United Nations Convention on the Rights of Persons with Disabilities
– Multidisciplinary Perspectives

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The Center for Human Rights of Persons with Disabilities (VIKE) is a joint project of the Finnish Association of People with Mobility Disabilities, the Threshold Association and the Institute for Human Rights at Åbo Akademi University. VIKE promotes the human rights of persons with disabilities through advocacy, lobbying, awareness-raising and research. Please visit the web site of VIKE at www.vike.fi.
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PREFACE

The United Nations Convention on the Rights of Persons with Disabilities was adopted by the United Nations General Assembly on 13 December 2006 and it entered into force on 3 May 2008. The Convention had the highest number of signatories in the history of United Nations treaties on its opening day. The drafting of the Convention was a magnificent experience for future States Parties, but most importantly for persons with disabilities and their organizations, which participated in the drafting process with unforeseen enthusiasm.

This book is about perspectives, as the name of the book indicates. The book may contain ambivalence and contradictions – reflecting the lives of persons with disabilities – much like the Convention itself. The 15 chapters of the book are both multidisciplinary and multidimensional in their substance. They look at the lives of persons with disabilities from multiple points of view. Still, the themes addressed are closely intertwined with the lives of individuals with disabilities. This illustrates the complexity of the relationship between human rights and disability.

Disability studies and studies on human rights and disability are not well-established areas of research and academic writing. This is not a bad thing. Instead, we can consider the current situation as providing momentum for scholars taking part in the development of a new, fresh, multidisciplinary field of scholarship. This book makes a contribution to that development, which has been ongoing for a few decades now.

Academia and disability rights activism often come hand-in-hand. The writing of academic articles, chapters and books has become a part of global disability rights activism. This could be called scholarship activism. By this we mean that because much of the lack of realization of human rights for persons with disabilities can be explained by a lack of awareness amongst relevant stakeholders, producing and receiving more information will raise the level of awareness, and ultimately have a real chance of changing the mindset of the reader.

Human rights begin at one’s own doorstep. The most important aspect in the realization of human rights of persons with disabili-
ties is the consciousness of individuals with disabilities of their own human rights. To be empowered means being aware of one’s human rights and claiming them. This requires knowledge about human rights and the broadening of one’s mindset – empowerment. This book is a part of that process of empowerment. It brings academia closer to the real lives of persons with disabilities by offering a wide range of perspectives on human rights issues occurring in the lives of persons with disabilities.

The editors would like to express their thanks to all of the authors for their precious contributions. The editors especially would like to thank Hisayo Katsui for helping in the search for authors and in finalizing the manuscript. Further, the editors thank Anna Seppänen-Lingenfelter for taking good care of the English proof-reading of the book and for translating Chapter 4 and Sarianna Mankki for translating Chapter 2. Finally, we thank Niina Kilpelä who handled the layout of the book.

We have given a free hand to each author, and thus the content of the chapters do not reflect the opinions of the publisher, editors or anyone besides the authors themselves.

The book is dedicated to persons with disabilities all over the world.

1 November 2009

Jukka Kumpuvuori and Martin Scheinin
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PART I: UN CRPD – WHY AND WHAT?
Chapter 1:

The Special Reaching for the Universal:
Why a Special Convention for Persons with Disabilities?
Jarna Petman

1. Introduction

"What makes human beings alike is the fact that every human being carries within him the figure of the other. The likeness that they have in common follows from the difference of each from each."¹

Within the heart of human rights there lies a tension. It is the same tension that characterizes international law in general: the tension between homogenization on the one hand and respect for pluralism and group difference on the other, between universalism and particularism, international community and state sovereignty. International lawyers tend to regard one side of each such pair as inherently good, the other as inherently bad. After all, to become an international lawyer is to be trained to promote the international rule of law as a humanitarian, progressive and cosmopolitan project. International law is for homogenization, universalism, and international community. International law is against difference, particularism, and State sovereignty — against politics. Politics is all that international law is not: it is passion and violence to our reason and restraint.²

Why should this be important? Because what I have just outlined is the cultural and professional vocabulary available to international lawyers, human rights activists and advocates alike – it is the universalist vocabulary in which our wish to do good, to strengthen the hand of tolerance and understanding takes shape.³ Significantly, this

vocabulary places us outside the centres of power in global affairs, casting us as people who speak to those powers but do not exercise power. Or so we like to think. We see ourselves as speaking truth to power, law to politics.

No wonder, then, that the book entitled Taking Rights Seriously should carry such huge influence among human rights advocates. This is a book in which Ronald Dworkin, an American law professor, in the late 1970’s first launched his particular understanding of rights as ‘trump cards’. The demands of rights, argues Dworkin, take precedence over other possible social goals, they trump everything else. Accordingly, his theory seems to offer lawyers a final escape from politics. As self-evident truths, rights will at last bring any political debate to an end; rights can be put on the table as apolitical and ahistorical. But can they? As I see it, this is a very mistaken conception of rights indeed. Human rights are not apolitical, free from politics. Quite the opposite. Human rights constantly keep referring back to politics for their meaning, for their purpose. Now, let me clarify at the outset what I do not mean by this. I do not mean that rights (or law in general) would be reduced to mere politics. No, and to this I shall return shortly. What I do mean, however, is that rights (and legal rules in general) do keep deferring back to politics, again and again – and that this is a good thing too. So, in what follows let me take rights seriously and briefly reflect on the impacts of the CRPD in a world where human rights cannot be defined in a neutral way.

2. Presumptions of International Human Rights Law

That rights have no intrinsic, essential meaning which would somehow be apolitically, ahistorically given, can be seen, for example, in the way in which the international human rights law has developed. This law has proceeded on the twofold assumption that everyone has

more or less the same capacities, and that what those capacities make possible is self-sufficiency in adult life. Such presumptions are understandable. Our political discourse is pervasively shaped by the idea of society based on a contract for mutual advantage, an idea that has dominated political theory in the historical tradition. All social contract theories adopt a fictional hypothesis that appears innocent: the fiction of competent adulthood. This seemingly innocent premise is found already in the writings of one of the most influential political thinkers of all time, John Locke. This 17th century English philosopher believed that human rights, not governments, came first in the natural order of things and accordingly he sought to justify a move from the absolute Sovereign to natural rights. People are born, Locke declared, in a ‘state of perfect equality, where naturally there is no superiority or jurisdiction of one over another’. For him, all humans, irrespective of their particular socioeconomic, cultural, or political conditions, possessed a title ‘to perfect freedom’ and ‘uncontrolled enjoyment of all the rights and privileges [. . .] equally with any other man or number of men in the world’. In his view, people had formed societies and set up governments to preserve those rights, not to surrender them. As a consequence, governments received their powers from the governed with whom they signed a contract. Any government that acted without limits imposed by the consent of the governed and thereby violated their natural rights, said Locke, thus dissolved the contract and gave people the right to resist. Citizens should be empowered to revolt if they felt that the State was abusing its power.

Ever since Locke wrote those words they have had a powerful hold on our political imagination as a very specific form of liberalism – ‘liberalism of fear’ – that regards abuses of public powers with trepidation and assumes that most agents of governments will behave lawlessly and brutally in minor or major ways most of the time unless they are prevented from doing so. The prevention of such conduct

10 Ibid., pp. 96-112.
requires a constant division and subdivision of political power. The doctrines of human rights that we now have are direct descendants of this thinking. And it has been much cherished as such, since it did give power to the people. There is, however, also another, less charitable, way in which our doctrines of rights are direct descendants of this thinking. The presumption that the parties to the social contract are ‘free, equal and independent’\textsuperscript{12} is not an innocent one.

Our political discussions and structures are now shaped by the idea of society based on a contract for mutual advantage. Contemporary social contract theories now explicitly adopt the hypothesis that, in a social contract, rational parties choose mutually advantageous arrangements in a process of coming to agreement about the fundamental principles of justice. In this, the citizens are (according to John Rawls) assumed to be ‘fully cooperating members of society over a complete life’.\textsuperscript{13} That is, they are presumed to be roughly equivalent to each other in strength, abilities, intelligence, sensibilities and status; they are also presumed to resemble each other in not only desiring to exercise sovereignty over themselves but also in being capable to do so.

Why should that matter? Why should I wish to talk about theories at such length? After all, they are just theories. But, and this is important, they are not ‘just’ theories. Theories shape the way in which we see the world, the way in which we perceive each other, the way in which we organize our inter-relationships, our societies. As things are, our political (and legal) world has been shaped by the idea of society based on a contract for mutual advantage. And this has had profound consequences on those who have special needs: people with disabilities, people resident in the poorest nations. You see, when the societal partnership that we envisage is for the mutual advantage of the contracting parties, provisions for people who are not part of the bargain can only be an afterthought – not part of the basic institutional structure to which they must agree.\textsuperscript{14} Indeed, as yet another theorist (David Gauthier) would bluntly tell us, people of unusual needs ‘are not party to the moral relationship grounded by

\textsuperscript{12} Locke, \textit{supra} note 9, p. 44.
a contractarian theory’. A dark implication inherent in the very idea of a social bargain for mutual advantage is that those who remain dependent are not full participants. This is reflected in the way in which global human rights treaties have been framed.

These treaties stem from the 1948 Universal Declaration of Human Rights. Before the CRPD, they hinged around seven key conventions and their monitoring bodies. There are two separate general conventions dealing with civil and political rights on the one hand and economic, social and cultural rights on the other. In addition to these, there are a number of more specific conventions dealing with torture and other cruel, inhumane or degrading treatment or punishment; with the elimination of all forms of racial discrimination, the elimination of all forms of discrimination against women, rights of the child and the protection of the rights of all migrant workers and their families. These are the afterthoughts, provisions for specific groups of people who were not part of the original bargain and whose rights were thus felt, in the years to come, to be in need of special protection. All of these treaties originated in an attempt to guard against future occurrences of the types of abuse and exploitation of marginalized groups witnessed in the years leading up to and during the Second World War. Although disabled people were one of the groups to be subjected to programs of brutal persecution and annihilation during that period, there is very little specific reference to

them in the seven treaties just listed. Reference to disability appears only once in these instruments of human rights, in an article of the Convention of the Rights of the Child.\(^{24}\) Other than that, human rights treaties have been silent on the issue of disability.

But then again, why should they mention disability? The rights conferred in these instruments are, after all, ‘universal’ in nature. They are rights conferred on all human beings, including those who are disabled, simply by virtue of their humanity. And so, States parties to these conventions are required to guarantee all the rights enshrined in them — civil and political rights, the right to life, the right to liberty and security of person, the right to be free from degrading treatment and from discrimination, the right to economic, social and cultural opportunities such as education, the right to work, the right to et cetera, et cetera — all of these to everyone, to disabled people as to everybody else. However, and here is the crucial issue, any meaningful enjoyment of those rights by persons with disabilities will require their ability to participate actively in their communities. And this is precisely why a special convention for disabled people was needed. This is where the reasons for and the impact of CRPD lie.

3. Why a Special Convention for Persons with Disabilities?

The CRPD for the first time recognizes that disability is — and the rights of the disabled are — a function of social environment. In doing so, the Convention changes the way disability is conceptualized. Traditionally, understandings of disability have been oriented towards the medical or diagnostic model, in which the focus has been on the physical or intellectual limitations of particular individuals and on their therapeutic and other needs.\(^{25}\) Such understandings have built upon the presumption that the obstacles encountered by people with disabilities are entirely a function of their own physical or other limitations. As a consequence, attempts to improve the lives of disabled persons have mostly taken the form of medical intervention or the provision of technical aids. That is to say, the emphasis has been

\(^{24}\) See Article 23 of the Convention on the Rights of the Child, supra note 22.

