.[16] More precisely: it is a normative interpretation of these ideas that is relevant here.[17] In this interpretation, these ideas indicate – broadly speaking – that human rights *ought* to be seen as a package, with no particular human rights being more important than others. If one accepts this idea, one can very well acknowledge that human rights can on occasion conflict, as (for example) non-discrimination of certain kinds can conflict with freedom of religion. This means that one will in practice at times be condemned to give priority to one right or to the other; but this does not mean that one needs to acknowledge a principled priority of one over the other.

As for the reluctance to specify second-best realizations of rights, firstly, the most important human rights documents again do not provide such specifications. To be sure, one does in the human rights practice find the idea of minimum standards that are to be met, in particular in relation to socio-economic rights.[18] However, the most prominent documents of the practice only provide one

[14] CRPD, Article 3.
[15] CRPD, Articles 18, 29.
[16] CRPD, Preamble, (c).
[17] These ideas can also, among other interpretations, be given a conceptual and an empirical interpretation. These interpretations refer, respectively, to the conceptual implications between different rights and to what it takes empirically to realize various rights. The conceptual and empirical interpretations do secondarily have normative implications: they show that it is in important respects impossible to sever the realization of some human rights from the realization of others, and as such they set important limits to how (and to what extent) priorities among rights *should* be set.
[18] See, among others, the UN Committee on Economic and Social Rights, since 1990. Cf. T. Degener and G. Quinn, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, (New York and Geneva: United Nations, 2002), 191-196; K.G. Young, "The Minimum Core of Economic and Social Rights: A Concept in Search of Content," *Yale Journal of International Law*, 33(2008): 113-175.

articulation of particular rights, and do not give us "first-best" as well as second-best specifications of rights. In this sense, the practice lacks prominent and principled second-best specifications of rights. Admittedly, however, on this point the human rights practice is less clear than when it comes to rejecting a prominent and principled priority between human rights.

Nonetheless, ideas like the indivisibility of human rights do, although somewhat implicitly, amount to opposition against the articulation of "cores" of particular rights, which would imply "hierarchies" *within* a right. If such hierarchies were accepted, we could as a matter of principle distinguish between, say, "serious" and "mild" violations of a particular human right – a distinction which, as a principled one, the main human rights documents would find very hard to digest. In this light, it seems no coincidence that these documents do not provide principled second-best specifications of particular rights, but prefer to resort to ideas like progressive realization of a right, in cases where not all can be done at once.[19]

Thus the main human rights documents, among which the CRPD, oppose the articulation of a hierarchy of rights, and of second-best specifications of rights. What reasons could justify this opposition? I mention three, which have a firm foothold in the human rights practice as we find it. These reasons will be evaluated in the next section.

The first reason is that a principled prioritization could not be agreed on by the most relevant agents in the international human rights practice (governments, intergovernmental organizations, NGOs, etc.). This amounts to saying that it is in the practically relevant senses *impossible* to provide a hierarchy of rights or second-best specifications of rights. The second reason, which was already adumbrated in the previous section, and which is in tension with the first reason, is that the human rights practice *positively contains* the ideas that at a principled level all human rights are equally important, and that there are no "cores" of particular rights. In other words, the practice would positively assert that, and possibly also explain why, there is not a normative principled hierarchy of priority

[19] International Covenant on Economic, Social and Cultural Rights, Article 2.

between human rights, nor within particular human rights. For example, if it is a prominent idea in the practice that human rights are interdependent, this may well imply that one should not (and even cannot) construct a hierarchy between them; and it may explain why not. Finally, the third reason for not wanting to articulate a principled priority between human rights, nor second-best specifications of particular rights, is that such an articulation would hamper the full realization of human rights. This would be a largely empirical claim. The idea may be that providing a hierarchy of rights and second-best specifications of rights would unleash motivational and institutional dynamics that work against the full realization of all human rights for all – in the case of the CRPD, the full realization of all human rights of all disabled persons – : once the most important rights and the cores of those rights were clear, the relevant agents may not work very hard to also achieve what lies beyond those most important rights and those cores; hence the full realization of all human rights for all would be thwarted. And obviously, this full realization is an ideal that we cherish for our international order.

4 Are the Doubts about Prioritization Justified?

We will now evaluate the three reasons just discussed for opposing certain forms of prominent and principled prioritization within human rights. In doing so, we will discuss some ideas that are prevalent among many philosophers who take a more favourable view of prominent, principled priority-setting within human rights.[20]

[20] Incidentally, human rights lawyers and philosophers generally agree that priority-setting is *not* to be done (1) by providing, prominently and principledly, very concrete *specifications* of the contents of certain rights, or (2) by giving, in a prominent and principled way, priority to either a larger group or a worse-off group of beneficiaries.

Concerning (1), the human rights practice generally leaves very concrete specifications outside its core documents, and philosophically, one may say – after David Wiggins, who remarks about needs that "overspecificity in a needs statement makes it false"; I can rightly claim that I need food, but not that I need bread – that too great specificity in a rights-claim may well make it false. Now rights are not needs, but still I more plausibly have a right to access to relevant services and facilities in the physical environment

1. Let us first consider the idea that the main participants in the human rights practice (states, interstate organizations, NGOs) will not agree about a hierarchy of priority between rights, nor about second-best specifications of particular rights. On the one hand, this idea seems not too far-fetched. Famously, Jacques Maritain, of the UNESCO Committee on the Theoretical Bases of Human Rights, described a colleague as saying: "We agree on the rights *but on the condition that no one asks us why*."[21] This suggests that it was easier to agree about lists of human rights than on the justifications for those lists (or, for that matter, on the concept of human rights: what exactly the lists were lists of). Similarly, one may think that it may be easier to agree about lists of human rights than about the relative importance of the items on those lists, and about the cores of those items. What, for instance, would be the ranking and the cores of the right to live in the community, the right to an adequate standard of living, and the right to participate in political and public life?[22]

On the other hand, however, it is not true that all governments and other relevant agents agree on the contents of the most important

---

(CRPD, Article 9) than to, say, elevators being available in libraries. See D. Wiggins, *Needs, Values, Truth: Essays in the Philosophy of Value*, (Oxford: Oxford University Press, 1998, 2nd ed.), 23.

As for (2), in cases where the rights of one group of people can be realized or those of another, but not those of both groups, the human rights discourse does not attempt to tell us for which group to go. In particular, it does not tell us whether to go for the largest group or for the worst off, where there is a conflict between them. In philosophical debates, this is a hotly debated question, but it seems fair to say that most resist principled priority too: most authors hold that, in deciding the issue, at least some extra weight should be given to the worst-off, while on the other hand we cannot get around giving some attention to quantitative issues – where this is not to say that we will automatically choose to protect the largest group if we cannot protect everyone. Cf. S. Scheffler, *The Rejection of Consequentialism*, (Oxford: Oxford University Press, 1994, 2nd ed.); D. Wasserman, "Distributive Justice," in *Disability, Difference, Discrimination*, edited by A. Silvers, D. Wasserman, and M. Mahowald, (Lanham MD/Oxford: Rowman and Littlefield, 1998), 147-208; R. Arneson, "The End of Welfare As We Know It? Scanlon vs. Welfarist Consequentialism," *Social Theory and Practice* 28(2002): 315-336. Cf. T. Pogge, *World Poverty and Human Rights,* (Cambridge: Polity Press, 2008).

[21] J. Maritain, "Introduction," in UNESCO, *Human Rights: Comments and Interpretations* (London: Allen Wingate, 1949), 9, emphasis in original. Quoted after Beitz, *Idea of Human Rights*, 21.

[22] CRPD, Articles 19, 28, 29.

Declarations and Conventions in the human rights practice, and still those Declarations and Conventions remain the heart of the public practice.[23] So why could a principled hierarchy of rights, even if disagreement about it persisted, not become a prominent part of the practice? Furthermore, it is unlikely that governments and other main agents will disagree about all aspects of a principled hierarchy of rights. This, at least, is suggested by many philosophers who take seriously that there are some matters about which reasonable people are going to agree and some matters about which they are not: many authors think that the matters on which people will agree include certain orders of priority between certain rights, duties, or values.[24]

However, even if this is so, it remains likely that in many cases the relevant agents are in no way going to reach this agreement on priorities between rights, and within rights, while such agreement *is* needed. In such cases, it is a moot point whether it is wise to seek such agreement, or whether such endeavours will only engender dispute, strife, and bitterness.

All in all, then, as far as the possibility of reaching agreement is concerned, it remains undecided whether it is a good idea to strive for prominent articulations of principled priorities between rights.

2. Let us now consider the idea that it is simply part of the human rights tradition as we find it to oppose the prominent articulation of principled priorities between rights, and of second-best specifications of rights. Above we referred, in this context, to such notions as the interrelatedness and indivisibility of human rights.

However, is it really part of the practice of human rights to deny a priority between particular rights? We may begin by observing what

---

[23] It is beyond my present aims to deal with the very fundamental issue of whether agreement matters at all – and if so, exactly what kind of agreement matters for what purposes.

[24] Cf. Pogge, *World Poverty and Human Rights*, who says that there will be agreement among philosophers with very different backgrounds that so-called negative duties (duties not to harm) are, if all else is equal, more stringent than so-called positive duties (duties to help). And cf. J. Rawls, *The Law of Peoples*, (Cambridge, MA: Harvard University Press, 1999), who asserts that governments, at least if they are minimally reasonable, will agree that the observance of some human rights as mentioned in the UDHR, but not others, are a precondition for being a member in good standing in an ideal world order.

many philosophers think who are working on justice (with which human rights as we have understood them are related) or on related topics: it is often their view that some values or rights *are* more important than others. Here we may, for example, think of certain liberties or certain rights – for example, liberties that are central to developing one's moral powers as a reasonable and rational person,[25] and rights that are a precondition for any other rights,[26] or that prevent a system of social cooperation from becoming purely coercive.[27]

Now the emerging human rights practice does show some affinities with this position,[28] as certain rights (e.g. the right to life or the right to freedom from torture[29]), or some aspects of those rights, are in certain situations to receive great emphasis in the practice. However, on the whole, and as argued above, the practice is clear in rejecting principled priorities between and among rights.

Furthermore, we can observe that this rejection does have some foothold in the philosophical justice literature after all. It does in the sense that many theorists resist assigning further principled priorities among rights or values within an already prioritized domain. For example, Martha Nussbaum resists assigning further priorities within her list of real freedoms (capabilities), which are at the centre of her theory of basic political justice.[30] A different example is provided by John Rawls, who does not assign further priorities within a scheme of liberties that should, as the first requirement of justice, be socially guaranteed to everyone.[31]

---

[25] Cf. J. Rawls, *A Theory of Justice*, (Cambridge, MA: Harvard University Press, 1971); J. Rawls, *Political Liberalism*, (New York: Columbia University Press, 1993).
[26] Cf. Shue, *Basic Rights*.
[27] Cf. Rawls, *The Law of Peoples*.
[28] I leave open the question of whether certain philosophical debates are themselves part of the human rights practice.
[29] CRPD, Articles 10, 15.
[30] E.g. in M.C. Nussbaum, *Women and Human Development*, (Cambridge: Cambridge University Press, 2000).
[31] Rawls, *A Theory of Justice*; Rawls, *Political Liberalism*; J. Rawls, "The Idea of Public Reason Revisited," in idem, *Collected Papers*, edited by S. Freeman, (Cambridge, MA: Harvard University Press, 1997), 573-615.