\(^{25}\) See M. Oliver, *Understanding Disability: from Theory to Practice* (Palgrave, Basingstoke, 1996).
on adapting the individual to function in the surrounding reality.26 Measures that aim to maximize the independence of disabled individuals are certainly important and necessary, but quite as certainly not enough. Most often the obstacles that the disabled face are a function of the social environment in which they live.27

By rejecting the traditional approach to disability, the CRPD starts from the awareness that the issues raised are not just personal and particular, but also systemic and societal; not merely therapeutic but also political and cultural. In this regard, it is not inconsequential that the title and the text of the Convention invite us to think in terms of people ‘with disabilities’ rather than ‘disabled’ people, in so far as the latter formulation can be (and has been) seen as conveying the message that disability is a pathology determining an individual’s existence and role in the social world.28 With its choice of terminology the Convention shifts our focus from an exclusive preoccupation with the limitations of individuals to an equal concern with the disabling impact of societies.

Moreover, by recognizing that conditions affecting abilities differ between and within societies and with respect to different kinds and degrees of functional limitation, the Convention breaks the illusion of homogeneity so easily imposed by the concept of disability. The acknowledgement of the seemingly banal fact that people with disabilities are not alike carries radical implications as it reveals the contingencies in the social constitution of abilities. This opens a wholly new perspective to the institutions and practices that have

26 See S. Linton, Claiming Disability: Knowledge and Identity (Cultural Front Series, New York University Press, 1998).
28 On the importance of language and labels in the disability movement, see, e.g., R. Luckasson, ‘Terminology and Power’, in S. Herr, L. Gostin and H. Hongju Koh (eds.) The Human Rights of Persons with Intellectual Disabilities: Different but Equal (Oxford University Press, 2003) pp. 49-58; and Oliver, supra note 25, pp. 6-18. In this article, I shall use both the term ‘people with disabilities’ and ‘disabled people’ under the premise that a person’s identity cannot be reduced to her disability.
been established for the cure and care of the disabled.\(^{29}\) Indeed, as long as disability was approached as a problem located entirely within the individual, all that seemed to be required was treatment and adaptation. What the Convention makes evident, however, is that a much more comprehensive change will be needed. By highlighting the role that structures (be they social, cultural, legal, economic or political), values and collective modes of imagination play in creating and reinforcing the power hierarchies to which people with disabilities are subjected, the Convention moves for a change that truly implicates the complex of law, government, public policies, private businesses, national cultures, international networks, development strategies and so forth.

To be sure, by focusing on the need to modify the social practices and institutions that turn disability into disadvantage, the Convention in an important fashion acknowledges that the relationship between people with disabilities and those without them is a relationship of subordination on the one side and domination on the other.\(^{30}\) Furthermore, and even more importantly, it acknowledges that this relationship is no more natural, no more permanent or unavoidable than any other power relationship.\(^{31}\) Here, the impact of the Convention’s argument that people with disabilities should be seen as citizens and social agents – that is to say, equal bearers of human rights – cannot be over-emphasized. It is this argument that will provide for visibility for disabled people as subjects of rights.\(^{32}\)

Hitherto, people with disabilities have in a very real sense been invisible: lawyers, politicians, and rights advocates have simply not

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\(^{29}\) See, e.g., S. Mor, ‘Between Charity, Welfare, and Warfare: a disability legal studies analysis of privilege and neglect in Israeli disability policy’, 18 Yale Journal of Law and the Humanities (2006) p. 63 (for a critical analysis of the way in which the very welfare laws and policies that have been considered a major source of rescue and relief for people with disabilities have also served to reinforce and reconstitute their societal subordination); see also M. Cole, ‘In/ensuring Disability’, 77 Tulane Law Review (2003) p. 839 (a critical analysis, inspired by queer theory, of the ‘closeting’ of people with disabilities).


\(^{31}\) Cf. Marks and Clapham, supra note 7, p. 112; cf. also Linton, supra note 26.

perceived them as citizens whose sufferings spring from failures to adequately protect their rights.\textsuperscript{33} Rather they have been perceived as (mere) users of social services, recipients of care and thus objects of welfare or charity. Because of this, they have been unable to take full (or any) advantage of the existing human rights instruments: existing legal protections have either not been applied or have been applied with much less rigour in their case.\textsuperscript{34} This invisibility is an inevitable result of their exclusion from the social category of normalcy and the subsequent separation from the public sphere. Such separation may be physical or social and be caused by the sheer inability to access public facilities due to architectural barriers (such as high curbs), legal barriers (such as laws denying them the right to vote), organizational barriers (such as inflexible time-tabling) or plain prejudice and hostility.\textsuperscript{35} The Convention now demands that states facilitate the inclusion and participation of disabled people by introducing laws and policies which will remove these barriers. In doing so, it views people with disabilities not as somewhat burdensome objects of pity and charity but as people who are entitled to be fully included in the life of their communities.\textsuperscript{36}

In this way, the CRPD provides a concrete form for human rights for persons with disabilities, endowing lofty generalities with political life and relevance in the specific context of disability.\textsuperscript{37} Here, rights are not defined in a neutral fashion. And how could they? For rights are not a good in themselves. Instead, they serve to protect other social goods. Rights have no intrinsic meaning, no essence that would be apolitically given. Instead, they reflect socially and cultur-
ally conditioned ways of thinking about the demands of good society. They constantly refer back to politics.

4. About the Universality of Rights

At the level of general expressions and abstract language, human rights may, perhaps, be universal. But as soon as they are invoked in particular contexts to defend or criticize particular distributive choices, particular preferences or policies, choices will have to be made. Why? Because we are different. Because the international system is different.

States and nations represent societies with radically different moral and religious traditions, political cultures, economic and technological capacities. In view of this plurality, there is a whole range of plausible interpretations about the content and application of any human right. States will unavoidably come to disagree about the intrinsic importance of rights. And there will be no impartial way to solve the controversy, for there is no objective meaning to human rights as a legal concept. Their objectivity (universality) works only in the abstract, as an open-ended horizon. But in the abstract they have no concrete meaning that could provide guidance for action. In the concrete, they are but an image of the moral beliefs of a particular instance. That is, once human rights are to be applied in a concrete case, choices must be made. Privileging one assumption over another about the intrinsic importance of a right is inevitably a political choice between different moral beliefs, different sets of values. In the end, it is a question of whose idea of what is important prevails.38

The universal acceptance of rights language may hide from sight the fact that behind it, legislative choices and political priorities are made. There is no authoritative catalogue of rights that would be politically innocent. The Universal Declaration of Human Rights, the International Covenants, regional conventions on human rights, The UN Convention on the Rights of People with Disabilities, each one

has come about as a deeply political document.\textsuperscript{39} In a classical international negotiation process, drafts have been prepared, discussed, redrafted, accepted or rejected, points argued and bargained, deals struck, compromises made, issues dropped. Only those human rights that were successfully formulated in political bargaining have been included into the rights catalogues. In this way, only certain aspects of reality have come to be recognized as a ‘human right’ and afforded protection.\textsuperscript{40} And as time goes by and our values change, our conception of what might qualify as a ‘right’ also changes and, so, additional aspects of life become characterized in terms of human rights by enriching the original treaties’ catalogue of rights with additional protocols. In this, only selected problems come to be characterized in the language of ‘rights’. Again, such selectivity is not dictated by any ‘essential’ nature of those problems. It is a matter of political preference. What we end up calling human rights are the end results of the contextual balancing of different priorities, alternative notions of the good life.\textsuperscript{41} The same applies, of course, to our notion of who that ‘human’ is whose rights we protect. Should asylum seekers be included? What about divorcees? Or transsexuals? Should homosexuals have the right to marry and found a family? Should people with disabilities be included? Should they be allowed to vote? Have children? At different times we have had different answers to the above questions. Our conception of rights does not hold for all times and all places.\textsuperscript{42}

In a sense, we are already aware of this when we legislate rights into being. We know, there and then, that like all legal rules, human rights will cover cases we did not wish to cover and leave uncovered cases that we think should have been covered had we only come to think of them when formulating the rule.\textsuperscript{43} This is because we only have


our past as the basis on which to legislate. But whatever took place yesterday or today will not be enough for us to even begin to imagine what we might face tomorrow. As the future remains unknown and the experience of the past is insufficient to grasp it, we do not know what we might come to hope to be either included in or excluded from the application of the rule. So, we need an exception to govern this uncertain future. Accordingly, rights are always supplemented with exceptions. While the scheme of right/derogation is inevitable, it is at the same time also insufferable, for there is no definite rule or standard to determine when to apply the right and when the derogation. This deformalizes human rights and makes their application a matter of bureaucratic administration.\textsuperscript{44} In this sense too, rights are a product of a political community; their creation, administration and adjudication is about struggle and compromise, power and ideology. It matters who decides.

This applies even to the rights that we wish we somehow intrinsically ‘knew’; rights that that we tend to call fundamental, ‘inalienable’. It is hard to imagine a standard that would seem more straightforward than the right to life. Yet even its application is revealed as a weighing standard, and receives sense only in a political context. For instance, from what point does life deserve protection and in what circumstances should the deliberate extinction of life be authorized? Does the right to life include euthanasia? Or abortion? Whose life should we preserve and protect? If a foetus is regarded as enjoying an absolute and non-derogable right to life, then this would justify a limitation on any countervailing right, fundamental right, of the mother. Surely the rights of the mother need to be protected as well? And what about the rights of the father? Even if we were to assume that we were to protect the unborn life, there are other rights and interests involved that have to be weighed against each other. In such cases, even a core right like the right to life has no meaning independent from the way it is interpreted by the relevant authorities.

5. A Special Reaching for the Universal

So, at the level of general expressions and abstract language, human rights may, perhaps, be universal. But as soon as they are invoked in particular contexts to defend or criticize particular distributive choices, particular preferences or policies, they reveal their partisan nature. They become instruments in the allocation of resources and struggle over institutional competencies. And this will happen with regard to the CRPD as well. It will turn into an intergovernmental administrative process in which rights are recognized, limited, weighed against each other and overruled as a matter of routine. In this, rights will become institutionalized as a banal, everyday administration of the Convention mechanism. The commitment to human betterment that went into the Convention is difficult to transfigure into a call for support for the Committee that will start monitoring the Convention. The critical moment of winning rights is brief and gone before we notice. That is the point at which well-dressed men and women begin meeting in rooms with high ceilings to talk to each other from behind enormous piles of paper. That is the moment of institutionalization, routine, stasis. At that point the language of rights starts to intermingle with the language of perdiems, allowances, and flight schedules and before long, the next meeting will be about coordination of the meetings that will follow. This should not, however, be taken as recipe for cynicism. It is true that in normal periods, and as part of the administrative routines of international organizations and liberal States, rights often lose their critical nature and become inseparable from the general techniques of conflict settlement and resource allocation – they become ‘politics as usual’.  

The critical potential of rights is revealed, however, in moments when liberal actors themselves step beyond their own liberal principles and when action is needed against illiberal or authoritarian ones. A claim of right has a special nature. It is not just an assertion of privilege or an appeal to charity. To say, ‘this is my right’ is radically different from saying ‘this is my interest’: it constitutes the claimant as a member of the legal, and thus political, community. Engaging in legal discourse, persons recognize each other as carriers of rights and duties who are entitled to benefits from or owe obligations to

45 See Petman, supra note 41, pp. 86-90
each other – not because of charity or interest but because such rights or duties belong to every member of the community in that position. This is what human rights do. This is what the CRDP does. Rights construe us as equal members of the community.

Applied in the context of international human rights work, the conclusion shifts the focus away from tinkering with the institutional management of right-regimes. It is not that regimes would be unimportant but they are insufficient alone. They can be part of a project about solidarity and community only once they are embedded in a live culture of claiming rights. What is needed is awareness that rights alone can mean anything, and that when embedded in a particular institutional context such as the Convention on the Rights of People with Disabilities, they come to mean what the current policies of the states parties are. And there is, as we know, no intrinsic guarantee that those in positions of power will always aim to advance a good policy. To respond to claims of solidarity and community, rights and rights-institutions need to be accompanied by political work that expresses critique and contestation from such perspectives. If there is no sense of solidarity in the community, no rights will save us. Rights operate in an acceptable way only once their meaning and limits, and the weight we give to them, is inspired by the ideal of solidarity.

So let me suggest that we do take rights seriously and take to political action.

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46 See Koskenniemi, supra note 44, p. 43
47 See Petman, supra note 41, pp. 87-90.
Chapter 2:

UN CRPD and the Human Rights of Persons with Disabilities

Pentti Arajärvi

1. Introduction

Without a doubt, the UN CRPD opens a new path within the international human rights framework. However, disability rights have not been entirely overlooked in the past either. Disability is explicitly mentioned, among other issues, in the Convention on the Rights of the Child (CRC), the Revised European Social Charter (ESC) and the ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention No. 159. Earlier, the UN adopted a Declaration on the Rights of Disabled Persons¹ and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.² Most of these conventions address non-discrimination and equality in society, education and employment. The Charter of Fundamental Rights of the European Union includes provisions pertaining to non-discrimination (Article 21) and the general status of persons with disabilities (Article 26). When the Lisbon treaty enters into force, the Charter, presently a declaration will become a binding legal document.³

The UN CRPD has not yet entered into force in Finland although Finland has signed it. What is interesting about the UN CRPD is that it has also been signed by the European Community. Both have also signed the Optional Protocol. This means that there are parallel ratification processes in progress in the member countries that have signed the Convention: on the national level and on the community level.

According to estimates, the Finnish ratification process may take several years. There are fundamental changes that need to be made in the national legislation. My object in this article, however, is not to evaluate the ratification and implementation process in Finland nor in the European Union. In the future, we might have a situation where it is not clear whether the UN CRPD is in force as a national or community law and to what extent it should be applied nationally or internationally. This depends substantially on whether the Convention falls under exclusive or shared competence or whether the member countries and the communities make their decisions independently of each other in this matter. Regardless, the scope of the Convention may be unclear. According to the Article 300 of the Treaty on European Union, each member state is bound to a convention together with the Union. If the Union is party to a convention, the convention might also apply to individual member states. At the very least it applies to EU institutions and legislation. In this case, the member states are legally bound to implement the convention as community law.\(^4\)

In Finland, the problems of ratification stem from the provisions and applications of the Municipality of residence act (201/1994) and related questions on municipal state subsidies. Problems also arise from organizing the monitoring system for the convention and Finnish provisions on coercive special care of persons with mental disabilities.

According to the Municipality of residence act, one’s municipality of residence does not change if one lives in an institution or in similar arrangements in another municipality. The object of this legislation is to avoid excessive costs to the municipalities in which these institutions are located. From the resident’s point of view, however, this creates a fundamental problem in the sense that he cannot, for example, influence matters in his or hers actual home municipality by participating in municipal elections. This issue also relates to the municipal state subsidy system, which makes it all the more difficult because the overall renewing of the legislation on state subsidies is in process. It often takes a relatively long process to solve such questions.

Finland also faces problems with the national monitoring of the UN CRPD. These difficulties stem from the ongoing consolidation and possible combination of the Acts on equality between men and women (609/1986) and the Non-discrimination Act (21/2004). The monitoring system provided in the UN CRPD could be integrated with the Non-discrimination Act. However, this would require that the aforementioned process of renewing the equality and non-discrimination legislation is also finalised in other aspects.

Using coercive treatment in the special care of mentally disabled persons is based on the Act on special care for mentally disabled persons (519/1977). The existing provisions on coercive special care are more or less in accordance with general requirements and human rights conventions. The need for this type of care is another question.

2. UN CRPD as part of the Human Rights Framework

The status of persons with disabilities has varied in different conventions and agreement systems. In the human rights system, the significance of the UN CRPD is, in a way, twofold. The UN CRPD can be seen as a "disability-adapted version" of other human rights conventions, which is to say that in addition to its status as an independent convention, the UN CRPD would influence the adaptation and interpretation of other conventions in matters concerning persons with disabilities. However, it can also be strictly seen as an independent disability convention, in which case one should consider the relationship of disability provisions in other conventions to the UN CRPD. This raises even more clearly the question of which convention should be applied in individual cases. The difference between these two functions is fundamental.

If the essential function of the UN CRPD is to be a disability-adapted version of other conventions, it challenges the application of other conventions to persons with disabilities. This may in some cases present a problem for persons with disabilities, as there might be contradictory or competing provisions in different conventions, and their interpretation and monitoring can belong to different actors.
However, this kind of situation is not unprecedented in the human rights system. Most significant conventions include a provision that states that nothing in that convention shall be interpreted as impairing the rights provided in other conventions or national legislation, which softens the contradiction.⁵

By establishing particular rights that belong exclusively to persons with disabilities, the UN CRPD challenges other conventions' special provisions on disability rights. Most conventions, the UN CRPD not excluded, also incorporate a provision stating that the convention in question is the minimum standard to be applied. Here, analysing the scope of application, content and monitoring system of the UN CRPD and other conventions is essential when specific rights for persons with disabilities are being integrated in the overall human rights framework.

It might also be possible to detach the General Principles for the human rights of persons with disabilities from the UN CRPD. These principles would then be observed in assessing the status of persons with disabilities. This creates a situation similar to the Convention on the Rights of the Child (CRC) that establishes the best interest of the child as a guiding principle, and is deemed to guarantee children special rights to protection, provision for the resources of the society and participation in decision-making that concern their lives.⁶

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5  E.g. European Social Charter, Article H states: “The provisions of this Charter shall not prejudice the provisions of domestic law or of any bilateral or multilateral treaties, conventions or agreements which are already in force, or may come into force, under which more favourable treatment would be accorded to the persons protected.”

2.1. Relation between the UN CRPD and other Human Rights Conventions

2.1.1. UN CRPD as an Independent Human Rights Convention

The UN CRPD is an independent human rights convention in the sense that it includes disability-adapted versions of almost all the rights provided e.g. in the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). The UN CRPD provisions are more detailed but the details may also include restrictions.

The UN CRPD contains rights and principles that would preferentially apply to all people and not just those with disabilities. For example Article 16 Freedom from exploitation, violence and abuse provides that States Parties take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities from these actions. This should also apply to all other people but at present such a general human rights provision does not exist. Paragraph 2 of the same Article provides that states give assistance and support to persons with disabilities and their families and caregivers in situations of exploitation, violence or abuse. Such assistance and support should be provided to all families in similar situations.

Some provisions in the UN CRPD are written so that persons with disabilities are directly compared to other persons. For example in health care, in addition to services that are needed because of the disability, persons with disabilities should receive the same range, quality and standard of health care and programmes as are provided to other persons. Some specific provisions in the UN CRPD are such that they could also be realized on the basis of the more general provisions. For example Article 30 Participation in cultural life, recreation, leisure and sport provides that States Parties take appropriate measures to enable persons with disabilities to use their creative and intellectual potential. These provisions could just as well be realized on the basis of Articles 4 and 9. Article 4 of the convention provides that States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for persons with disabilities. Article 9 on accessibility states that equal access has to
be provided to the physical environment, transport and other areas, and the Article includes a list of examples of this.

Many UN CRPD Articles merely repeat the provisions in other human rights conventions and add requirements of equality and disability adaptation. Paragraph 1 of Article 15 on torture and cruel treatment is word for word the same as the ICCPR Article 7, and equality and persons with disabilities are only mentioned in paragraph 2.

2.1.2. UN CRPD and Equality

The relation of the UN CRPD to other conventions is essentially defined through equality. According to the UN CRPD Article 1, the purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. In this respect, the convention is not limited to apply only to the rights and freedoms in the UN CRPD. Article 3 (General Principles) includes, among other things, non-discrimination, and Article 4 (General Obligations) contains the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. In addition, Article 5, paragraph 1 ensures equality before and under the law as well as equal benefit of the law. Paragraph 2 prohibits all discrimination on the basis of disability and provides that States Parties must guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. This means that protection must also be provided in cases where the basis of discrimination is other than the person’s disability.

The Convention for the Protection of Human Rights and Fundamental Freedoms (also European Convention on Human Rights, ECHR), as amended by Protocol no. 11, and the ICESRC and ICCPR do not contain specific provisions on persons with disabilities. However, they all require that the rights should be applied without discrimination. The list of prohibited grounds for discrimination included in these conventions does not include disability but the list is open. The situations where rights can be restricted are defined according to general principles on the restriction of human rights. The conventions prohibit any interpretation that restricts the rights
provided in the convention and the restriction of rights acknowledged in national legislation on the basis of the convention.

ICCPR Article 26 establishes an equal right to the protection of law without discrimination. This non-discrimination provision extends beyond the rights acknowledged in the ICCPR and applies to all individuals in every respect. The list that the Article provides does not include disability, but it is, again, an open list. The equality aspect in Article 26 is especially strong, because it guarantees equality in every respect and not just equal enjoyment of rights provided in that convention or other provisions. Combined with UN CRPD Article 1 on the realization of all human rights and fundamental freedoms, it offers an extremely wide scope of application for the human rights of persons with disabilities.

Article 2, paragraph 3 of the ICCPR is also significant for persons with disabilities. The paragraph asserts that if a person’s human rights are violated, he shall have an effective remedy, and requires that there be competent authorities to handle the matter. States Parties must then ensure that there are competent authorities to implement and enforce legal verdicts.

Article E of ESC, which prohibits discrimination, does not explicitly mention disability, but the list in this Article is also open. By forbidding discrimination, Article E supports Article 15 on disability rights and reinforces its aspect of affirmative action. In addition, Article G provides the context in which the ESC rights may be restricted, and Article H forbids interpretation of the Charter in any way that impairs more favourable treatment that would be accorded on other grounds. It is worth noting that the ESC appendix has an interpretation of Article E, according to which different treatment based on an objective and reasonable justification is not considered discriminatory.

CRC Article 2 is a general equality provision, which provides that the rights set forth in the convention are respected and ensured to all children without discrimination. Disability is mentioned in the list included in this Article, and the list is open. The core of the CRC is Article 3, which requires that in all actions undertaken by public or private social welfare institutions, the best interests of the child shall be a primary consideration. The corresponding obligation for parents and other guardians is set forth in Article 18 of the CRC. Also UN CRPD Article 7 states that the best interest of the child must be considered in all actions. CRC Article 41 states that the CRC cannot be used to violate any provisions in other international conventions or national legislation more conducive to the realization of the rights of the child.

Most CRC provisions illustrate specifically how the rights can be applied from a "child point of view". However, in some provisions this aspect is very thin or virtually non-existent and some do not have it at all. The inclusion of more general Articles in the convention can be seen to demonstrate that children also have these rights. A model example of this is Article 14 where the child’s right to freedom of thought, conscience and religion is written almost exactly the same way as in the first sentence of ICCPR Article 18. Paragraph 2 of Article 14 also corresponds almost word for word to ICCPR Article 18, paragraph 4, and paragraph 3 of Article 14 corresponds to Article 18 paragraph 3. The same applies to CRC Article 15 and ICCPR Articles 21 and 22.

2.1.3. CRPD and the European Union Charter on Fundamental Rights

The EU Charter on Fundamental Rights (EUC) also contains provisions important for persons with disabilities. These include Article 20 on equality before the law and Article 21 on non-discrimination. The list in Article 21 includes disability as forbidden grounds for discrimination. The list is open.

The EUC is addressed, as stated in Article 51, to the institutions, bodies and agencies of the European Union (with regard to the principle of subsidiarity) and to the Member States only when they are implementing Union law. This provision restricts the implications of
the EUC but its scope may be surprisingly wide in interpreting when Member States are implementing Union law. The most important reason why the EUC is significant is that it binds the EU Commission and Council when they make laws and the EU Court of Justice when it interprets them. Article 51, paragraph 2 is also important, as it states that the EUC does not extend EU competence.

EUC Article 52, paragraph 5 provides that provisions of the Charter that contain principles may be implemented only by legislative and executive acts of the Union and by Member State when they are implementing Union law. The provisions shall be judicially cognisable only in the interpretation of such acts and in the ruling on their legality. This provision is problematic in several ways. What is unclear, for example, is what are the legislative and executive acts taken by Institutions and bodies of the Union in the exercise of their respective powers.