All in all, then, the balance of arguments concerning this second reason for resisting prominent and principled priorities within human rights, seems to remain undecided.

3. Finally, we turn to the third reason for resisting principled prioritization among rights, and for resisting the prominent articulation of second-best specifications of rights. This reason was the concern that setting principled priorities could thwart the full protection and realization of human rights: once we identify the more important human rights, and the most urgent thresholds of realization of certain rights, the relevant agents could easily have the attitude that going beyond these most pressing matters is not very urgent. This, at any rate, seems to be the perception of many who are engaged in the practice of human rights; whether it is correct is a largely empirical matter.

Strikingly, many philosophers tend to embrace a diametrically opposed reasoning. They think that human rights advocacy is best served by having a consistent and principled approach to priority-setting in implementing human rights. An ad-hoc and unprincipled approach would hamper the full realization of human rights, because the relevant agents risk being overwhelmed or losing a sense of urgency, and because the cause of human rights would run the risk losing the moral high ground and being seen as opportunistic.

It should be noted that these latter claims too are largely empirical. Which of the two diametrically opposed claims is empirically most plausible is really hard to determine. For example, one gets the impression that the relative neglect that socio-economic rights have sometimes received has indeed gotten in the way of the realization of human rights as a whole, while a special emphasis on the abhorrent nature of genocide has surely helped the realization of human rights. However, a systematic assessment of which position is the more plausible – that for or that against principled and prominent prioritization within human rights – requires extensive empirical research, and to my knowledge we do not presently possess all the relevant empirical findings.

While the matter is pending, going with either position – setting or opposing principled priorities – seems equally justified, at least if we are concerned with the risks for the cause of human rights, which

are probably the most pertinent consideration. At the same time, we should keep in mind that both positions do entail great risks.

This conclusion, however, does not give us much guidance. In what follows, I want to explore an important point of common ground among most human-rights lawyers and philosophers, to see whether this can help out.

5 A Point of Convergence: the Importance of Human Rights

There is wide agreement among both human rights lawyers and philosophers that human rights as a whole ought to receive high priority in state policies, compared with other policy goals. Lawyers and philosophers alike see human rights as expressing forceful claims,[32] as having a banner function,[33] and as calling for priority in state policies and laws.[34] More precisely, even though one overstates the matter if one sees a consensus to the effect that human rights should *always* be overriding considerations in policy, it is no overstatement to say that there is a consensus that human rights should *usually* trump all other policy goals. (It is of course equally true, unfortunately, that states and other agents frequently do not put their money where their mouth is.)

What could this point of convergence mean for setting priorities in relation to human rights? I want to propose that it means that, when it comes to human rights and priority-setting, our main focus should be on the priority of human rights as a whole, compared with other policy goals. The remainder of this chapter will consider (1) why we should accept this proposal, and (2) what, more precisely, the proposal means for priority-setting. Finally, I will close by (3) discussing an important objection.

---

[32] Nussbaum, *Women and Human Development*.
[33] Cf. Griffin, *On Human Rights*.
[34] Cf. Beitz, *Idea of Human* Rights, 137 (parts 1 and 2).

Why, then, should we accept this proposal? First, we may, as just argued, with equal justification advocate and oppose setting prominent and principled priorities between (and within) human rights. So when it comes to priority setting in relation to human rights, we can make no strong claims concerning the priority of some human rights over others (or of some aspects of a particular human right over others). Therefore, if we *can* make strong claims concerning the priority *of* human rights vis-à-vis other policy considerations, this is what we should focus on.

Now we can indeed make strong claims of the priority *of* human rights as a whole. This is so for a conjunction of two reasons. First, reasonable people can agree that human rights express urgent considerations since they are concerned with urgent human interests, indeed much more urgent interests than those with which most other policy considerations deal. Secondly however, this urgency could still fail to translate into high policy priority, if the full realization of human rights should be an ideal that is hopelessly out of touch with the social realities and opportunities as we find them in the current world.

But it is, in fact, not out of touch. For human rights provide protection of certain urgent human interests *against standard threats*.[35] This is a complex notion in whose meaning a number of elements are implied. "Protection against standard threats" implies a certain degree and shape of protection: there must be (1) a certain, reasonable, probability of (2) a certain degree of protection against (3) certain important threats that are common in the present-day world.

Part of what this means is that those kinds and levels of protection are excluded that states can only provide at exorbitant cost – even if the interests in question are very urgent. Failure to provide multi-billion-a-piece hi-tech treatments to save a patient's life could not count as a human rights violation, nor could failure to protect the population against meteors. But failure to protect them, with a very great probability, from famine and from diseases that can be treated relatively easily and cheaply would count as human rights violations

[35] Beitz uses this expression, which is explicitly taken from Shue, *Basic Rights*, esp. 29-34.

(even though such protection may take quite something to achieve), as would the vast majority of cases where people are actively and severely harmed by a state's policies. While these brief remarks – and particularly the notion of "exorbitant cost" – would of course require much more elaboration, they may suffice to show that human rights are feasible in the sense that they are from the outset tuned to the realities of the social world that we live in.[36] This is not to say, to be sure, that it would be a sinecure to realize human rights, but only that it is doable to realize them if (with a variation on the Rousseauian adage) one takes people as they are and if one envisages institutions which are not too far removed from the ones that we presently find in most societies.

I now turn to question of what difference it would make, more precisely, to focus on the policy priority *of* human rights. This focus would mean a substantial reorientation of many discussions of human rights and priority setting. It implies that these, by immediately considering priority-setting *within* human rights, have started with the wrong question all along.

Now there may be contexts where states keep struggling to do full justice to all human rights, even if they give human rights the full policy priority that they are due. In such contexts, a focus on the policy priority of human rights invites us not to turn too quickly to priorities between and within human rights, but rather first to carefully consider the changes that might be made to institutional settings, and that might make it possible to more fully realize all human rights for all – emphatically including the protection and promotions all human rights of all disabled persons. As Thomas Nagel

[36] To see more clearly the feasibility of human rights as found in the contemporary practice, contrast this idea with a different idea of human rights that some might find attractive: human rights as giving a full catalogue of all central interests of all human beings and as saying that states must do all they possibly can to protect these interests. True, human rights as found in the practice of human rights are in a sense less urgent than they would be under the different idea of human rights that was just indicated. This may threaten their policy priority. On the other hand, human rights as found in the practice are still concerned with more urgent interests than almost all other policy goals. And, as argued, they are more feasible than certain alternative ideas of human rights, which help to secure their policy priority.

remarks (albeit in a somewhat different context): "We must turn our attention to the circumstances in which people act and by which they are formed, and we must change the question from: 'How should we live, whatever the circumstances?' to 'Under what circumstances is it possible to live as we should?'"[37]

Only then, as a third question – after considering firstly whether human rights as a whole receive due policy priority and secondly how institutions can for the sake of human rights be changed by looking to not-too-far-off alternatives – does the question arise of which human rights considerations to give priority over others. As argued above, this question is vexed indeed, especially when it comes to prominent and principled priorities, and all ways of deciding it entail risks.

6 Concluding Considerations

To summarize, I have argued firstly that, when dealing with the great challenges posed by the CRPD, it is equally justified to advocate and to oppose prominent and principled priorities between and within human rights. Secondly, the main emphasis, when we are talking about human rights and prioritization, should be on the policy priority of human rights as a whole, and on changing institutional circumstances so as to make it more possible to fully realize human rights.

To end, I wish to consider an objection, namely that the above story is not at all helpful with regard to human rights and priority setting.

My reply is that this story does have very clear implications in situations where human rights do not get the policy priority that they are due, and where a lot can be done to work towards nearby institutions that better realize all human rights for all. In such situations, the position defended above entails that rather than putting much

[37] T. Nagel, *Equality and Partiality*, (Oxford: Oxford University Press, 1991), 52. There is no implication that changing the circumstances is a painless process: cf. ibid., 170.

effort into advocating or opposing priorities within human rights, agents in the practice should focus on the policy priority of human rights and on institutional changes.

By contrast, in situations where one remains, after all efforts, unable to do full justice to all human rights of all, the position defended in this chapter simply implies that one is equally justified in opposing principled and prominent priority-setting between human rights, and in advocating it.[38] This may seem to offer little guidance, but then this may just be how things are. It may just be true that one could try to provide the human rights practice with prominent accounts of why, say, the fundamentals of autonomy are as a matter of principle more important than the fundamentals of participation – and that one could with equal justification oppose the construction of such accounts.

Many think, we must add, that situations where one will have to return to priority setting within human rights, are bound to be very frequent. The widespread perception has it that possibilities to realize human rights at the expense of other policy goals, or to make institutional changes to more fully realize human rights, run out very quickly. This perception is related to another perception: that human rights are extremely ambitious and wide ranging. The CRPD exemplifies this – heralded as a paradigm shift for stressing the positive sides of rights that had often been seen as primarily negative; and for showing that certain things are matters of rights after all, whereas thus far they had not been so regarded. But is this perception correct?

Here it will help to remember that human rights are by their very nature tuned to the present world order – they only require feasible protection against certain important threats that are common in this world order. All this is not very precise, but in any case it indicates that human rights only require protection against certain threats and that they only require a certain level of protection. To be sure, these two restrictions do for all their vagueness obviously not go so

[38] This is not to say, of course, that every prioritization between rights can be advocated with equal justification.

far as to make the protection and promotion of human rights a sinecure; but on the other hand they do help to reduce the number of situations where a choice *between* human rights cannot be avoided.

Returning to the CRPD, we can observe that it is surely demanding to credibly put into practice what this Convention demands. It may or may not be a good idea to set principled priorities among its general principles and rights. However, we should realize what kind of things the CRPD is about – such as the fundamentals of autonomy, the fundamentals of participation, and non-discrimination. And we ought also to keep in mind that human rights by definition protect against standard threats – which implies, among other things, that the feasibility of a given protection is from the outset taken into account. Once we realize all this, the policy priority *of* the CRPD surely has to be the main focus of its implementation.

9 Capability and Disability: The CRPD from the Perspective of the Capabilities Approach

Caroline Harnacke

1 Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) aims at empowering people with disabilities by granting them a number of civil and political, but also economic, social and cultural rights. This is a groundbreaking agreement for all persons with disabilities. But for those states who signed it, it also brings various governmental obligations. Implementing the Convention will clearly be challenging and also very expensive for all states, but even more so for poor ones.