Explanations relating to the Charter of Fundamental Rights⁹ are needed to be taken into account when interpreting EUC. According to the Explanations, the difference between rights and principles is that rights shall be respected whereas principles shall be observed.¹⁰ However, it has not been clearly defined which provisions of the Charter are rights and which of them are principles.

Principles become significant for the Courts only when the provisions in question are interpreted or reviewed. They do not however give rise to direct claims for positive action by the Union’s institutions or Member States’ authorities. This is consistent both with case-law of the Court of Justice and with the approach of the Member States’ constitutional systems to ‘principles’, particularly in the field of social law. The explanations on Article 52, paragraph 5 provide examples of principles in the Charter that include Article 26 on persons with disabilities. In the case of Finland, it is notable that the constitutional system is based solely on rights and not principles also in the field of social protection.

EUC Article 53 states that nothing in the Charter shall be interpreted as restricting or adversely affecting other rights that are recognized by Union law, international law or international agreements. In addition, Article 54 states that the Charter shall not be interpreted as implying any right to engage in any activity aimed at the destruction of any of the rights and freedoms recognized in this Charter or at their limitation to a greater extent than is provided for in the Charter.

2.2. UN CRPD and Disability Provisions of Other Conventions

The relation between the UN CRPD and other conventions’ provisions on persons with disabilities is interesting, because it raises the question of what should be done with provisions that regulate the same rights or principles. Essentially, each convention is an independent document with its own monitoring system. At the same time it is desirable and even necessary that the human rights of persons with disabilities are applied and interpreted consistently. This emphasizes the importance of provisions on the minimum level of application for the conventions. Also worth noting is the fact the UN system had previously not had many regulations on disability rights. Both the ICCPR and the ICESCR fail to mention disability, apart from their equality provisions where disability is only included in the term “other status”. Among extant human rights instruments only the CRC contains provisions that specifically take disability into account.

However, the application of other conventions, especially the ICESCR, to persons with disabilities has been widely discussed. The Committee on Economic, Social and Cultural Rights discusses persons with disabilities especially in its General Comment No. 5. The Committee notes that States Parties have a responsibility to eliminate discrimination based on disability. The Committee also goes through the ICESCR almost Article by Article from the disability point of view. The Committee has also paid attention to disability in some other Comments (e.g. General Comment No. 14 The right to the highest attainable standard of help). In General Comment

No. 5 the Committee stresses the importance of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and states that the Rules are a valuable reference guide in identifying how the ICESCR rights should be applied to persons with disabilities.¹²

There is a remarkable cross-reference in the UN human rights convention system between the UN CRPD and the CRC. Both are general instruments that discuss and apply human rights from the point of view of a certain group. A similar type of assessment is generated from the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the UN CRPD. This connection is not entirely clear, as the CEDAW mainly contains provisions on equality. A clearer connection can be seen between the UN CRPD Article 7 and the CRC Article 23, both concerned with children with disabilities.

UN CRPD Article 7, paragraph 1 deals primarily with the equality between children with disabilities and other children. The paragraph provides that States Parties take measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms. Article 23, paragraph 1 of CRC basically provides that the general conditions to live a good physical, psychological and social life are ensured to children with disabilities.¹³ UN CRPD Article 7, paragraph 2 mentions one key concept of the CRC, the best interest of the child, and states that the best interests of the child shall be a primary consideration for all children, including those with disabilities.


In CRC Article 23, paragraph 2, States Parties recognize the right of the child to receive special care and assistance because of the disability. Paragraph 3 provides that the financial resources of the people caring for the child are taken into account. Paragraph 4 requires States Parties to use international cooperation in promoting the rights of children with disabilities. The provisions in CRC Article 2 correspond largely to UN CRPD Article 7, paragraph 2. The hearing of the child is included in both conventions.

Article 15 of ESC is specially focused on persons with disabilities. The provision expresses the wide commitment of the Contracting Parties to promote the participation in society by persons with disabilities, and requires parties to take any required action. Essential in this aspect are education, employment and participation in society, including cultural activities. With this equality objective, persons with disabilities are integrated into practically all articles of the convention. The article on persons with disabilities virtually ensures that special needs for persons with disabilities are taken into account.

The ESC takes disability specifically into account in numerous ways. In Part I, which contains principle-esque provisions, the Contracting Parties accept as their policy aim to effectively realize rights and principles by ensuring that persons with disabilities have the right to independence and participation. In the actual convention articles, persons with disabilities are mentioned in provisions concerning vocational guidance and training. In Article 9 on vocational guidance, persons with disabilities are explicitly mentioned in order to emphasize their inclusion in the expression “all persons” (“all persons, including the handicapped…”). The same formulation is repeated in Article 10, section 1. However, this kind of emphasis was apparently not considered necessary in paragraphs 2-5 of Article 10. The articles can – and should – be interpreted so that the principle of including persons with disabilities from paragraph 1 also applies to paragraphs 2-5 (although paragraph 1 is not a general clause relative to the subsequent paragraphs). This interpretation is supported by the fact that all paragraphs begin in the same manner:

“With a view to ensuring the effective exercise of the right to vocational training, the Parties undertake”.

In the EUC, the core article for persons with disabilities is Article 26. It includes the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community. The EU has also agreed to respect this right. Explanations relating to the Charter of Fundamental Rights discuss Article 26, and it appears as if the Article becomes applicable only as a principle. This means that it must be observed, but active measures are not required.

3. Nature of the UN CRPD

The UN CRPD is part of a series of international conventions that have as their particular objective to take into consideration the characteristics and typical living conditions of a certain group of people in relation to human rights regulations. Comparable provisions would then be for example provisions that forbid discrimination, above all the Convention on the Elimination of all forms of Discrimination against Women and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Conventions that contain other aspects in addition to the elimination of discrimination, like the UN CRPD, are the Convention on the Rights of the Child

(CRC) and the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families.

The starting point for the CRC is that although children have the same rights as adults, there are different aspects that relate to them.\textsuperscript{16} This basis is strong as long as we succeed in avoiding the misconception that children are not ‘human beings’ in the sense intended in other human rights conventions.

The UN CRPD is an independent convention, and most of its provisions become applicable with the same content as human rights provisions generally do. In these cases however, human rights are examined from the disability and equality points of view. The UN CRPD also contains some rights that apply only to persons with disabilities, but as a whole these amount to a relatively small number. In this respect, as an independent human rights convention, the UN CRPD is in many ways comparable to the CRC. To a great extent, the UN CRPD can be seen as a disability-adapted version of human rights while also maintaining a role as an independent human rights instrument.

The aforementioned interpretation is supported by UN CRPD Article 1, according to which the purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. This purpose is not limited to the rights and principles in the UN CRPD, thus extending its applicability to any right that can be included in the concept of human rights and fundamental freedoms.

Is the CRC a special agreement or application of human rights to a certain group or living situation? Or does it assemble and arrange the human rights of a certain group or living situation? It seems that the CRC can be placed in either of these groups. It examines the application of general human rights to children, but some of its Articles also create new rights meant especially for children. Perhaps the most important aspect in this regard is that all of the articles are examined from the point of view of the child’s best interests. Special

rights for children include e.g. the rights to engage in play and recreational activities.

There are good justifications for why the UN CRPD should be regarded as comparable to the CRC. The UN CRPD is predominantly a convention that creates new points of view. This can be noted for example in paragraph (e) of the Preamble and Article 1 of the Convention. The paragraph defines disability as an evolving concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers. Article 1 presents the concept of long-term physical, mental, intellectual or sensory impairments that may prevent full and effective participation in society. In this sense the point is to remove any barriers that are caused or might be caused by disability. This viewpoint forms the basis for the whole convention by emphasizing the importance of equality, meaning de facto, functional equality. General human rights conventions apply equally to persons with disabilities and children. Therefore granting them human rights would not require new conventions. The logic of the convention system requires that these conventions have a particular function in realizing the rights of their special groups, too.

4. Special meaning of the UN CRPD

A special characteristic of the UN CRPD is its heavy emphasis on equality and non-discrimination. This impression is supported by the formulation of nearly all of its articles, and by the adoption by the UN of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The principle of equality is stressed in paragraphs (b, without distinction), (c, without discrimination) and (e, equal basis) of the UN CRPD Preamble, Article 1 on the purpose of the convention and in the general principles in Article 3.

Article 3 defines both non-discrimination (b) and equality of opportunity (e) as principles for the application of the convention. Equality of opportunity might be a problematic concept if merely construed to mean putting people on the same level in the use of opportunities. Equality in the use of opportunities can be examined in different ways. It could mean (i) an equal starting point where everyone is afforded the same basics to start from, (ii) equality in the use of resources and
(iii) equality of outcome, where everyone is guaranteed to achieve a certain (minimum) level. For persons with disabilities, an equal starting point or an equal opportunity to use resources do not necessarily guarantee equality. For persons with disabilities, most critical is gaining access to more resources in order to actually achieve genuine equality. Equality of outcome is concerned with actually achieving an equal outcome for everybody, albeit that ‘equal outcome’ can only be defined such that all achieve a certain minimum level. This latter interpretation of equality is supported by Article 5, paragraph 4 of the convention. The paragraph explicitly allows affirmative action to accelerate or achieve real equality. 17

Another essential section in a general examination of the convention is Article 4 on general obligations. States Parties undertake, among other responsibilities, to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the Convention, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination, and to improve the situation of persons with disabilities in various areas explicitly mentioned in the convention. Additionally, the protection and promotion of human rights is considered in all policies and programs. Therefore it can be stated that States Parties have committed to take action in order to implement the rights, eliminate discrimination and improve the actual conditions of persons with disabilities.

UN CRPD Article 4, paragraph 2 on general obligations, which is comparable to ICESCR Article 2, paragraph 1, contains the commitment of States Parties to take measures to the maximum of their available resources, in order to achieve progressively the full reali-

vation of the rights in the convention. Additionally, paragraph 3 explicitly provides the special right to participation by persons with disabilities. Paragraph 4 contains a provision typical for human rights conventions, according to which the convention cannot be used as grounds to impair other rights already in force.

Equality is the leading principle in the UN CRPD. Its implementation means that disability is not and cannot be a barrier to bringing the rights and conditions of persons with disabilities to an equal level with others. Furthermore, disability cannot form a barrier to any other activity. This means that the examination is two-way. Participation by and inclusion of persons with disabilities are general principles in the convention. These principles are reflected in the Preamble paragraph (g) on the mainstreaming of disability issues, in paragraph (m) on the value of relations between persons with disabilities and other members of the society and the contributions made by persons with disabilities to the overall well-being of their communities, as well as in the Article 2 definitions on reasonable accommodation and universal design. Together, equality and participation create the principle of accessibility that is introduced in Article 9 of the Convention.

Taking action to achieve equality can be regarded as the functional principle in the UN CRPD. This is reflected particularly in the fact that the convention requires States Parties to promote equality with positive action that creates special chances, negative action that eliminates discrimination, and optimal action that accommodates the environment to suit persons with disabilities.

Another functional principle in the convention is inclusion. Inclusion means that the influence and participation by persons with disabilities has to be regarded as a key point in implementing the convention and that persons with disabilities have to be raised, as

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much as possible, to the same status as other persons. Inclusion is reflected, in addition to the equality principle, in Articles 3, 19, 29 and 30 discussing influencing and participation, and in Article 2 requiring reasonable accommodation and universal design. Reasonable accommodation refers to modifications and adjustments undertaken in particular cases. Universal design refers to the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design is a form of accessibility in which there is no longer need to pay special attention to accessibility.

Mainstreaming disability is the third functional principle in the UN CRPD. Mainstreaming indicates that disability issues are seen as a part of all other activities and policies. At best, this leads to a situation where disability questions don’t have to be deliberately raised again every time because they are already built into and integrated in all actions.19

The UN CRPD is both an independent human rights convention and an instrument that takes into account and develops the interpretation of disability issues. Thus, it offers an excellent possibility to increase actions towards respecting, protecting and fulfilling the rights of persons with disabilities. It advances measures by government officials and acts as a tool for the horizontal implementation of human rights.