Therefore, questions might arise as to whether the requirements set in the Convention are actually justified. A justification can be given from various perspectives. For example, the CRPD might be justified from a legal perspective because of its correspondence with certain methods and regulations of international law. Yet in this chapter the focus will be on ethical justification. That is, if the rights laid down in the Convention claim moral authority, they are in need of an ethical argumentation. Various ethical theories could be candidates for a normative justification to support the Convention. However, already at first glance some theories seem more promising than others. Amartya Sen's and Martha Nussbaum's Capabilities Approach belongs to the more promising ones. In a nutshell, the Capabilities Approach views the state as having the duty to provide certain capabilities, which are practical or real opportunities, at an appropriate threshold level for each. Thus, the CRPD and the Capabilities Approach both aim at State measures to empower individuals regardless of their own abilities and therefore seem to fit together well. Furthermore, the Capabilities Approach is interesting because it has much influence in contemporary international human rights policies. Sen and Nussbaum developed the Capabilities Ap-

proach in response to the inadequacy of traditional approaches to welfare economics, which focused exclusively on GNP growth and income deprivation. And their criticisms have had a significant impact. The United Nations Human Development Index (HDI), a popular measurement for development used in the annual UN Human Development Reports, relies heavily on the Capabilities Approach.[1] Here, development is evaluated not only by advances in national income as it is traditionally done, but by improvements in human well-being which are captured in life expectancy, education and income.

This chapter investigates whether the Capabilities Approach provides a theoretical framework that can be a basis for the requirements set forth in the CRPD. I will first introduce the Capabilities Approach and its central features.[2] The second part examines disability within the Capabilities Approach. It concludes that the Capabilities Approach and the social model of disability share the same understanding of disability. In the third part, I argue that the Capabilities Approach supports the requirements set out in the CRPD and thus provides its philosophical foundation. However, the Capabilities Approach does not provide much guidance for the implementation of the CRPD with regard to setting priorities between and within the various rights. But such guidance *is* needed, if for no other reason because the implementation of the Convention obviously will take some time. In the meantime, rights need to be balanced within the normative theory if the ethical framework is to be not only meaningful but also workable.

[1] United Nations Development Programme (UNDP), "Origins of the Approach," 2010, http://hdr.undp.org/en/humandev/origins/.

[2] Whereas Amartya Sen mainly applied the Capabilities Approach in economics, Martha Nussbaum extends it to an application in feminist and disability ethics and wants to provide a philosophical justification (M.C. Nussbaum, *Frontiers of Justice,* (Cambridge: Harvard University Press, 2006), 70). Therefore, I will concentrate on Nussbaum's thoughts.

2 The Capabilities Approach

Criticism of John Rawls's understanding of justice provides the starting point for the development of Nussbaum's version of the Capabilities Approach, which Nussbaum sees as "an extension or complement to Rawls's theory".[3] Crucial is Rawls's idea of a society of free and independent citizens who are fully cooperating members of society over a complete life. Sen and Nussbaum refute that understanding.[4] Basically, they claim instead that individuals have varying needs for resources and varying abilities to convert resources into functioning.[5] The Capabilities Approach aims to include all members of a society.[6] It argues that it is not equality of resources or the equality of satisfaction that is fundamental, but equality of capabilities. Capabilities are defined as "what people are able to do and to be",[7] thus their practical, real opportunities and liberties. Capabilities should not be conflated with functionings. Lorella Terzi explains:

> Functionings are the beings and doings that individuals have reason to value. Walking, reading, being well nourished, being educated, having self-respect or acting in one's political capacity are all examples of functionings. Capabilities are the real opportunities and freedoms people have to achieve these valued functionings.[8]

But why should we aim for equality of capabilities?

---

[3] Nussbaum, ibidem, 69.
[4] Ibidem, 98.
[5] Ibidem, 164-165.
[6] S. Graumann, *Assistierte Freiheit: Von einer Behindertenpolitik der Wohltätigkeit zu einer Politik der Menschenrechte*, (Utrecht: Publications of the Department of Philosophy Utrecht University, 2009), 119. Revised version Frankfurt a.M.: Campus, 2011.
[7] M.C. Nussbaum, *Women and Human Development*, (Cambridge: Cambridge University Press, 2001), 5.
[8] L. Terzi, "Beyond the Dilemma of Difference: The Capability Approach to Disability and Special Educational Needs," *Journal of Philosophy of Education* 39(2005): 449.

Nussbaum starts with the idea of a life that is in accordance with human dignity, a life that has "truly human functioning" available in it.[9] Thus, certain functions are central in human life and there is something it is to do these functions in a truly human way. Her conception of the person, Nussbaum argues, is primarily Aristotelian rather than Kantian, because she sees a person as both capable – this refers to the capabilities for those functions – and needy – because she is in need of support for the development of central functions.[10] Yet Nussbaum also takes up the Kantian notion of seeing each and every person as an end.[11] Therefore, a legitimate claim for the development of capabilities exists because of the "bare minimum of what respect for human dignity requires".[12] From this essential worth follows their moral importance.[13] Nussbaum herself sums up this idea as follow: "Capabilities are understood as ways of realizing a life with human dignity in the different areas of life with which human beings typically engage".[14] It can obviously be debated in how far this justification is convincing and sufficient. Does it really justify the moral importance of the capabilities? And what is "human functioning"? What does it involve? These considerations should be left aside for now, but I will return to them later on. Nussbaum gives us a list of capabilities that need to be supported. She hopes that her list can be the object of an overlapping consensus in the Rawlsian sense.[15] Accordingly, the list is open-ended and therefore subject to discussion and change. Indeed, it has already been

[9] Nussbaum, *Frontiers of Justice*, 180.
[10] M.C. Nussbaum, "Capabilities as Fundamental Entitlements: Sen and Social Justice," *Feminist Economics* 9(2003): 54.
[11] Nussbaum, *Frontiers of Justice*, 70.
[12] Idem.
[13] M. Düwell, "Needs, Capacities and Morality: On Problems of the Liberal in Dealing with the Life Sciences," in *The Contingent Nature of Life*, edited by M. Düwell, C. Rehmann-Sutter, and D. Mieth, (Dordrecht: Springer, 2008), 126.
[14] Nussbaum, *Frontiers of Justice*, 161.
[15] Ibid, 70. Here, earlier normative justifications refer to Aristotle and his understanding of what human flourishing contains. See also the section below entitled "Universal Relevance".

modified since it was first introduced.[16] The current version contains capabilities in the following key areas:

- Life
- Bodily health
- Bodily integrity
- Senses, imaginations and thought
- Emotions
- Practical reason
- Affiliation (both personal and political)
- Other species
- Play
- Control over one's environment (both material and social)[17]

I will now briefly mention several features of the Capabilities Approach that are relevant for the subsequent discussion of the applicability of the Capabilities Approach to the CRPD, i.e. in how far the Capabilites Approach can provide a basis for the CRPD.

2.1 Universal Relevance

Nussbaum explicitly claims that her list of capabilities has universal application. People might "have very different comprehensive conceptions of the good,"[18] but the capabilities are important for everyone. According to Nussbaum the underlying human needs are universal, they do not depend on culture, tradition or local circumstances. As components of human nature they have no metaphysical grounding. In her view, and as I said above, the list represents an overlapping consensus in the Rawlsian sense. Thus, Nussbaum rejects cultural relativism at this point. Yvonne Denier explains that the items on the list are therefore defined in an abstract and general

[16] Y. Denier, *Efficiency, Justice and Care*, (Dordrecht: Springer, 2007), 180 footnote 100.
[17] M.C. Nussbaum, "Human Rights and Human Capabilities," *Harvard Human Rights Journal* 20(2007): 23-24.
[18] Nussbaum, *Frontiers of Justice*, 5.

way. It leaves room for specifications and it is appropriate that different nations specify them differently in accordance with their background.[19]

2.2 Capabilities Instead of Functionings

It is important to point out that capability, not actual functioning is the appropriate political goal. People should be left free to make their own choices as to what they would like to do with the provided real opportunities and whether they would actually like to realize a functioning or not. As Nussbaum explains, allowing choice in these matters is an aspect of respect for human dignity.[20] Thus, the Capabilities Approach "seeks to provide individuals with the means through which to develop their potential regardless of whether targeted recipients of resources elect to use them."[21] There are still some choices to be made; the Capabilities Approach does not dictate how to lead a flourishing life and thus shows regard for human agency.[22]

2.3 A Minimum Account of Justice

It is important to keep in mind that the Capabilities Approach is a partial and not a complete theory of justice. The ten capabilities on Nussbaum's list represent a minimum standard of justice. This

---

[19] Denier, *Efficiency, Justice and Care*, 183.
[20] Nussbaum, *Frontiers of Justice*, 186.
[21] M.A. Stein and P. Stein, "Beyond Disability Civil Rights," *Hastings Law Journal* 58(2006): 1216.
[22] Nevertheless, in earlier writings, Nussbaum has developed an idea about how to lead a flourishing life. It is clear for her "that functionings, not simply capabilities, are what render a life fully human in the sense that if there were no functioning of any kind we could hardly applaud it" (Nussbaum, *Women and Human Development*, 87). Furthermore, there are actually some cases where functioning is the appropriate goal: in the area of self-respect and dignity and for children even in all areas (Nussbaum, *Frontiers of Justice*, 172). The reason for this is that a functioning is crucial to attain and maintain other capabilities here (Nussbaum, *Women and Human Development*, 92). For instance, health care for children must be compulsory to enable them to have certain other capabilities later on in life.

means that these are basic entitlements such that, without providing each and all of them, a society cannot lay claim to justice.[23] Hence, if a society neglects only one of those capabilities, let us say the capability of emotion, this society is not a just one. All capabilities are on an equal standing and there is no lexical or other ordering among them.[24] All of them need to be provided at or above the threshold level where a flourishing human life becomes possible. How exactly this threshold is chosen does not become clear. Nussbaum only explains that it is determined by an intuitive and rough selection.[25] This is the decent social minimum, which answers the crucial question whether a society is just or not. Yet it says nothing about how to treat inequalities above the threshold level.[26] Indeed, the theory is compatible with several different distributions above the threshold, as Nussbaum herself admits.[27]

2.4 Relation to Human Rights

The Capabilities Approach refers to justice to claim the provision of the social basis of various capabilities. Thereby, it reminds strongly of human rights claims. Nussbaum herself views the Capabilities Approach as "one species of a human rights approach"[28], because capabilities "have a very close relationship to human rights".[29] The concept of human rights, she argues, is not a clear concept, and the best way of thinking about what it is to secure a right is to think in terms of capabilities.[30] Rights are thus claims to the development of capabilities.[31] On this view the two concepts are closely interrelated.