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PART II: ‘TRADITIONAL’ DISABILITY RIGHTS AND THE UN CRPD
Chapter 3:


Jukka Kumpuvuori and Martin Scheinin

1. Introduction

Equality and non-discrimination are the key concepts when considering the human rights of persons with disabilities. Ultimately, all issues arising in the lives of persons with disabilities can be framed within the context of equality and non-discrimination. It will then depend on the scope and substance of the actor’s approach to equality and non-discrimination whether these norms will deliver or not. This is why the domain of disability rights is so much devoted to promoting equality and non-discrimination, although it of necessity addresses other substantive and procedural issues as well.

International law on non-discrimination has evolved to include the obligation to treat different cases differently. This is particularly important in the domain of disability rights, as the complexity of discrimination in the context of disability calls for new tools in examining equality and non-discrimination. The aim of this article is to explore the dimensions of the norm of non-discrimination in international human rights law and its implications for different stakeholders.

The article starts with a review of the notions of equality and non-discrimination, especially looking at the development of the approach of considering as a distinct form of discrimination the failure to treat different cases differently. After this, the article moves to the area of disability and asks why particularly persons with disabilities should be treated differently. Finally, the article looks at the implications of
the proposed wide understanding of non-discrimination for different stakeholders.

2. Equality and Non-Discrimination

2.1. Evolution of the Norm of Non-Discrimination

Entering the discourse on equality and non-discrimination, we are immediately confronted with the question on the relationship between the concepts of ‘equality’ and ‘non-discrimination’. Are they symmetrical counterparts or do they differ in some regard? At first sight, it appears logical to use these two concepts as interchangeable, as they basically refer to the same matter, the notion of equal treatment of human beings. If one wants to make a distinction, it is possible to argue that equality represents an ideal, while non-discrimination rests on particular forms of actions. Within this distinction, the positive counterpart for ‘non-discrimination’ would be ‘equal treatment’. When thinking about achieving equality, equal treatment does not necessarily lead to equality.\(^1\) Herein lies the essence of this article, in demonstrating the need to consider non-discrimination (also) outside the scope of equal treatment, including the notion of positive measures that aim at achieving equality. In the context of this article equality is considered as an ideal, which is pursued through conduct of non-discrimination by different actors. Acknowledging the need to address both direct and indirect discrimination serves well both the academic needs of differentiation between concepts and the examination of the practical significance of the concepts.

The recognition of positive measures in achieving equality takes us to the distinction between formal and substantive equality, which is the foundation for the whole domain of treating different cases differently. Formal equality means treating similarly situated individuals in an equal (same) manner. Substantive equality means treating all individuals equally, even if they are in fact different, i.e.

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not equal. Substantive equality recognizes the wide spectrum of human diversity. Thus, it triggers the possibility for positive measures, not only making them acceptable but mandatory in cases of factual inequality.

As to terminology, direct discrimination can be seen mostly functioning in the context of formal equality and being based on treating every similar case in the same way, without paying attention to differences that may be relevant. Indirect discrimination can be seen to function mostly in the context of substantive equality, and it requires paying particular attention to the differences of the elements at hand. Under that notion it logically follows that ignorance of the differences of the elements at hand inevitably amounts to indirect discrimination. Different cases must be treated differently in order to achieve substantive equality. We will now look more closely at the notion of indirect discrimination in international human rights law, and especially at the development of the idea of considering the failure to treat different situations differently as a part of the concept of indirect discrimination.


3 However, Schiek pinpoints that also the recognition of direct discrimination may require acknowledging social reality in practice, see D. Schiek, ‘Chapter Three. Indirect Discrimination’, in Schiek et al (eds.), supra note 1 (pp. 323-475) p. 328. Thus, also direct discrimination works partly in the framework of substantive equality.

4 The judgment by the European Court of Human Rights in the case of Thlimmenos v. Greece of 6 April 2000 illustrates well the development of the jurisprudence on the notion of the obligation to treat different cases different. In the ruling, the Court states:

"The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different." (paragraph 44).

De Schutter points out that the European Court of Human Rights has not yet affirmed an obligation to provide disabled people with effective accommodations but that nevertheless there are signs that the Court is moving towards such an affirmation, see O. de Schutter, ‘Reasonable Accommodation and Positive Obligations in the European Convention on Human Rights’, in A. Lawson and C. Gooding (eds.), Disability Rights in Europe. From Theory to Practice. Essays in European Law (Hart Publishing, Oxford, 2005, pp. 35-64) p. 61.
The definition of indirect discrimination is complex and varies widely between different legal regimes. As an illustrative and comprehensive definition, and one suitable in the context of this article, we may take the definition of indirect discrimination laid down in the European Council Directive 2000/78/EC:

“(…) indirect discrimination shall be taken to occur where an apparently neutral provision, criterion or practice would put persons having a particular religion or belief, a particular disability, a particular age, or a particular sexual orientation at a particular disadvantage compared with other persons unless (i) that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary, or (ii) as regards persons with a particular disability, the employer or any person or organisation to whom this Directive applies, is obliged, under national legislation, to take appropriate measures in article 5 in order to eliminate disadvantages entailed by such provision, criterion or practice.”

There may be problems with this particular definition of indirect discrimination, such as introducing the elements (i) and (ii) under the notion of indirect discrimination, rather than the concept of (direct or indirect) discrimination as such. Nevertheless, the key element of seemingly neutral (identical) treatment of individuals who are in different situations resulting in discriminatory outcomes is properly captured as the essence of indirect discrimination. 7

To put it in other words, indirect discrimination means that ‘provisions, criteria or practices’ have a detrimental effect on a particular group or a persons, while these ‘provisions, criteria or practices’ do not necessarily mention the grounds for discrimination specifically. Thus, indirect discrimination of persons with disabilities may be present in a ‘provision, criterion or practice’, which does not say anything about disability. To be clear, detrimental effect in itself does not constitute indirect discrimination. As the Directive cited above

6 Article 5 regulates the duty to provide reasonable accommodation for persons with disabilities in the sphere of employment and training.
7 For case law by the United Nations Human Rights Committee applying the notion of indirect discrimination, see Cecilia Derksen and her daughter, Kaya Marcelle Bakker v. the Netherlands (Communication No. 976/2001), Final Views of 1 April 2004.
regulates, the establishment of indirect discrimination further requires that the 'provisions, criteria or practices' are not objectively justified, meaning that they either do not serve a legitimate aim or the measures of achieving a legitimate aim are disproportionate. This latter part of the definition belongs, however, in our view, at the level of defining discrimination generally, be it direct or indirect.

The background of the doctrine of indirect discrimination is in the Anglo-American legal sphere, especially in case law in the United States and the legislation and case-law of the United Kingdom and Ireland. Schiek describes indirect discrimination as one of the rare cases of legal transplants from the Anglo-American legal order into Continental legal orders and addresses the problem of very mixed receptions of the concept in different legal orders relating to this overseas reception.⁸

In pursuing factual equality, various types of measures can be taken. Here, we look more closely at notions of reasonable accommodation and positive measures. The examination of these concepts brings us to the very heart of disability discrimination. Disability discrimination is a domain in which the theme of accommodation is highly relevant. Therefore, developments in the field of disability discrimination have contributed considerably to the whole discourse of international human rights law on non-discrimination. To illustrate this, we present four legal instruments that will serve as a point of departure for an examination of the notions of reasonable accommodation and positive action. The four instruments are Articles 2 and 5 of the UN CRPD, the Americans with Disabilities Act (ADA)⁹, the European Council Directive 2000/78/EC, and General Comment No. 5 of 1994 of the Committee on Economic, Social and Cultural Rights.

ADA addresses reasonable accommodation in the field of employment:

"(9) Reasonable accommodation
The term "reasonable accommodation" may include
(A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and

⁸ Schiek, supra note 3, p. 324.
(B) job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities.”

Further, ADA recognizes particularly the failure to provide reasonable accommodation as a form of discrimination, in its section on public accommodation:

“(2) Specific prohibitions
(A) Discrimination
For purposes of subsection (a) of this section, discrimination includes (…)
(ii) a failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations; (…).”

Also the European Council Directive 2000/78/EC regulates the duty of employers to provide reasonable accommodation for persons with disabilities:

“Article 5

Reasonable accommodation for disabled persons

In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.”

10  ADA, section 1119 (9).
Even though Article 5 refers to the ‘principle of equal treatment’, it does not explicitly address the relationship between the duty to provide reasonable accommodation, and equality and non-discrimination. Waddington points out that in early proposals for the Directive, the link was more visible, as the notion of reasonable accommodation was placed in Article 2 on the concept of discrimination.\(^{13}\) While the Directive does not explicitly regulate the failure to provide reasonable accommodation as a form of indirect discrimination, it can surely be said that it at least implicitly carries this notion, which will be operationalized through the joint interpretation of the provisions on the concept of discrimination and the duty to provide reasonable accommodation.

Further, General Comment No. 5 (1994), Persons with Disabilities, by the Committee on Economic, Social and Cultural Rights, addresses the denial of reasonable accommodation as a form of discrimination:

> “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 the recognition, enjoyment or exercise of economic, social or cultural rights.”\(^ {14}\)

The latest development in the field of human rights law on considering the failure to provide reasonable accommodation as a form of discrimination is the Convention on the Rights of Persons with Disabilities (the UN CRPD)\(^ {15}\). Article 2 of the UN CRPD addresses the issue:

> “Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other

field. It includes all forms of discrimination, including denial of reason-
able accommodation; (...)”

The UN CRPD also addresses the notion of reasonable accommodation in Article 5:

“3. In order to promote equality and eliminate discrimination, States
Parties shall take all appropriate steps to ensure that reasonable
accommodation is provided.”

While equality and non-discrimination are at the heart of the UN
CRPD, and disability is a notion that has added value for developing
and understanding these concepts, it must be noted that the UN
CRPD is the result of a long process in the evolution of notions of
equality and non-discrimination in international law in general.17

A landmark case in the context of non-discrimination and disability
is the case of Glor v. Switzerland decided by the European Court of
Human Rights.18 In this judgment, the Court makes, for the first time in
the history of international human rights jurisprudence, the following
findings: 1) it finds a violation of the right of non-discrimination on
the basis of the applicant’s disability;19 2) it makes a reference to the
UN CRPD,20 and 3) it makes a reference to the notion of ‘reasonable
accommodation’ in the context of disability.21

2.2. Reasonable Accommodation / Positive Measures

The discussion on the relationship between considering measures
of accommodation as positive actions stepping outside the realm
of non-discrimination, or as measures tackling discrimination, has
been pursued in the particular context of persons with disabilities.
Waddington describes comprehensively the discussion on this

16  CRPD, Article 2.
17  O. M. Arnardóttir, ‘3. A Future of Multidimensional Disadvantage Equality?’, in
O. M. Arnardóttir and G. Quinn, The UN Convention on the Rights of Persons with
Disabilities. European and Scandinavian Perspectives (Martinus Nijhoff Publishers,
19  Ibid., paragraph 98 (violation of article 14 in conjunction with article 8).
20  Ibid., para. 53.
21  Ibid., para. 95.
theme, illustrating the views of different authors, whose points of view vary from considering reasonable accommodation as a mere form of positive measures or affirmative action to considering reasonable accommodation as an inherent component of non-discrimination.22

Stein argues that the ADA mandated accommodations are, in fact, anti-discrimination remedies that are an essential normative device for enhancing equality for persons with disabilities.23 This is the essence of disability discrimination law, where the area of labour law has played a pioneering role and contributed to the development of disability discrimination law in general. In order to tackle disability discrimination in a manner consistent with human rights, failure to provide accommodation must be identified as a form of discrimination. It appears that the evolution in international human rights law is moving in this direction, the latest remarkable demonstration of this being the United Nations Convention on the Rights of Persons with Disabilities.24

We can conclude this section of our article by stating that there has been a shift in international human rights law towards considering the failure to treat different cases differently to be a form of discrimination, and that disability is increasingly recognized as constituting a ‘different case’ requiring different treatment. Thus, the framework of international human rights law provides a rather new way of looking at disability discrimination. In the following section, this article sketches a platform through which it is possible to examine the new paradigm in the interplay of international law, national law and policy, actions of the civil society and at the grassroots level of persons with disabilities.