---

[23] Denier, *Efficiency, Justice and Care*, 180.
[24] Nussbaum, *Women and Human Development*, 12.
[25] Nussbaum, *Frontiers of Justice*, 181.
[26] M.C. Nussbaum, "Capabilities and Disabilities," (presented at Cognitive Disability: A Challenge to Moral Philosophy, New York, September 18, 2008), 75.
[27] Nussbaum, *Women and Human Development*, 12.
[28] Nussbaum, *Frontiers of Justice*, 78.
[29] Nussbaum, *Women and Human Development*, 97.
[30] Nussbaum, "Capabilities as Fundamental Entitlements: Sen and Social Justice," 37.
[31] Graumann, *Assistierte Freiheit*, 134.

The Capabilities Approach can even be seen as further specifying the abstract content of human rights.[32]

Furthermore, the Capabilities Approach incorporates negative and positive rights and does not even make a difference between civil and political rights on the one hand and economic, social and cultural rights on the other hand. "All rights," Nussbaum explains, "have material and social preconditions, and all require government action."[33]

3 Disability within the Capabilities Approach

What does the Capabilities Approach teach us for our understanding of disability? The Capabilities Approach provides already a good starting point from which to analyze disability: it presumes the idea that a society does not consist of independent citizens with the same needs and abilities. In social contract theories, the contracting agents are typically imagined as free, equal and independent with some sort of idealized rationality. Physical and mental impairment can therefore be taken into account only as an afterthought. This is what the Capabilities Approach aims to avoid. It takes the special position of disabled people into account by acknowledging that people differ in their needs for resources and their abilities to convert resources into functioning.[34] As we have seen, the Capabilities Approach views the state as having the duty to provide the social basis of the ten capabilities at an appropriate threshold level for each. In light of this, how much an individual needs in order to reach the threshold of the capability might differ from person to person. An individual who needs more resources to attain a certain capability also has a legitimate claim to the development of that capability. What matters for justice is the outcome of reaching the threshold of that capability, not the resources needed to do so. Thus, the applica-

[32] Stein and Stein, "Beyond Disability Civil Rights," 1216.
[33] Nussbaum, "Human Rights and Human Capabilities," 21.
[34] Nussbaum, *Frontiers of Justice*, 164-165.

tion to disability issues is straightforward: for instance, capability number 10, control over one's environment, includes "being able to participate effectively in political choices that govern one's life".[35] In our current society, this might already be possible for a person without impairments simply with the established range of protections against infringements of the realization of one's freedom, like non-interference with public discussions and so forth. However, a person who is not able to see might currently need active governmental support that is not always provided at the moment like for instance information material in Braille and special voting machines to reach the same threshold level of that capability as a person who is able to see. Thereby, the "relevant question to ask is not how much money individuals with impairments have, but what are they actually able to do and to be".[36] The Capabilities Approach acknowledges varying needs of resources, as a person with an impairment might not be able to do many things that a person without impairments can do, with the same resources.

This idea establishes a strong link to the social model of disability.[37] According to the social model, disability results from impairment in interaction with the environment. Therefore, it is the environment together with an impairment that disables a person and not the person who is disabled per se. The Capabilities Approach declares now that the State is "at 'fault' if certain groups are systematically prevented from attaining (...) full functioning".[38] Carolyn Baylies states further: "To this degree, the Capabilities Approach can become a powerful complement to a human rights approach and a social model of disability."[39] How is this to be understood?

Within the Capabilities Approach, an impairment simply becomes one characteristic among many which interacts with the social, economic and physical environment to produce a profile of advantage

---

[35] Nussbaum, "Human Rights and Human Capabilities," 24.
[36] Nussbaum, *Frontiers of Justice*, 168.
[37] Terzi, "Beyond the Dilemma of Difference," 451-452.
[38] C. Baylies, "Disability and the Notion of Human Development: Questions of Rights and Capabilities," *Disability & Society* 17(2002): 735.
[39] Idem.

or in this case probably rather of disadvantage for an individual.[40] It is now the obligation of the State to compensate for this and provide the social basis for the capabilities to the same threshold for persons with impairments as well as for everyone else. If this does not happen, a person with impairment becomes disabled due to (unjust) social arrangements and environments. Disability is thus an (unjust) lack of capability.[41] This is in agreement with the social model of disability. Hence, the Capabilities Approach and the social model of disability share the same understanding of disability.

3.1 A Lower Threshold: Are All Disabled People Included?

Yet even though the social model of disability and Nussbaum's Capabilities Approach seem to fit together well, some have criticized Nussbaum for actually not including all people with disabilities in her theory. Instead, she excludes citizens with certain severe impairments, which leads to strong criticism of her theory.[42] Michael Ashley Stein for example argues:

> However, because her [Nussbaum's] scheme requires levels of minimal function as a condition precedent to acknowledging an individual's equal humanity and social participation, it is fundamentally under-inclusive of some people with intellectual disabilities, conditions the inclusion of others through proxies, and inadequately accounts for the development of individual talent.[43]

---

[40] T. Burchardt, "Capabilities and Disability: The Capabilities Framework and the Social Model of Disability," *Disability & Society* 19(2004): 746; S. Mitra, "The Capability Approach and Disability," *Journal of Disability Policy Studies* 16(2006): 241.
[41] J.-L. Dubois and J.-F. Trani, "Extending the Capability Paradigm to Address the Complexity of Disability," *European Journal of Disability Research* 3(2009): 198.
[42] Baylies, "Disability and the Notion of Human Development"; M. A. Stein, "Disability Human Rights," *California Law Review* 95(2007): 75; Stein and Stein, "Beyond Disability Civil Rights".
[43] Stein, "Disability Human Rights," 94.

What is Nussbaum's argumentation? As we have seen, Nussbaum establishes a threshold up to which the State has to provide the social basis for the ten capabilities. Yet besides this high threshold, she also argues for a lower one and if individuals do not reach this low threshold, they do not have to be treated according to the framework of the Capabilities Approach. She explains:

> among the many actual features of a characteristic human form of life, we select some that seem so normatively fundamental that a life without any possibility at all of exercising one of them, at any level, is not a fully human life, a life worthy of human dignity, even if the others are present. If enough of them are impossible (...), we may judge that the life is not a human life at all.[44]

How the selection of those prerequisites that characterize a life "worthy of human dignity" happens, is not clear. She selects functions that she sees as essential because engaging in them is a uniquely human, as opposed to animal or mechanical, mode of existence.[45] This process of selection seems to resemble the "intuitive and rough" selection of the higher threshold (see above) and as Graumann acknowledges correctly, Nussbaum's interpretation of a fully human life seems to be somewhat arbitrary.[46] A human mode of functioning involves for Nussbaum "the availability of both practical reason and affiliation"[47] or in later writings "possibilities of thought, perception, attachment, and so on".[48] She mentions counterexamples of anencephaly, persons in a persistent vegetative state or with severe forms of mental disability or senile dementia.[49] In earlier writings, she also includes "an absence of mobility so severe that it makes speech, as well as movement from place to place, im-

[44] Nussbaum, *Frontiers of Justice*, 181.
[45] Stein, "Disability Human Rights," 99.
[46] Graumann, *Assistierte Freiheit*, 137.
[47] Nussbaum, *Women and Human Development*, 82.
[48] Nussbaum, *Frontiers of Justice*, 181.
[49] Idem.

possible".[50] This is surprising because she also attributes some sort of moral standing to animals and states this even in the same book. She explains:

> if a creature has *either* the capacity for pleasure and pain *or* the capacity for movement from place to place *or* the capacity for emotion and affiliation *or* the capacity for reasoning, and so forth, (we might add play, tool use, and others), then that creature has a moral standing.[51]

Thus, animals quite easily obtain a moral standing whereas criteria for a dignified human life are more difficult to fulfill. Thereby, it seems entirely unclear where those criteria come from. Moreover, it begs the question how normative implications are derived from these rather arbitrary criteria.

Importantly, Nussbaum never says how society should treat those who fall below this lower threshold. The state does not need to provide the social basis of the ten capabilities for them, but does this mean that they have no rights at all? How should we treat them? It is not at all clear what implications the (non-)attribution of some kind of dignity has.[52] This is a lacuna in Nussbaum's theory that has especially important implications for its applicability to disability issues. Furthermore, the idea of a lower threshold obviously subtly alters the Capabilities Approach, because a minimal level of functioning is now required to allow full participation.[53] It is ironic that Nussbaum thereby abandons her own explicit claim that she in-

---

[50] M.C. Nussbaum, "Human Capabilities, Female Human Beings," in *Women, Culture and Development: A Study of Human Capabilities*, edited by M.C. Nussbaum and J. Glover (Oxford: Clarendon Press, 1995), 82.

[51] Nussbaum, *Frontiers of Justice*, 362.

[52] This lack of clarity became also apparent in Nussbaum's barely helpful answer to the question whether apes should count in the way as human beings with disabilities do, which was raised after a speech she delivered. No, she explains, for an elephant it is not crucial to have a vote, it does not count for him, but for a human not to be treated as other humans is very serious (M. Bérubé and M.C. Nussbaum, "Question & Answer Session," presented at Cognitive Disability: A Challenge to Moral Philosophy, New York, September 18, 2008.) Obviously, this reply does not address the problem at all.

[53] Stein, "Disability Human Rights," 105.

cludes all members of a society. This claim was exactly the starting point of her critique of Rawls.[54]

At the same time, criticizing Nussbaum for being under-inclusive makes the assumption that all human beings have to be included in the same account of justice.[55] Especially if we assume that not including some of them might still make it possible to grant them certain rights, this assumption is disputable. Some severely disabled persons might have to be treated according to a different standard than the Capabilities Approach. We might for instance argue that it can be permissible to let a person with a very severe disability, who comes close to a persistent vegetative state, die by not treating pneumonia and thus acting according to a standard of beneficence. In other cases, where an otherwise healthy person is affected by pneumonia, this might not be permissible. It is difficult to argue for this distinction within the Capabilities Approach, which defends the capability of not dying prematurely.[56] I therefore wish, at this point, to refrain from joining in the criticism that Nussbaum is under-inclusive, and leave that point up for future discussion. Instead, I will now consider the applicability of the Capabilities Approach to the CRPD.

4 The CRPD in the Light of the Capabilities Approach

Like the CRPD, the Capabilities Approach adopts the social model of disability. Based on the understanding of impairment as one of many characteristic of a person, it is the duty of the state to provide the social basis for the ten capabilities up to an appropriate threshold level. This does not depend on the question of whether a person has an impairment, even though this might determine the resources

[54] Some argue that Rawls is actually more inclusive than Nussbaum (S. Wong, "The Moral Personhood of Individuals Labeled 'Mentally Retarded': A Rawlsian Response to Nussbaum," *Social Theory and Practice* 33(2007): 579-594; H. Richardson, "Rawlsian Social-Contract Theory and the Severely Disabled," *The Journal of Ethics* 10(2006): 419-462).
[55] Graumann, *Assistierte Freiheit*, 120.
[56] Nussbaum, "Human Rights and Human Capabilities," 23.

needed to reach the threshold level. Doing so is simply a matter of justice based on the dignity of a human being. The CRPD was developed in the same spirit. It applies the canon of human rights – which is also commonly based on dignity – to persons with disabilities in the understanding that the existing human rights instruments neglect their specific demands, that is, the additional resources needed. Thus, the CRPD does not want to establish new rights, it only aims at redefining the well-known human rights for persons with disabilities. It presupposes that these human rights are obviously valid for persons with impairments as well as for persons without impairments. Therefore, the state has additional obligations to make sure that human rights are also guaranteed for persons with impairments. Or, to speak in the language of the Capabilities Approach, the state must provide all the resources needed so that citizens with impairments can develop their capabilities up to the same threshold level as persons without impairments. According to the CRPD and the Capabilities Approach, a society is just if the state guarantees for all citizens the social basis of their capabilities, regardless of existing impairments.[57] The focus of justice is not on the question of what resources the state has to spend on every person, but on the question of what outcome is attained. Thus, the CRPD and the Capabilities Approach reach the same conclusions here. Up to this point, the Capabilities Approach can therefore provide an ethical justification of the requirements stated in the CRPD.

Let us go a step further. The CRPD lists a broad range of rights that should be implemented by states. As this implementation is challenging and expensive, some rights will be implemented later than others. Therefore, the question arises which rights should be assigned greater priority even though all rights need of course to be implemented in the long run. An ethical theory should be able to provide some normative guidance here as well. Otherwise, balancing the various rights will simply be a question of political negotiations. If the ethical framework is to be not only a meaningful but also a

[57] Graumann, *Assistierte Freiheit*, 126.

workable concept, this should be avoided. So, how does Nussbaum deal with this problem?

My analysis made clear that all capabilities have an equal standing instead of having a lexical ordering. Nussbaum says herself that she defends a partial rather than a complete theory of justice. The social basis of all of the ten capabilities has to be secured and none of the capabilities can be excluded in a just society. This is all that Nussbaum argues for. Therefore, the Capabilities Approach is only a minimum account of justice. All capabilities are considered to be of central relevance to social justice.[58] Nussbaum does not say anything about what should be done if a state cannot ensure all capabilities immediately at the same time. It is true that she acknowledges this problem, but this is all she has to say about it:

> In desperate circumstances, it may not be possible for a nation to secure them all up to the threshold level, but then it becomes a purely practical question what to do next, not a question of justice. The question of justice is already answered: justice has not been fully done here.[59]

However, even if it is the case that "justice has not been fully done", what should a state do? How can we answer the "purely practical question"? On this issue, Nussbaum is largely silent.

Perhaps it would be possible to draw on elements of the Capabilities Approach in order to set priorities among rights. For this, we have to think back to the foundation of the capabilities on Nussbaum's list. This foundation might tell us something about the normative ordering of the capabilities. If we understand what the capabilities are based on, we can understand how they can be prioritized in situations when not all can be fulfilled. I argued above that, on Nussbaum's view, the capabilities are simply essential for human existence and Nussbaum hopes that the list can be the subject of an overlapping consensus. I also argued that this foundation of the

[58] Nussbaum, "Capabilities as Fundamental Entitlements," 40.
[59] Nussbaum, *Frontiers of Justice*, 175.

capabilities leaves several questions open. The moral obligation to provide the social basis of the capabilities is not justified by this argumentation and the long list might not that easily be the subject of an overlapping consensus. "Realizing a life with human dignity" is not as clear a notion as Nussbaum believes. An unclear grounding of the capabilities also means that it is impossible to establish a hierarchy among the capabilities. Even an ordering that places the capability of playing below the capability of bodily integrity does not follow logically from her foundation of the capabilities. Ultimately, the Capabilities Approach remains completely silent facing the stepwise implementation of the CRPD.

5 Conclusion

I have argued that the Capabilities Approach does indeed provide an ethical justification in support of the moral authority of the requirements set forth in the CRPD. Those who are wondering how the various challenging provisions that the CRPD puts forward can be normatively justified might be well advised to have a look at the Capabilities Approach. Unfortunately, however, the Capabilities Approach does not provide much guidance for the implementation of the Convention, as it does not allow for a hierarchy of capabilities. Nussbaum's idea of bringing justice about immediately might be unrealistic; it certainly is not helpful at this point. Nussbaum herself points out that the Capabilities Approach might be hopelessly unrealistic and states that "[o]nly time and effort will answer that question".[60] Additionally, she admits that she refrains from challenges of realizing the Capabilities Approach: "I have not yet shown that the realization of justice as I construe it is possible".[61]

Where does this leave us now? To make sense of the CRPD, we are not only in need of an ethical justification that supports it, but also of some practical guidance to balance the various provisions in the

[60] Ibid., 140.
[61] Ibid., 414.

process of the stepwise implementation of the Convention. More precisely, at this point we are in need of a foundation of the capabilities that provides normative criteria that can be used to set priorities in practical situations. Nussbaum's Capabilities Approach does not convince at this point.

10 Setting the Agenda for Ethical Debates about the Rights of Persons with Disabilities

Marcus Düwell

1 Introduction

The UN Convention on the Rights of Persons with Disabilities (CRPD) articulates a great number of obligations that states have with regard to people with disabilities. In particular, the CRPD formulates a wide variety of provisions aimed at enabling people with disabilities to live an autonomous life. This includes, for example, potentially very expensive requirements concerning education and participation in public life. These requirements raise various questions about the scope of the human rights framework and its possible ethical justifications. In the following, I first discuss what an ethical theory able to justify the requirements of the CRPD would look like before turning to two contested questions in the context of this debate, namely, the problem of setting priorities between the different human rights and the issue of inclusion, that is, of extending human rights protections to all members of the "human family".[1] In the process, I propose some elements of an agenda for future ethical debates about the CRPD.

2 Is There an Ethical Justification for Rights of People with Disabilities?

I assume that the CRPD formulates rights for people with disabilities not as a special category of rights but as a special application of the general human rights framework to people with specific needs

[1] My thinking about these issues has been greatly inspired by discussions with Sigrid Graumann and especially by her book, *Assistierte Freiheit: Von einer Behindertenpolitik der Wohltätigkeit zu einer Politik der Menschenrechte* (Frankfurt am Main: Campus, 2011). In addition, I am grateful for debates about the topic with Joel Anderson, Jenny Goldschmidt, Caroline Harnacke, Jos Philips, and Jackie Leach Scully.

and vulnerabilities.[2] Furthermore, I assume that human rights are in the first place political provisions laid down in international law. However, these provisions claim a *moral authority* and states commit themselves to using political and legal power in correspondence with these provisions. To say that human rights claim moral authority is not to say that human rights are moral rights but it is to say that the human rights framework as such claims moral authority. This means that we act morally wrongly if we do not respect this framework. This moral authority is in need of justification and such a justification cannot be given with the means of international law. Since there are moral claims behind the CRPD, an ethical justification is needed.[3] This raises the question of what kind of ethical theory would support the requirements of the CRPD. To be clear about my aim here: I do not want to assess the validity of ethical theories by discussing to what extent they support or reject the CRPD but I want to understand what kind of normative justification would be needed in order to support the Convention. I will therefore discuss some features an ethical theory would have to have in order for it to be able to justify the moral claims underlying the CRPD.

First of all, such a theory would have to justify the relevant requirements as *rights*. This means that it would see the rights of the right-holders as reasons for some categorically binding moral obligations of other agents. By "categorical" moral obligations I mean obligations that have the feature of overriding all other possible practical obligations. Therefore, these obligations are not just any kind of value or ideal to which agents may be committed. The basic idea of the human rights regime is to provide a general normative framework that all political orders should respect; the requirements of human rights pretend to override all possible concurrent practical obligations. To deny this overriding nature of human rights is to

[2] Graumann, *Assistierte Freiheit*, 115-134.

[3] For an alternative reading of the relationship between the human rights regime and morality see C. Beitz, *On Human Rights*, (Oxford: Oxford University Press, 2009). See also, in this context: M. Düwell, "Human Dignity and Human Rights," in *Humiliation, Degradation, Dehumanization: Human Dignity Violated*, edited by P. Kaufmann, H. Kuch, C. Neuhäuser and E. Webster (Dordrecht: Springer, 2010), 215-230.

treat the acceptability of, say, genocide as, in principle, open to negotiation. Of course there may be conflicts of duties with regard to different human rights and it may be disputable whether the diverse rights are binding to the same degree (it seems to be implausible to regard the obligations correlative to the right to paid vacation as binding to the same degree as those correlating to basic rights). However, the human rights regime as such claims priority over other practical considerations. This understanding of "categorical obligations" seems to be a basic requirement for all theories that support human rights in general. That raises, for example, questions as to whether an ethics of care is a plausible ethical background theory for the human rights regime, since such theories often reject rights approaches in general. Similar questions could be asked with regard to utilitarianism.

Secondly, an ethical theory that would be able to justify the moral claim underlying the CRPD would have to include a broad range of positive rights, meaning rights of rights-holders to be supported in the development and fulfilment of basic needs. That requires a theory of rights that includes not only protections of the right-holder against infringements of the realization of his freedom but also positive rights.[4]

Thirdly, the aim of the provisions is to enable the right-holder to *lead an autonomous life*. Since the CRPD defends the principle that people with specific needs should be supported in living an autonomous life, the Convention makes a necessary presupposition: the Convention must necessarily assume that human rights protect the possibility of living an autonomous life. If it is true that the CRPD has to assume the value of an autonomous life, then it is thereby incompatible with all theories that do not assume the moral priority of respect for the possibility of an autonomous life. That does not mean that we must accept the form of liberalism that assumes that all legitimate actions must be justified by the actual consensus of all

[4] Concerning this conceptual distinction cf. H. Shue, *Basic Rights: Subsistence, Affluence, and U.S. Foreign Policy*, (Princeton, NJ: Princeton University Press, 1980); A. Gewirth, *The Community of Rights*, (Chicago: University of Chicago Press, 1996), 36-70.

agents involved. But in any case, all restrictions of liberties would have to be justified on the basis of what is required for enabling an autonomous life. This also leads to the question of what theory of rights is required here. In general, one can distinguish between *interest theories* and *will theories of rights*. Whereas will theories see rights as protecting the authority of the right-holder in his attempt to realize his freedom, interest theories see rights as supporting certain (basic) interests of the right-holder. Because the CRPD focuses so strongly on the empowerment to an autonomous life of the right-holder, a will theory seems to be more compatible with it. But I do not want to take a stance here regarding the extent to which these theories are mutually exclusive.