3. Why Should Persons with Disabilities in Particular be Treated Differently?

In the context of non-discrimination and the duty to treat different cases differently, we obviously encounter the question: Why should some particular group, or its individual members, be treated differ-

22 Waddington, supra note 13, p. 745-750.
23 Stein, supra note 2, p. 583.
ently? This chapter identifies some fragments of the answer to this question.

The paradigm in disability discrimination has evolved from treating persons with disabilities in a similar way to others, to taking the differences of persons with disabilities into account.25 This reflects a change from a liberal mindset, which carries the notion that human beings are more similar than they are different26, to a mindset that conflicts with a simplistic liberal theory of equality by recognizing the differences between human beings, such as gender or disability.27 Ball provides an examination of the ADA antidiscrimination statutes on disability discrimination. In this context Ball argues that the application of a sameness model of equality28 is not enough for guaranteeing equality to all individuals with disabilities, because sometimes those disabilities can negatively affect work performance unless they are accommodated.29 Ball goes on to explain that the difference model recognized in the ADA consists of the refusal by an employer to reasonably accommodate the disability of an employee. He argues on the implications of the difference model:

"In cases where an employee with a disability asks to be accommodated, the employer may be legally required to (1) take the disability into account (as opposed to deeming it irrelevant) in accommodating the employee and, as such, (2) treat the disabled employee differently from able-bodied employees (...) in the same workplace."30

Treating persons with disabilities in a same way as others, in cases where disability constitutes a relevant element, does not promote but rather acts against the ideal of equality.31

27 Ball (ibid.) analyses the connections of liberal, feminist and communitarian theories of liberty and the place of disability discrimination in this setting.
28 Meaning the liberal vision of equality that imposes an obligation to treat similarly those who are similarly situated, see Ball, ibid., p. 136.
29 Ibid.
30 Ibid.
31 Ibid., p. 137.
One could at this point ask, why, in the particular context of persons with disabilities, a superficially neutral rule or situation would cause indirect discrimination, as opposed to a fair, but unfortunate result. This brings us to questions such as: “Why is or is not something discriminatory?” and “Why are equality measures needed to achieve de facto equality?” Stein and Waterstone argue that “Societal perceptions and reactions are crucial to defining disability”. 32 Their argument is that “Exogenous factors (such as the way mainstream societies create environments), rather than endogenous qualities, are what by and large create the disability classification.” 33 They go on by arguing that “Much like people of colour, people with disabilities are not inherently dissimilar from one another because of medically ascertainable facts. Rather, the disabled are placed outside the mainstream and constitute a coherent ‘other’ group that society considers as being apart from the biological norm”. 34

It is evident that people differ from each other. No person is identical to another. 35 It seems clear that the notion of formal equality has not been able to address human diversity, and a more comprehensive notion of substantive equality has been developed in international human rights law. 36 Nevertheless, it is a matter of assessment which differences are considered relevant in terms of pursuing equality. 37 The result of assessments can, in practice, be looked at in different rights catalogues, such as international human rights conventions and national constitutions. In those, one can pinpoint which grounds of non-discrimination are at each time considered to be relevant enough. In this sense, it would be delusional to claim that grounds for differentiation are fixed and universal. This is highly relevant, when considering the notions of equality and non-discrimination in a global context.

33 Ibid.
34 Ibid.
35 Sen argues on this: “Human diversity is no secondary complication (to be ignored, or to be introduced ‘later on’); it is a fundamental aspect of our interest in equality”, see A. Sen, Inequality Reexamined (Oxford University Press, Oxford, 1992) p. xi.
37 Schiek et al, supra note 1, p. 27.
Persons with disabilities can be argued to have group characteristics that allow them to be considered to be different from the mainstream population in the negative sense of being less capable, as opposed to being stronger or smarter. This has the effect that persons with disabilities are easily subjected to stigma stemming from membership in this group of people. Stein and Waterstone argues that this has two implications, namely that this kind of heuristics creates both prejudice and group classification. In terms of disability discrimination and means to tackle it, this is important in at least two ways. First, prejudices are the major cause of discrimination. Acknowledging prejudices and assessing the actions or omissions of people makes it easier to determine whether or not we are dealing with discrimination. Second, identifying persons with disabilities as a group facing constant discrimination will result in demands for laws and policies that produce equality.

4. Conclusion

Equality and nondiscrimination form a well-established and essential dimension of human rights law. Despite this, the law of equality and nondiscrimination has been, and still is, in a state of dynamism and evolution. At different times, within different legal regimes and in different geographic, areas the exact outcomes of provisions on equality and nondiscrimination have proven to be quite different. In their most modest versions, equality and nondiscrimination can be seen as a dimension of other, already protected rights, and simply requiring formal equality, i.e. the identical treatment of persons in the same situation.

Be it under modern constitutions, traditional United Nations human rights treaties, European Union law or the new Disability Convention, the scope of application of the provisions on equality and nondiscrimination has expanded way beyond formal equality. Substantive equality, indirect discrimination, reasonable accommodation, special measures and the obligation to treat differently persons in different situations are distinct but related notions that

38 Ibid.
both capture this process of expansion and provide a platform for its further development.

The Convention on the Rights of Persons with Disabilities is a milestone in this process and will no doubt provide inspiration for dynamic developments in years to come.
Chapter 4:

The Changing Relationship between Disability and Education

Joel Kivirauma and Matti Laitinen

1. Disability as an Object of Classification

Traditionally, research on disability has, in line with the medical model of disability, centred on an individual’s limitations and inabilities when reasons are sought to explain problems persons with disabilities face. The medical approach has also been called the limitation model, because it focuses on the individual’s limited ability to perform. The social model for disability, developed in the 1970s and 1980s, is the total opposite of this way of thinking. According to this model, the problems faced by individuals with disabilities are not primarily caused by the qualities of that individual; rather, they are caused by society’s unwillingness or inability to remove disabling obstacles and social restrictions.¹

The situation briefly discussed above has over the past years become more multifaceted. The traditional, British, masculine approach to social disability studies is tied to the material and structural prerequisites for disability, whereas the newer post-modern approach with a more feminist emphasis is tied to cultural factors. The materialistic approach is blamed for negating cultural factors, neutralising the disability and neglecting to investigate it. Additionally, this approach makes a sharp distinction between the private and the political in such a way as to dismiss personal experiences related to disability as irrelevant to research. In other words, this approach embodies a very traditional socio-political rift between structures and

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¹ S. Vehmas, Vammaisuus. Johdatus historian, teoriaan ja etiikkaan (Gummerus, Helsinki, 2005).

Translated from Finnish to English by Anna Seppänen-Lingenfelter
actors. The former have attempted to investigate the material prerequisites for disability conditions, the latter its cultural construct.²

Although the divisions within social disability studies may seem irreconcilable, they are not necessarily so. Carol Thomas, for example, maintains that the main problem with researchers who emphasise cultural factors is their tendency to view material factors such as employment, education and the constructed environment as uninteresting. Researchers who emphasise culture have, rightly so, taken to investigating discourse prominent in medicine, in the production of welfare services and in education. However, this does not negate the significance of material factors. It should also be asked: why do dominant discourses prevail? What social groups have the power to beget and maintain said discourses? Thomas also calls for the sociological examination of disability for determining its meaning and consequences. Now, in post-modern research, corporality is in danger of disappearing in the wake of language and discourse.³

According to Thomas, varying theoretical approaches enrich disability research. Becoming entrenched behind dogmatic positions should be avoided. Developing a tolerance for diversity, or perhaps better said, increasing respect for diversity is one of the goals of disability research. According to Thomas, the correct question is not whether it is social factors or impairment that causes this or that functional limitation. Rather, “How does a prejudiced, disability-producing social relationship develop and endure within social structures and cultural constituents?”⁴

Tom Shakespeare has also voiced loud criticism of the traditional social model.⁵ Shakespeare maintains that his interactional approach converges with Thomas’ relational model in many ways. Both approaches hold that disability is to be understood as a result of multiple factors, both internal (an impairment, etc.) and external (the environment, support systems, discrimination, etc). Although an

³ Thomas, supra note 2, pp. 141-142.
⁴ Thomas, supra note 2, pp. 155-156.
observation of any positions of power should hold a significant role in each theory that pertains to disability, defining disability as one form of discrimination as Thomas does is, according to Shakespeare, an incorrect point of departure for the following reasons. Firstly, defining disability as a form of discrimination results in circular reasoning, because it obligates the researcher to find and identify said discrimination. The researcher’s degrees of freedom exist on the continuum much discrimination - minimal discrimination. Secondly, separating persons with disabilities into two categories based on either the disability or the environment is not practical. The precedence of the impairment or the environment can alternate depending on the person and on the situation. Shakespeare describes his personal experiences in the following way: “…in some situations I am a person with impairment, and in other situations I am disabled person…”

Thirdly, the positive experiences of persons with disabilities may be ignored if disability is defined as discrimination. Positive experiences in relationships with non-disabled people shape, for persons with disabilities, the core of everyday life. Admittedly discrimination and social barriers do, in part, produce disability for the majority of persons with disabilities in varying situations. This does not mean, however, that disability should be defined as discrimination or as a social barrier. The impairment and its physical and mental consequences remain even if all social barriers ceased to exist.

According to Shakespeare, impairment is a necessary but not sufficient condition for the disability relationship. Disability is always the result of the interaction of certain physical and mental factors. The most central of these are the impairment, personality, attitudes, environment, politics and culture. Thomas and Shakespeare share the view that disability is the sum of many factors. However, they differ in that Thomas emphasises the significance of discrimination and Shakespeare that of the impairment. Central for Shakespeare is a balance between the medical and social models, not their juxtaposition as polar opposites.

The purpose of the above introduction to the critique of the social model is not to trivialise the model, but rather to show that the original social model does not present the final truth on the matter. The indisputable merit of the social model is, for one, the removal of the

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6 Shakespeare, supra note 5, p. 57.
burden of guilt from the shoulders of persons with disabilities – the fault lies not with them but with the disabling society. This implicated the rise of self-respect and self-confidence for persons with disabilities. Further, the social model provided, for persons with disabilities, a political strategy that centred on the removal of societal barriers. It drew the attention away from individual tragedy to the limiting structures constructed by society. Simultaneously, it had to do with the unravelling of the concept of the “naturalness” of disability.\(^7\) The dialogue and disputes the social model generates prove that it continues to provide a functional framework in disability research.

Questions pertaining to the education of children with disabilities have traditionally been examined from the vantage point of special education. The starting premises of the traditions of social disability research and that of special education are quite far removed. The field of special education represents –excluding a few exceptions\(^8\) - a traditional style of research which is focused on the individual. It is largely in response to this that the social model of disability research was borne. Problems that arose were seen as an individual pupil’s problems. Also, the given environment and any classifications founded on medicine and psychology were accepted without question. Is there any way these approaches can be examined side by side?

If we assume there are no points of convergence for the two approaches, that their starting premises are too far apart to make it worth finding fruitful connections between the two, we have adopted a stance according to which scientific paradigms are eternal, unchanging and worse: completely independent of our actions. This is not true, however, as Thomas S. Kuhn most recently convincingly established nearly half a century ago.\(^9\) Paradigms come and go. Paradigms don’t necessarily disappear from social sciences, but they evolve and further supplement their points of origin. According

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7 Shakespeare, supra note 5, pp. 29-30.
to Kuhn, each researcher that has adopted a paradigm has essentially been socialised to the paradigms of the generation during which he/she acquired his/her scientific education. From a generational theory perspective, it could be said that the original socialisation to certain behaviours becomes a significant scientific learning experience affecting all of the researcher’s later actions.  