Fourthly, an adequate theory would have to be *inclusive* in the sense that all human beings would be included in the protection of human rights, independent of their specific capacities. The general debate about rights of people with disabilities has focused centrally on this aspect. Very often contract theories and Kantian theories, in particular, are criticized for allegedly excluding human beings who lack specific basic rational capacities.[5] However, it is highly doubtful whether this criticism is valid.[6]

Fifthly, an adequate theory should not justify human rights in terms of *mutual advantages between contracting parties*. All theories that consider rights as contractual rights would have a problem with the fact that a significant group of people with disabilities would not be able to do something to the advantage of others. A counterargument could be that all of us could come in a situation to be disabled and dependent and therefore it would be in our mutual interest to be protected in such a situation. But such a strategy would at least make it doubtful whether the whole scope of protection should be granted as a human right. Someone could argue: I may have a risk to be dependent and disabled when I am old but I have no risk to have particular genetic disorders (I can be sure about

[5] E.g. M. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership*, (Cambridge MA: Harvard University Press, 2007), 96-154.

[6] See: M. Düwell, *Bioethics: Methods, Theories, Areas*, (London: Routledge, 2012, in press), ch. III.1

that). So, it is not in my strategic interest to demonstrate solidarity with all those disabilities based on genetic disorders.

Sixthly, it seems necessary for an adequate theory to offer some guidance with regard to the priorities within the rights.[7] As the CRPD broadens the scope of rights significantly, and the realization of some rights could be extremely expensive (e.g. the right to education and public participation of people with some rare disabilities), there must be a way to balance and weigh these rights with other rights; otherwise the human rights-framework would turn out to be unworkable. Here, it seems necessary to ask for a systematic justification of these priorities as it is not at all plausible to think of human rights as categorical if the priority-setting would merely be an ad hoc activity carried out in political negotiations. There may be different strategies to justify priorities but in order to defend the categorical status of human rights, it is necessary to determine the content of these rights in a non-arbitrary way.

I do not claim that these requirements are compatible with each other and I do not claim that the list of requirements is comprehensive. There are other questions to be discussed, such as: who should bear the corresponding duties? and, what is the role of the state in this context? However, I consider these six requirements as especially challenging for the discussion of how human rights fundamentally are to be understood. Therefore, they should be high on the agenda of the ethical discourse. This means that, if an ethical theory is to provide support for the CRPD, it must (1) provide a justification of rights as categorically binding requirements for morally justified action, (2) be inclusive, (3) entail positive and negative rights, (4) consider the real opportunity for an autonomous life to be the aim of a system of rights, and (5) provide a criterion for setting priorities among the relevant rights. Furthermore one would expect that a theory of human dignity that assumes the inherent worth of each individual would be the strongest candidate for the justification of these rights, because it can grant these rights without the relying on contractarian presuppositions, according to which the reason we

[7] In this regard, cf. the contribution of J. Philips in this volume.

must fulfil our duties is, ultimately, mutual advantage. If the rights granted to people with disabilities are considered to be categorically obligating, it has to be assumed that there are obligations to provide people with disabilities (as far as we are able to do so) with the means they need to live a life of their own, regardless of their ability to give something back. A justification for this claim would need to presuppose that they have an inherent worth that justifies our having this obligation towards them. For this moral status, the human rights framework uses the term human dignity.

3 Rights for Persons with Disabilities: Contested Questions

In this context I will limit myself to two contested questions: the problem of *priorities within the human rights-framework* and the problem of *inclusion*.

The *priority-problem* arises with special force for the CRPD because of the extent of positive rights that are laid down in the Convention. People with disabilities have far-reaching claim-rights to support in the domains of education, participation in public life, and assistance in daily tasks. To fulfil these rights is not trivial even within affluent Western societies, let alone in poorer countries. This raises the question of how we can set priorities within human rights. Is this only a matter of political negotiations? Is it a problem if different countries set different priorities? Or do we need more systematic criteria for appropriate priorities – and where could we find them? These questions challenge our understanding of the human rights framework as such. It is scarcely convincing to consider human rights to be categorically obligatory sources of duties that outweigh other practical considerations and yet, at the same time, to leave open the question of which rights are more urgently in need of implementation than others. The broader the human rights framework is and the more rights are laid down in the framework, the more pressing the problem of setting priorities will be. If there are no systematic criteria, states can simply decide for themselves whether they prefer to attend to liberty rights or welfare rights, whether they will give priority to education of children or assist people with sensory impairments, and so on. Of course it is not unu-

sual for political debates to have some "values" or "principles" that are subject to political negotiation. But it is conceptually confusing to call those values "rights" since "rights" are claims or entitlements that have the central feature that their openness to negotiation is limited. If we view human rights not only as political declarations but if we regard ourselves, from a moral perspective, as categorically obliged to respect these rights, then the problem becomes even more pressing: one cannot justify the claim that we have a categorical obligation to respect human rights if the content of the rights is just a matter of negotiations. Any convincing ethical justification of the human rights-framework will therefore have to offer some criteria for setting priorities within these rights.

In the present context, two possible strategies can be singled out: one might argue for a priority of negative liberty rights, which would be considered as always and indispensably obliging, while positive rights would be seen as political ideals whose fulfilment is much less obligatory. The priorities would then be to guarantee, first, the fulfilment of negative liberty rights and then, as resources allow, the fulfilment of positive rights. The implication would be that the most of the provisions of the CRPD would have a low priority on the morally obligatory political agenda. An alternative view would be as follows. Human rights protect the possibility of an autonomous life for everybody (as the CRPD assumes), and the priorities among human rights then depend on the urgency of the goods that are protected by the right in question. If we assume that A and B have the same status in the rights-framework and if A needs X more urgently than B needs Y in order to live an autonomous life, then X has priority over Y. Even if it may be difficult to compare the need and urgency in various concrete circumstances, it seems obvious that the criterion "urgency for the possibility of living an autonomous life" leads to a different hierarchy within the rights than the criterion "negative rights before positive rights". This is only an illustration of possible solutions to this problem. The problem would have to be discussed in detail for the CRPD and its status within the human rights-framework.

The *second* problem is whether human rights are *inclusive* with regard to all human beings. There is a fundamental tension in this

regard within the human rights framework. On the one hand, human rights are granted to all "members of the human family". On the other hand, if the aim of human rights is to enable human beings to lead an autonomous life that presupposes some basic capacities that not all "members of the human family" have. Now this tension becomes especially pressing in the context of the CRPD, especially in the case of people with severe mental impairments. There are several ways resolving this tension. The first option would be simply to take membership in the "human family" as the justificatory reason for granting human rights and to avoid referring to the possibility of leading an autonomous life. However, this would raise the question as to why we should grant rights to all human beings. The obvious criticism would be that this is "speciesistic": ascribing rights to certain beings merely because they are member of a specific biological species would be a morally unjustified prejudice. Peter Singer has famously criticized the mainstream of traditional morality for being biased by such a speciesistic prejudice. According to Singer speciesism is comparable to racism: the racist gives moral priority to protecting the interests of the members of his own race and in a similar way the speciesist gives priority to the protection of the interests of his own species. According to Singer, however, "membership in a biological species" is not a morally relevant feature – any more than skin-colour, height, weight, sex, or hair-colour is.[8] Instead, he argues, we should respect the interests of all beings equally, which means that the necessary prerequisite for being morally respected is the ability to have interests.

The term "speciesism" always characterizes a moral fallacy. However, it is safe to say that in the tradition of justifying the specific dignity of human beings, hardly anyone has used membership in the biological species as a justificatory reason for ascribing human dignity: there were always references to, for example, the will of the creator or specific human capacities (rationality, agency, personhood) that have been used as justifications for a specific status of human beings. Those justifications may or may not valid. They are

[8] P. Singer, *Practical Ethics*, (Cambridge: Cambridge University Press, 1993, 2nd ed.).

not, in any case, speciesistic – if speciesism refers to the obvious fallacy in moral reasoning that Singer has in mind. Only if we derive the moral status of human beings from their membership in a specific biological species can we be accused of this fallacy. For all other forms of justification, one would have to show that they are wrong and it would have to be demonstrated that Singer's egalitarian view provides a better justification. Thus far, Singer hasn't shown this.[9]

If we abstract from the debate about the very specific position of Singer, we can say more generally that there is a fundamental tension here: all reasons we could think of as justifying a specific moral status will be properties like "being rational", "being a person" or "being created in the image of god". What is unclear is how any of these features could be empirically determined. It is obvious that "being created in the image of god" is not an empirical property. But the same holds for properties such as rationality or freedom. There are of course countless theories about the nature of these concepts. However, note that for the very activity of forming theories about rationality or personhood – or of empirically testing a hypothesis – we must already presuppose that we have the capacity of rationality and that we have the free will to pursue those activities. Hence, if we must presuppose rationality and freedom as a condition for the possibility of conceptualizing them, this would mean that those properties are not just empirical properties but that they are prior to the possibility of conceptualizing them. That means that it is problematic to give those characteristics the status of empirical properties. We cannot assess our rationality in the same empirical way we can assess our vision. We can, of course, describe an individual's behaviour as an expression of personal capacities. We can also identify those biological features that are necessary for the development of specific personal capacities. But that does not mean that we can test rationality, freedom and personhood as such empirically. However, if rationality and freedom are not empirical properties, there is a

[9] For a detailed criticism of Peter Singer, see: M. Düwell, "Philosophical Presuppositions of Practical Ethics," in *Singer under Fire: The Dangerous Ethicist Faces His Critics*, edited by J. Schaler, (Chicago & La Salle: Open Court, 2009), 395-419.

fundamental problem here: the ascription of dignity and rights has to happen in the empirical world. There must be empirical criteria if rights are to be ascribed, otherwise institutions (such as states, the police, and judges) will be unable to determine whether the conditions have been met that are required for granting the status of a right-holder. This means that the justification for granting dignity and rights must be based on morally significant, non-empirical features, even though the criteria of application must make reference to empirically measurable properties. This fundamental tension is a pressing issue for human rights theory and any reference to species-membership as a criterion (not a justificatory reason) for the application of rights should be interpreted in the context of this tension between, on the one hand, the need to offer a non-empirical justificatory criterion (in order to justify the specific moral status of right-holders) and, on the other hand, the need to find publicly observable criteria that are applicable in concrete regulatory contexts.

This brief discussion only hints at how to interpret this fundamental problem, and it is important to add that these considerations also have profound implications for issues regarding the beginning and end of life. While in earlier times we could just speak about humanity in the sense of a value concept that at the same time would be applied to all members of the species homo sapiens, there are more and more cases on the borderline of human existence where the status of human beings is unclear, for example in coma or brain death or with regard to human embryos etc. In all those cases the personal features that characterize human beings and their existence as biologically human do not coincide. As the CRPD make particularly obvious, there is a need for further analysis.[10]

My primary aim here, in sketching some intellectual challenges posed by the CRPD, has been to demonstrate that debates about rights of people with disabilities confront us not only with regulatory and implementation problems but that they challenge our understanding of the human rights framework in such a way as to make a debate about the moral basis of this framework unavoidable.

[10] See: M. Düwell, *Bioethics: Methods, Theories, Areas.*

Bibliography

List of Conventions, Treaties and other International Instruments

The Universal Declaration of Human Rights (adopted 10 December 1948 by the United Nations General Assembly, Resolution 217 A(III))

International Convention on the Elimination of All Forms of Racial Discrimination (adopted 7 March 1966, entered into force 4 January 1969) 660 UNTS 195.

International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3.

International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171.

Convention on the Elimination of All Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13.

Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (adopted 10 December 1984, entered into force 26 June 1987) 1465 UNTS 113.

Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 44.

International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (adopted 18 December 1990, entered into force 1 July 2003) 2220 UNTS 93.

Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 70.

Optional Protocol to the Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) GA Res. A/RES/61/106 (13 December 2006).

International Convention for the Protection of All Persons from Enforced Disappearance (adopted 20 December 2006, entered into force 23 December 2010) GA Res. A/RES/61/177 (2007).

References

Aichele, V., "Die UN-Behindertenrechtskonvention und ihr Fakultativprotokoll: Ein Beitrag zur Ratifikationsdebatte," (Berlin: Deutsches Institut für Menschenrechte, 2008).

Anderson, E. and R. Pildes, "Expressive Theories of Law: A General Statement," *University of Pennsylvania Law Review* 148(2000): 1503–1575.

Anderson, J. and R. Claassen, "Sailing Alone: Teenage Autonomy, Parental Supervision, and Regimes of Childhood," *Law and Philosophy* 31(2012): 495-522.

Anderson, J., "Autonomy," in *International Encyclopedia of Ethics*, edited by H. LaFollette, (Oxford: Blackwell, 2013).

Appelbaum, P.S., R.J. Bonnie, and J.H. Karlawish, "The Capacity to Vote of Persons with Alzheimer's Disease," *American Journal of Psychiatry* 162(2005): 2094-2100.

Arnardóttir, O.M. Oddný, and G. Quinn, "A Future of Multidimensional Disadvantage Equality?," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* edited by O.M. Arnardóttir and G. Quinn (Leiden: Martinus Nijhoff, 2009), 41-66.

Arneson, R., "The End of Welfare As We Know It? Scanlon vs. Welfarist Consequentialism," *Social Theory and Practice* 28(2002): 315-336.

Barnes, C., "The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists?," in *The Disability Reader: Social Science Perspectives*, edited by T. Shakespeare, (London: Cassell, 1998), 65-78.

Baylies, C., "Disability and the Notion of Human Development: Questions of Rights and Capabilities," *Disability & Society* 17(2002): 725–739.

Beitz, C., *The Idea of Human Rights*, (Oxford: Oxford University Press, 2009).

Benhabib, S., *The Rights of Others: Aliens, Residents and Citizens*, (Cambridge: Cambridge University Press, 2004).

———, "Ein anderer Universalismus: Einheit und Vielfalt der Menschenrechte," *Deutsche Zeitschrift für Philosophie* 55(2007), 501–519.

Bérubé, M. and M.C. Nussbaum, "Question & Answer Session," presented at Cognitive Disability: A Challenge to Moral Philosophy, New York, September 18, 2008.

Beyleveld, D. and R. Brownsword, *Human Dignity in Bioethics and Biolaw*, (Oxford: Oxford University Press, 2001).

Bielefeldt, H., "Diskriminierungsschutz als menschenrechtliche Verpflichtung," (Berlin: Deutsches Institut für Menschenrechte, 2005).

———, "Zum Innovationspotential der UN-Behindertenrechtskonvention," (Berlin: Deutsches Institut für Menschenrechte, 2009).

Blais, A., L. Massicotte, and A. Yoshinaka, "Deciding Who Has the Right to Vote: A Comparative Analysis of Election Laws," *Electoral Studies* 20(2001): 41–62.

Boerefijn, I. and J. Oyediran, "Article 20 of the International Covenant on Civil and Political Rights," in *Striking a Balance: Hate Speech, Freedom of Expression and Non-Discrimination*, edited by S. Coliver, (Essex: Article 19 International Centre Against Censorship, Human Rights Centre University of Essex, 1992).

Bourdieu, P., *Outline of a Theory of Practice*, (Cambridge: Cambridge University Press, 1977).

Bowen, J., "The Americans with Disabilities Act and Its Application to Sport," *Journal of the Philosophy of Sport* 29 (2002): 66–74.

Brennan, J., *The Ethics of Voting*, (Princeton: Princeton University Press, 2011).

Brown, R.S. and D.J. O'Rourke, editors, *Case Studies in Sport Communication*, (Westport Conn.: Praeger, 2000).

Burchardt, T., "Capabilities and Disability: The Capabilities Framework and the Social Model of Disability," *Disability & Society* 19(2004): 735–751.

Campbell, J. and M. Oliver, *Disability Politics: Understanding Our Past, Changing Our Future*, (London: Routledge, 1996).

Chouliaraki, L. and N. Fairclough, *Discourse in Late Modernity: Rethinking Critical Discourse Analysis*, (Edinburgh: Edinburgh University Press, 1999).

Daes, E.-I.A., *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder*, (New York: United Nations, 1986).

Davis, D., "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27(1997): 7-15.

Degener, T., "International Disability Law – A New Legal Subject on the Rise: The Interregional Experts' Meeting in Hong Kong, December 13-17, 1999," *Berkeley Journal of International Law* 18(2000): 180-195.

———, "Die UN-Konvention: Menschenrechtsschutz für behinderte Menschen," (presented at Fachtagung NW Art. 3 / DGRW / IMEW, Berlin, Januar 14, 2010).

———, "The Right to Political Participation in Context of Disability (Art. 29 CRPD)," Opening Statement to the Fourth Interactive Debate on the Rights of Persons with Disabilities (19th Session of the Human Rights Council, March 1, 2012), <https://extranet.-ohchr.org/sites/hrc/HRCSessions/RegularSessions/19thSession/OralStatements/CRPD%20Committee.pdf>

Degener, T. and G. Quinn, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, (New York and Geneva: United Nations, 2002).

Denier, Y., *Efficiency, Justice and Care*, (Dordrecht: Springer, 2007).

Despouy, L., *Human Rights and Disabled Persons*, (New York: United Nations Economic and Social Council, Commission on Human Rights, 1993).

Donnelly, J., *Universal Human Rights in Theory and Practice*, (New York: Cornell University Press, 2003).

Doe v. Rowe, 156 F.Supp.2d 35, U.S. District Court, Maine, 2001.

Dubois, J.-L. and J.-F. Trani, "Extending the Capability Paradigm to Address the Complexity of Disability," *European Journal of Disability Research* 3(2009): 192–218.

Düwell, M., "Needs, Capacities and Morality: On Problems of the Liberal in Dealing with the Life Sciences," In *The Contingent Nature of Life*, edited by M. Düwell, C. Rehmann-Sutter, and D. Mieth, (Dordrecht: Springer, 2008), 119-130.

———, "Philosophical Pressupositions of Practical Ethics," in *Singer under Fire: The Dangerous Ethicist Faces His Critics*, edited by J. Schaler (Chicago & La Salle: Open Court, 2009), 395-419.

———, "Human Dignity and Human Rights," in *Humiliation, Degradation, Dehumanization: Human Dignity Violated*, edited by P. Kaufmann, H. Kuch, C. Neuhäuser, and E. Webster. (Dordrecht: Springer, 2010), 215-230.

———, *Bioethics: Methods, Theories, Areas*, (New York/London: Routledge, 2012, in press).

Edelman, M., *The Symbolic Uses of Politics*, (Champaign etc.: University of Illinois Press, 1964, second edition, 1985).

Emery, S., T. Blankmeyer Burke, A. Middleton, R. Belk, and G. Turner, "Clause 14(4)(9) of Embryo Bill Should be Amended or Deleted," *British Medical Journal* 336(2008): 976.

Estlund, D., "Beyond Fairness and Deliberation: The Epistemic Dimension of Democratic Authority," in *Deliberative Democracy: Essays on Reason and Politics,* edited by W. Rehg and J. Bohman, (Cambridge, MA: MIT Press, 1997), 173-204.

European Commission for Democracy through Law (Venice Commission), *Code of Good Practice in Electoral Matters: Guidelines and Explanatory Report*, Council of Europe, CDL-AD (2002) 23 rev., adopted 19 October 2002.

Feinberg, J., "The Child's Right to an Open Future," in *Freedom and Fulfillment,* edited by J. Feinberg, (Princeton NJ: Princeton University Press, 1992), 76-97.

Flóvenz, B., "The Implementation of the UN Convention and the Development of Economical and Social Rights as Human Rights," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, edited by O.M. Arnardóttir and G. Quinn, (Leiden/Boston: Martinus Nijhoff, 2009), 257-278.

Fraser, N., "Social Justice in the Age of Identity Politics: Redistribution, Recognition, Participation," in N. Fraser and A. Honneth,

Redistribution or Recognition?: A Political-Philosophical Exchange, (London: Verso, 2003), 7-109.

Gewirth, A., *The Community of Rights*, (Chicago: University of Chicago Press, 1996).

———, "Duties to Fulfill the Human Rights of the Poor," in *Freedom from Poverty as a Human Right*, edited by T. Pogge, (Oxford: Oxford University Press, 2007), 219-236.

Graumann, S., *Assistierte Freiheit: Von einer Behindertenpolitik der Wohltätigkeit zu einer Politik der Menschenrechte*, (Utrecht: Publications of the Department of Philosophy Utrecht University, 2009. Revised version Frankfurt a.M.: Campus 2011.

Griffin, J., *On Human Rights*, (Oxford: Oxford University Press, 2008).

Hammarberg, T., "The Rights of Disabled Children: The UN Convention on the Rights of the Child," in *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments,* edited by T. Degener and Y. Koster-Dreese, (Dordrecht: Kluwer Academic Publishers, 1995), 147-155.

Holmes. S. and C. Sunstein, *The Costs of Rights: Why Liberty Depends on Taxes*, (New York: Norton, 1999).

Honneth, A., *Kampf um Anerkennung: Zur moralischen Grammatik sozialer Konflikte*, (Frankfurt a.M: Campus, 1998).

Kallehauge, H., "General Themes Relevant to the Implementation of the UN Disability Convention into Domestic Law: Who is Responsible for the Implementation and How Should It Be Performed?" In *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, edited by O.M. Arnardóttir and G. Quinn, (Leiden/Boston: Martinus Nijhoff, 2009), 201-213.

Karlan, P.S., "Framing the Voting Rights Claims of Cognitively Impaired Individuals," *McGeorge Law Review* 38(2007): 917-30.