Social disability research has, in our opinion, a lot to offer to research done in the field of special education. We mention a few as an example. The voice of pupils with disabilities and that of their parents has been very faint in special education research. The activities and significance of disability organizations in special education issues have not been studied. How is the position of persons with disabilities defined during a time in which social justice questions have been replaced by bureaucratic rationale, which pursues the most effective methods for performing tasks dictated by higher authorities?  

Further research should, in the spirit of social disability research, be increasingly directed to studying the whole life span of children with disabilities. The discourse pertaining to the concept of pupils with special needs should be analysed in all its implications and effects. Is this merely a question of a new legitimate manner of speech which produces the same dualistic system it was intended to unravel?  

How does the inclusion discourse exist and thrive in schools where more and more emphasis is placed on effectiveness and excellence in the spirit of neo-liberalism? What is the standing and the subjective right of a differently-abled pupil in an environment that increasingly emphasizes competition? There are suspicions that these competing discourses cannot be integrated. Should this prove

13 The significance of language in disability research should not be underestimated. The social model prefers the term “disabled people” because it implies that disabled people are disabled as a result of society. The term “people with disabilities” is not acceptable according to the social model, because there the disability is tied to an individual. Still many prefer to use this term because it puts the person before the disability (Shakespeare 2006, 32-33).
true, the ones who incur the greatest losses are, once again, the pupils with disabilities.14

Next we briefly discuss about international developments in special education. Then we will examine the Finnish school system and its development, keeping in mind especially the position of and the educational arrangements made for pupils and students with disabilities in compulsory education and in institutions of higher education. The chapters concerned with compulsory education are structured in part historically, because even the oldest special education arrangements are, to a certain extent, in use today. The more extensive arrival of students with disabilities in higher education is, compared to those in compulsory education, a fairly recent phenomenon. As a result, the emphasis in the chapters addressing higher education is on the present.

2. International Developments in Special Education

Special education cannot be understood by examining it in a vacuum. Special education is a part of society – more specifically, a part of the educational system – and it should be examined as such. Special education is not arranged for the sake of special education. Pupils are labelled deviant by other parts of the system. Each society (and school) must define the parameters beyond which behaviour is defined as deviant. In his theses Emile Durkheim, a pioneer in sociology, makes reference to this need to label and define. According to him, deviance is a normal phenomenon in society. In other words, deviation exists in every society.15 Durkheim’s thesis also depicts quite accurately the ambiguous line between the normal and deviant, which is in a permanent process of being redefined. Where this line is drawn is a result of complex economic, political, social and religious factors at a given time. The humanity and equality of a society can

15  E. Durkheim, Sosiologian metodisäännöt (Tammi, Helsinki, 1982).
be assessed by how it treats those of its citizens that are physically, mentally and socially different from the mainstream.\textsuperscript{16}

The systematic education of individuals with disabilities is a fairly new phenomenon in human history. It has existed for barely 300 years. As a result of the new European movement, enlightenment, persons with disabilities were no longer viewed as beings permanently crippled by original sin. Rather, they were viewed as perpetually developing individuals who could be affected through educational measures. The upbringing of children with disabilities was based on principles of child protection of that time: protection, isolation and dependence. Institutions were the concrete product of this organized social responsibility, places where protective upbringing was realized in practice. The protection of children with disabilities in the spirit of philanthropy – and often under the guidance of religious leaders – was the visible side of institutions' activities. Simultaneously, however, institutions were taking on the responsibility for social control by placing a marginalized group of people into a setting of productive and supervised activities. The goal was to make this otherwise consuming populace productive, a group capable of sustaining itself. The isolation of special institutions from elementary education continues even today. This isolation has its roots in the commencement of institutions, when the educational system had not yet taken shape.\textsuperscript{17}

The original philanthropic perceptions of special education were trampled by the eugenics movement that became prevalent at the beginning of the century. The eugenics movement, which aimed to create a genetically and socially pure population, had very negative repercussions for persons with disabilities, such as the creation of sterilisation laws in many countries. Divergent individuals were deemed worthless, and a burden to society. Winzer calls the time period from 1880-1925 a time of scientific racism.\textsuperscript{18} Winzer also sees this time to have had a significant impact on the increase of separate educational facilities. Defenders of separate educational facilities presented special classes as the only effective method for protecting

\textsuperscript{16} J. Rawls, \textit{Oikeudenmukaisuusteoria} (WSOY, Helsinki, 1988 [1971]).
\textsuperscript{18} Ibid, p. 28
society from the threat of persons with disabilities, and for making persons with disabilities a productive part of society. Separate educational facilities became common practice and increased in number until the 1960s.

The first critiques of traditional special education are usually linked to two articles published in Exceptional Children magazine in the United States. These articles brought the special education subjects of dispute into open dialogue.\textsuperscript{19} The critical theses presented by Deno and Dunn could be simply stated as follows: (1) is an isolated special education system necessary? (2) An individual approach is not sufficient, a more holistic approach is needed (the Ecological Perspective), (3) the learning results of separate educational facilities are questionable, and (4) special education classes label their pupils. These articles were part of a rising human rights movement in the United States which demanded equal rights for all minorities. Persons with disabilities made up one of these minorities. One of the starting premises of the citizenship movement was the court decision made in 1954\textsuperscript{20} where it was clearly stated: “Separate educational facilities are inherently unequal”.\textsuperscript{21}

In addition to the problems of special education stated above, there was the problem that a great majority of pupils with disabilities were representatives of cultural minorities\textsuperscript{22}. At the same time, numerous pedagogical studies appeared which emphasised the

\begin{footnotes}
\item[20] Brown vs. Board of Education.
\end{footnotes}
impact of the environment on disability. This directed attention to special education, particularly to when and where it was carried out. The foundation was laid for the segregation-integration debate which continues even today. Supporters of integration to the fullest extent use the term “inclusion” to describe the right of all pupils to be with peers of their own age from the start. According to this view, integration as a term represents the past, because it implies that some pupils have already been excluded and must now be included.

Great variation among special education practices is found from country to country, however. Still the shaping of special education practices seems to follow a certain pattern. First special education is offered to deaf and blind pupils already during voluntary education. After compulsory education is mandated, those pupils who are slower in cognitive development, the pupils with a physical disability and those pupils prone to behavioural problems are offered their own special education services. As compulsory education becomes lengthier, smaller and smaller differences, for example problems related to reading or speech, are handled through special education services. Integration, on the other hand, pushes the educational system towards one that is more comprehensive. This phase model describes quite accurately the development of the Finnish special education system as well. This will be examined next.

3. Primary School Special Education

The law on compulsory education was passed in 1921. This signified a transition in the history of education, but for pupils with disabilities, the situation remained mostly unchanged. Compulsory education legislation only mentions pupils with “weak comprehension skills” who were released from schooling obligations or placed in a special

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school if one existed in the municipality. According to the compulsory education legislation, cities with more than 10,000 inhabitants had to found a special school. Other municipalities freed pupils with disabilities from compulsory schooling obligations and sent them home. At the time compulsory education laws were passed, there were nine cities in Finland with over 10,000 inhabitants, seven of which already had a special school. Hundreds of municipalities existed at the time, however, and as a result, only a small fraction of children with “weak comprehension skills” or other children with disabilities were provided with an education.\textsuperscript{26} The order was clear: schooling services for normal pupils were a priority, and pupils with disabilities came after. This order was also prevalent in other parts of society. "Disability in Finnish society in the 1800s and early 1900s was a marginal problem."\textsuperscript{27}

At the beginning of the 20th century, solutions to social problems were sought, but not in such a way as to benefit children with disabilities. The genetic divergence of individuals, and the threats of divergence to the whole of Western culture, was at the heart of societal debate. The first international eugenics conference was held in London in 1912 to prevent the degeneration of Western civilisation.\textsuperscript{28} In Finland, these international trends were well known, and the possibility for preventing reproduction via “medical methods” as was done in “some American states when it comes to criminals” was advertised.\textsuperscript{29} The sterilisation act of 1935 required school inspectors to report each “dull-minded or simple-minded” child to the public health board for the potential procedure to “remove reproductive ability”.\textsuperscript{30} Even in the 1950s, a more wide-spread practice of sterilisation was recommended in the follow-up health care of special school pupils. Finnish primary school officials were not very enthusiastic eugenics

\textsuperscript{26} Kivirauma, supra note 8.

\textsuperscript{27} M. Harjula, Vaillinaisuuden tulkinat suomalaisessa huoltokeskustelussa 1800-luvun lopulta 1930-luvun lopulle (Suomen historiallinen seura, Helsinki, 1996) p. 195.


\textsuperscript{29} A. V. Laitakari, Heikkokykyiset ja tylsämieliset lapset (WSOY, Porvoo, 1919) p. 166.

supporters, however. By 1947, of the more than 1 000 former special school pupils, only 21 had been sterilised.\(^{31}\)

According to mainstream beliefs of the time, the only correct place for deviant individuals was in an institution. Institutions were a sign of a civilised society. They represented progress and modern expertise based on classification and procedural differentialisation. Opposing opinions were presented, but in general, institutions were widely supported and hence, they became prevalent.\(^{32}\) The institutionalisation of poorly behaved and less skilled pupils was seen as natural, since their genetic makeup was thought to be different from the norm. In primary school, the education and activities of these pupils were organized so as to keep them separate from others. Often, the teaching of these pupils was called “school”, even when there was only one class. The premises available for special schools were ones that were deemed unsuitable by others. The position of special schools within the school communities was marginal, and they were not held in high regard.\(^{33}\)

The uneven distribution of intellectual skills within the population served as the ideological foundation for this parallel school system. That theoretical giftedness was spoken of on one hand and practical giftedness on the other reflected this way of thinking. It also attempted to make the difference between the two less discriminating by calling both groups “gifted”.\(^{34}\) The school system had to be built based on this approach, utilising the following kind of separation: grammar schools were for the theoretically gifted and civic schools for the practically gifted. One could proceed to university through grammar school, or through intermediate schools to vocational institutes or working life.


34 For example; *Kansakoulun opetussuunnitelmakomitean mietintö I* (Helsinki, 1946) p. 51 and *Kansakoulun opetussuunnitelmakomitean mietintö II. Varsinaisen kansakoulun opetussuunnitelma* (Helsinki, 1952) pp. 20 and 175.
From the latter, one could proceed to working life directly or via a vocational school. Special education, based on special schools and classes, fit this system well. Some of the pupils were seen as so different from normal pupils in their mental and physical make-up that a permanently separate education seemed like a perfectly reasonable solution. It was reasonable from a historical point of view as well. Up until now, pupils of different backgrounds and different skills had been taught separately. In the 1950s, committees still recommended hard of hearing pupils attend their own boarding school type special school. On the other hand, the popularity of special schools waswaning and legislation in 1952 (the primary education decree) presented the opportunity for pupils with disabilities who had previously attended national special schools to receive teaching in municipal primary schools. In some cases, this represented the first step towards integration, i.e. physical integration.

4. Transition to Comprehensive School

Originally, primary school was designed to be an independent school after which pupils were prepared to transition to society and the work force. Although the transition to grammar school was possible also from primary school, the most reliable route to education was through preparative schools. Little by little, primary school became the prerequisite for grammar school, however, and the academic requirements for primary school increased. As educational requirements increased, smaller and smaller divergences became evident as they inhibited the achievement of academic skills. Deficiencies in the most important communication skills, speech, reading and writing, began to draw attention first. These difficulties were, by nature, of the sort that didn’t benefit from the kind of assistance that could be provided through the special schools and classes of the special education system. Another important factor, in addition to the rising performance demands of the primary school, was the start-up of the child guidance clinics. Child guidance clinics’ activities resulted

36 Tuunainen and Nevala, supra note 35, p. 74.
in a more systematic and effective way to monitor pupils’ physical and mental qualifications for learning. In many municipalities, child guidance clinics made the initiative for the establishment of part-time special education.37

Comprehensive school, realized in Finland during 1972-1977, signified a radical shift in the way of thinking. Now education was seen as a tool for implementing wide-spread societal change. Education – and here specifically, the transition to comprehensive schools – aimed to further societal, regional and gender equality. Strives for societal equality had important implications for special education, since dividing pupils into various venues of education regardless of the reason was in more or less in opposition to this goal. Comprehensive school resulted in the whole age-group being taught together for nine years (instead of the previous four). This also meant there was pressure to draw special education and normal education closer to each other.