Karlawish, J.H., R.J. Bonnie, P.S. Appelbaum, C. Lyketsos, B. James, D. Knopman, C. Patusky, R.A. Kane, and P.S. Karlan, "Addressing the Ethical, Legal, and Social Issues Raised by Voting by Persons With Dementia," *Journal of the American Medical Association* 292(11)(2004): 1345-1350.

Kayess, R. and P. French, "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities," *Human Rights Law Review* 8(2008): 1-34.

Koch, I.E., "From Invisibility to Indivisibility," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* edited by O.M. Arnardóttir and G. Quinn, (Leiden: M. Nijhoff, 2009), 67-77.

Kymlicka, W., *Contemporary Political Philosophy: An Introduction*, (Oxford: Oxford University Press, 2001, 2nd ed.).

Laclau E. and C. Mouffe, *Hegemony and Socialist Strategy* (London: Verso, 1985).

Lindqvist, B., "Standard Rules in the Disability Field: A United Nations Instrument," in *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments,* edited by T. Degener and Y. Koster-Dreese, (Dordrecht: Kluwer Academic Publishers, 1995), 63-68.

Loland, S., "Normative Theories of Sport: A Critical Review," *Journal of the Philosophy of Sport*, 31(2004): 111-121.

MacIntyre, A., *Dependent Rational Animals: Why Human Beings Need the Virtues*, (Chicago: Open Court, 1999).

McAdam, R., "The Origin, Development and Regulation of Norms," *Michigan Law Review* 96(1997): 338-433.

Mégret, F., "The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?" *Human Rights Quarterly* 30(2008): 494-516.

Merleau-Ponty, M., *Phenomenology of Perception*, (London: Routledge, 2002, originally 1945).

———, *The Structure of Behaviour*, (Boston, MA: Beacon Press, 1967, originally 1942).

Mitra, S., "The Capability Approach and Disability," *Journal of Disability Policy Studies* 16(2006): 236.

Morgan, J.W. and K.V. Meier, editors, *Philosophic Inquiry in Sport*, (Champaign: Human Kinetics, 1988).

Mundy, L., "A World of Their Own," *Washington Post Magazine*, March 31, 2002.

Nagel, T., *Equality and Partiality*, (Oxford: Oxford University Press, 1991).

Nussbaum, M.C., "Capabilities and Disabilities," presented at Cognitive Disability: A Challenge to Moral Philosophy, New York, September 18, 2008.

———, "Capabilities as Fundamental Entitlements: Sen and Social Justice," *Feminist Economics* 9(2003): 33-59.

———, *Frontiers of Justice*, (Cambridge MA: Harvard University Press, 2006).

———, "Human Capabilities, Female Human Beings," In *Women, Culture and Development: A Study of Human Capabilities*, edited by M.C. Nussbaum and J. Glover, (Oxford: Clarendon Press, 1995), 61-104.

———, "Human Rights and Human Capabilities," *Harvard Human Rights Journal* 20(2007): 21-24.

———, *Women and Human Development*, (Cambridge: Cambridge University Press, 2001).

———, "The Capabilities of People with Cognitive Disabilities," *Metaphilosophy* 40(2009): 331-351.

O'Cinneide, C., "Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and Possibilities," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* edited by O.M. Arnardóttir and G. Quinn, (Leiden: Martinus Nijhoff, 2009), 163-198.

Poffé, L. "De EU Partij bij het VN-Verdrag inzake de Rechten van Personen met een Handicap," *NJCM-Bulletin* 36(2011): 63-74.

Pogge, T., *World Poverty and Human Rights: Cosmopolitan Responsibilities and Reforms, 2nd ed* (Cambridge: Polity Press, 2008).

Quinn, G., "Resisting the Temptation of Elegance," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* edited by O.M. Arnardóttir and G. Quinn, (Leiden: Martinus Nijhoff Publishers, 2009), 215-256.

———, "The International Covenant on Civil And Political Rights and Disability: A Conceptual Framework," in *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments,* edited by T. Degener and Y. Koster-Dreese, (Dordrecht: M. Nijhoff, 1995), 69-93.

Rawls, J., *A Theory of Justice*, (Cambridge, MA: Harvard University Press, 1971).
———, *Political Liberalism*, (New York: Columbia University Press, 1993).
———, *The Law of Peoples*, (Cambridge, MA: Harvard University Press, 1999).
———, "The Idea of Public Reason Revisited," in idem, *Collected Papers*, edited by Samuel Freeman, (Cambridge, MA: Harvard University Press, 1997), 573-615.
Redley, M., "Citizens with Learning Disabilities and the Right to Vote," *Disability & Society* 23(2008): 375–384.
Richardson, H., "Rawlsian Social-Contract Theory and the Severely Disabled," *The Journal of Ethics* 10(2006): 419-462.
Robertson, J.A., *Children of Choice: Freedom and the New Reproductive Technologies*, (Princeton: Princeton University Press, 1996).
Sabin, J. and N. Daniels, "Determining 'Medical Necessity' in Mental Health Practice," *Hastings Center Report* 24(1994): 5-13.
Savulescu, J., "Procreative Beneficence: Why We Should Select the Best Children," *Bioethics* 15(2001): 413-426.
Scheffler, S., *The Rejection of Consequentialism*, (Oxford: Oxford University Press, 1994, 2nd ed.).
Scheinin, M., "The Human Rights Committee and Freedom of Religion or Belief," in *Facilitating Freedom of Religion or Belief: A Deskbook,* edited by T. Lindholm, W.C. Durham, and B.G. Tahzib–Lie, (Leiden: Martin Nijhoff, 2004).
Schriner, K., and L. Ochs, "'No Right Is More Precious': Voting Rights and People with Intellectual and Developmental Disabilities," *Policy Research Brief* 11(2000): 1–15.
Schriner, K., L. Ochs and T. Shields, "The Last Suffrage Move-ment: Voting Rights for Persons with Cognitive and Emotional Disabilities," *Publius: The Journal of Federalism* 27(1997): 75.
———, "Democratic Dilemmas: Notes on the ADA and Voting Rights of People with Cognitive and Emotional Impairments," *Berkeley Journal of Employment and Labor Law* 21(2001): 437-472.

Scully, J.L., *Disability Bioethics: Moral Bodies, Moral Difference*, (Lanham: Rowman & Littlefield, 2008).

———, "Disabled Embodiment and an Ethic of Care," in *Bioethics in Cultural Contexts: Reflections on Methods and Finitude*, edited by C. Rehmann-Sutter, M. Düwell, and D. Mieth, (Dordrecht: Springer, 2006), 247-262.

Shakespeare, T., *Disability Rights and Wrongs*, (Abingdon: Routledge, 2006).

Shue, H., *Basic Rights: Subsistence, Affluence, and U.S. Foreign Policy*, (Princeton N.J.: Princeton University Press, 1980).

Silvers, A., D. Wasserman, and M. Mahowald, editors, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, (Lanham MD/Oxford: Rowman & Littlefield, 1998).

Silvers, A., "Formal Justice," in *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy,* edited by A. Silvers, D. Wasserman and M. Mahowald, (Lanham MD/Oxford: Rowman, 1998), 131-146.

Singer, P., *Practical Ethics*, (Cambridge: Cambridge University Press, 1993, 2nd ed.).

Stein, M.A. and J.E. Lord, "Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities," in *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* edited by O.M. Arnardóttir and G. Quinn, (Leiden: Martinus Nijhoff, 2009), 17-40.

Stein, M.A., "Disability Human Rights," *California Law Review* 95(2007): 75-121.

Stein, M.A. and P. Stein, "Beyond Disability Civil Rights," *Hastings Law Journal* 58(2006): 1203.

Stolz, B.A., "Interpreting the US Human Trafficking Debate through the Lens of Symbolic Politics," *Law and Policy* 29(2007): 311-338.

Sturm, S. and L. Guinier, "The Future of Affirmative Action: Promoting Diversity in Education and Employment Requires Us to Rethink Testing and 'Meritocracy'," *Boston Review*, December 2000/January 2001.

Suits, B., "The Elements of Sport," in *Philosophic Inquiry in Sport*, edited by J.W. Morgan and K.V. Meier, (Champaign: Human Kinetics, 1988), 39-48.

Tännsjö, T. and C.M. Tamburrini, editors, *Genetic Technology and Sport*, (London and New York: Routledge, 2005).

Taylor, C., "The Politics of Recognition," in *Multiculturalism and 'The Politics of Recognition'*, edited by C. Taylor and A. Gutmann, (Princeton: Princeton University Press, 1992), 25–74.

Taylor, P.M., *Freedom of Religion: UN and European Human Rights Law and Practice*, (Cambridge: Cambridge University Press, 2005).

Terzi, L., "Beyond the Dilemma of Difference: The Capability Approach to Disability and Special Educational Needs," *Journal of Philosophy of Education* 39(2005): 443–459.

Torfing, J., *New Theories of Discourse: Laclau, Mouffe, and Zizek*, (Oxford: Blackwell, 1999).

Tucker, R. and J. Dugas, "Oscar Pistorius – Science and Engineering vs. Training: An Evaluation of All the Evidence," http://-www.sportsscientists.com/2007/07/oscar-pistorius-science-and-engineering.html, consulted on November 9, 2010.

United Nations, *From Exclusion to Equality – Realizing the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention of the Rights of Persons with Disabilities and its Optional Protocol*, (Geneva: United Nations, 2007)

———,"UN Enable: Promoting the Rights of Persons with Disabilities," 2010, available at <www.un.org/disabilities>.

United Nations Office of the High Commissioner for Human Rights, Thematic Study on Participation in Political and Public Life by Persons with Disabilities (December 21, 2011) A/HRC/19/36

United Nations Development Programme (UNDP), "Origins of the Approach," 2010, http://hdr.undp.org/en/humandev/origins/

Von Bernstorff, J., "Menschenrechte und Betroffenen-repräsentation: Entstehung und Inhalt eines UN Antidiskriminierungsübereinkommens über die Rechte von behinderten Menschen," *Zeitschrift für ausländisches öffentliches Recht und Völkerrecht* 67(2007): 1041-1063.

Vorhaus, J., "Citizenship, Competence and Profound Disability," *Journal of Philosophy of Education* 39(2005): 461–475.

Wasserman, D., "Distributive Justice," in *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy,* edited by A. Silvers, D. Wasserman, and M. Mahowald, (Lanham MD/Oxford: Rowman & Littlefield, 1998), 147-208.

Wiggins, D., *Needs, Values, Truth: Essays in the Philosophy of Value*, (Oxford: Oxford University Press, 1998, 2nd ed.).

Wong, S., "The Moral Personhood of Individuals Labeled 'Mentally Retarded': A Rawlsian Response to Nussbaum," *Social Theory and Practice* 33(2007): 579-594.

Young, I.M., *Inclusion and Democracy,* (New York: Oxford University Press, 2001).

Young, K.G., "The Minimum Core of Economic and Social Rights: A Concept in Search of Content," *Yale Journal of International Law* 33(2008): 113-175.