A special education planning committee was organized for the transition to comprehensive school. This committee published two reports during the years 1970 and 1971. This was the greatest attempt so far to get special education included in compulsory education, and the plans made are still, to date, the latest committee-level plan made regarding special education. In this way, special education as a whole was tied to the new schooling system from the start in an organized manner – not as an afterthought or as a reaction to local problems as they arose, as had been done in the past. A new administrative organization, the school department of the provincial governments, was given the task of implementing and supervising the primary education reform. This administrative body was also responsible for allocating sufficient resources to special education in the local municipalities. Special education had become a part of a systematic nation-wide educational policy.

The change in special education was part of a broader societal movement which emphasised the rights of minorities. In the 1960s, this movement voiced loud critique against government main-

tained (totalitarian) institutions. Those institutions which used the harshest forms of dictatorship were the object of unprecedented critique. The school system also got its share of this critique. In 1967 Pakkoauttajat (Caretaker Tyranny), a book which fiercely defended the rights of different minorities and controlled people groups, was published.\(^{38}\) Kettil Bruun had already criticised the school system in Sosiologia magazine a few years prior to the publishing of the book.\(^{39}\) International integration dialogue quickly established a foothold also in Finland.

Comprehensive school resulted in a rise in part-time special education. Part-time special education was intended primarily for pupils whose difficulties lay in the areas of speech, reading and writing. In general, it could be said that these pupils were so-called underachievers, whose school success did not correlate with their skills\(^{40}\). As a result of this part-time special education, a line was drawn. On one side of this line were the representatives and supporters of the traditional special schools and classes, on the other those who were advocates of part-time special education. International dialogue, which was very critical of traditional ways of providing special education, contributed to this division. The battle-field continues to be divided, as opinions on how special education should be provided vary. Advocates of integration appeal to each child’s general human rights, i.e. the right to attend school with peers of their own age group\(^{41}\), whereas advocates of segregation appeal to each child’s right to teaching which is tailored to his/her learning capabilities.\(^{42}\)

Special education can also be approached by examining how it has been shaped by the sometimes conflicting interests of different actors. Professionals in the field and the resources available have had

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\(^{38}\) L. Eriksson (ed.), Pakkoauttajat (Tammi, Helsinki, 1967).


\(^{42}\) For example, see J. M. Kauffman, ‘Can Inclusion Work?’, 52:4 Educational Leadership, pp. 7-11.
the greatest impact on the shaping of special education. In time, of course this battlefield, simplified here for the sake of illustration, also changes shape. From its first stages through the 1960s the special education politics of compulsory education could be described as having been shaped by necessity. Special education was increased so as to ensure the fluid functioning of the school. Dispute regarding the necessity of special education was virtually nonexistent. Conflict revolved mainly around the availability of resources and the use of these resources. For teachers, special education improved working conditions in the form of more homogenous classes. For supervisors and school officials, special education allowed for more effective teaching. School doctors were able to apply purposeful treatment for a pupil diagnosed as deviant. The resources allocated to special education by municipalities and the government, in the time of rebuilding after the war, did not allow for the improvements suggested by the committees already in the 1940s. The mutual accord was lost, however, as a result of the transition in to the comprehensive school system. Specially trained special education teachers came as a new addition to the field, and the interests and objectives of other actors began to conflict. School officials and teachers could not agree on the direction the development of special education should take. This resulted in complete discord. The school officials wanted special education to be developed in accordance with societal equality principles and goals. Teachers, on the other hand, approached the issue mainly as a problem for the schools, and more specifically, as a protection of interests issue. The voices of pupils with disabilities and that of their parents have been barely discernible in special education arrangements. They have, of course been requested to provide written permission for the decision to enrol the pupil in special education, but parents have rarely questioned professional suggestions pertaining to these decisions.43 According to current information, this is now changing.44

5. Neo-liberalist Comprehensive School: the Expansion of Special Education Continues

The activities and principles of comprehensive school have been reformed now and again over the course of its forty year history. A fairly significant reform was the decision to stop the streaming of pupils in the beginning stages of comprehensive school, as this was considered to promote inequality. Also, another major change was the transfer of pupils with disabilities from under the authority of the social welfare system to that of the educational system in 1985 and 1998.\textsuperscript{45} Integration was replaced by the ideology of inclusion, i.e. local schools were open to everyone. From a purely structural standpoint, the position of pupils with disabilities in the comprehensive schools is better than ever before. However, reforms in the 1990s spurred, for the first time, the conscious unravelling of equality aspirations in the comprehensive school system. These reforms may signify changes in the position of pupils with disabilities as well. One explanation for this change is that the political right was trying to gain recompense, having lost the battle to maintain private comprehensive schools during the transition into the comprehensive schools system.\textsuperscript{46} The neo-liberal socio-political thinking, which had been gaining foothold especially in the United States and Great Britain since the 1980s, provided a fertile backdrop for the political right’s aspirations. School districts were removed. This resulted in more freedom to choose, with certain restrictions, the school to attend and thus, the weakening of the local school principle. Schools now became competitors. As a result, the socio-economic differences between schools have increased. The municipalities’ right to manage the distribution of state subsidies furthers the growth of inequalities between municipalities. Standard guidelines for the curriculum were loosened. This led to differences between schools that could be seen in teaching, as well. The welfare service, once intended to educate the population,


\textsuperscript{46} S. Ahonen, \textit{Yhteinen koulu. Tasa-arvoa vai tasapäisyyttä?} (Vastapaino, Tampere, 2003).
is now becoming profit-seeking, and is shaped by the market and by competition in its attempts to achieve maximum profit.\textsuperscript{47}

In principle, paying attention to the needs of children with disabilities by providing special education is part of the comprehensive schools' endeavour for equality. Special education has, in fact, rapidly expanded during the existence of comprehensive schools. It is good to discuss whether the increase in special education supports the equality project, i.e. are the activities within special education appropriate or the best possible? Divergence among pupils in comprehensive schools is recognized, and considerable amounts of financial resources are allocated to this purpose. Today, most pupils who start out in special education, or are later moved into special education study either full-time or part-time in mainstream classes, not in special schools or classes. Special education serves in the best interest of others as well, such as teachers and special education teachers. However, this in and of itself does not make special education discriminating.\textsuperscript{48} If, however, the teachers' needs begin to dictate transfers into special education, or if the social background or gender of pupils in special education systematically differs from those of other pupil groups, the possibility of pupil discrimination must seriously be considered.

The central questions for special education in the 21st century are how does the moulding of comprehensive schools into the neoliberal market service –type institution affect special education? Is a well tended-to, multifaceted special education an advantage on the school market? Or will discomfort with deviance encourage parents to choose another school for their child, only to mould the school.


\textsuperscript{48} S. Tomlinson, \textit{A Sociology of Special Education} (Routledge & Kegan, London, 1982); Kivirauma, supra note 8 and Saloviita, supra note 41.
The portion of pupils enrolled in some form of special education in Finland totals nearly a third of the age group. This is nearly a world record portion. Compared to international figures, the proportion of special education classes in Finland is high as well. Reasons for the continuing growth of special education have been sought from many directions. The basic reason, however, should not be forgotten. The strive for equality in comprehensive schools signified a purposeful and methodical expansion of special education. It was one important way for teaching the whole age group together for nine years instead of the previous four. Part-time special education, in particular, can be thought of as positive discrimination in that it attempts to even out pupils' beginning differences to ensure a successful school career for as many pupils as possible. Some of the increase can be explained by the transfer of pupils with a mental disability from the social welfare system into the educational system. New classifications (medicalisation) have also increased the number of potential children with disabilities. It is unclear how the municipalities’ tight financial situation has led to an increase in pupils in special education for financial reasons, due to larger state subsidies granted for children with disabilities compared to other pupils. It is also possible that municipalities’ budget restrictions have weakened teachers’ working conditions to the extent that they don’t have time to teach children with disabilities, thus transferring them into the special education system more easily. There has been an increase in small groups in recent years. This can be seen as a result of local decision making on one hand and medicalisation on the other. As a result of medicalisation, the range of special pupil classifications has increased, and it has been difficult to organize suitable teaching for each group.

A condensed description of the relationships between compulsory school, special education and various actors has been compiled in

the following chart. The arrangement describes A) the ideology and practices of the compulsory school, B) the type of special education, practices and actors.
## Chart1. Summary of the relationship between comprehensive education and special education

<table>
<thead>
<tr>
<th>A.</th>
<th>Primary school before compulsory education</th>
<th>Compulsory education school</th>
<th>Transition to comprehensive school</th>
<th>Neo-liberal comprehensive school</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal</td>
<td>To unify the population</td>
<td>To train the whole age group</td>
<td>Equality</td>
<td>Competitiveness, effectiveness, special emphasis investing in the ones with most potential</td>
</tr>
<tr>
<td>Practices</td>
<td>Small countryside schools, classes with combined grade levels, practical skills</td>
<td>Age group-specific classes, growth of class size, pressure to be more academic</td>
<td>The whole age group together for nine years, academic curriculum</td>
<td>School district divisions removed, pupil’s subjective rights, choice of school</td>
</tr>
<tr>
<td>B.</td>
<td>Style of teaching</td>
<td>Practice</td>
<td>Practice</td>
<td>Practice</td>
</tr>
<tr>
<td>Style of teaching</td>
<td>Special schools</td>
<td>Special classes</td>
<td>Part-time special education</td>
<td>Small groups</td>
</tr>
<tr>
<td>Practices</td>
<td>Majority of children with disabilities didn’t attend school</td>
<td>Majority of children with disabilities received education in segregated setting</td>
<td>All children with disabilities into the comprehensive school setting, preventative care, normalisation, equal access to services</td>
<td>Local decision-making power increased, municipal special education politics, differences among municipalities also in terms of educational services for persons with disabilities</td>
</tr>
<tr>
<td>Actors</td>
<td>Inspectors, the first school doctors in larger cities</td>
<td>Child guidance clinics started</td>
<td>Office of Special Education functions now within National Board of General Education, provinces, profession of special education teacher</td>
<td>Parents, committees, principals</td>
</tr>
</tbody>
</table>
When reading this chart, one must bear in mind that the changes noted here do not usually signify the disappearance of earlier practices. Old practices don’t change at the same rate as ideologies do. In special education, this can be seen in the continued existence of all the forms of special education, regardless of what is in question: over one-hundred-year-old special schools or the small groups formed in more recent years. On the other hand, some of the actors have ceased to exist (for example, the Office of Special Education within the National Board of General Education, and the school inspectors) or only have a marginal role (school doctors). Parents, committees and school principals have always had input regarding special education decisions, but beginning in the 1990s there has been a conscious strengthening of their role through schooling politics. It remains to be seen if the parents will become significant actors in special education in the coming years, and if so, where they will focus their active roles. Until now, parents have not actively challenged national special education politics. Rather, their activities have been aimed at strengthening already existing systems by demanding special education services for new classifications such as ADHD and autism.

6. Development toward More Accessible Higher Education

6.1. Students with Disabilities in Universities and Polytechnics

The Finnish higher education institution is made up of two complementary sectors, universities and polytechnic schools. Universities are involved in scientific research and offer both teaching and postgraduate education based on research. Polytechnics train students for the workforce, but they also teach and partake in R&D activities which support regional development. The polytechnic system was built in the 1990s by gathering together institutes that provided college-level and professional-level vocational training. This was also done to improve their level of education.50

Neo-liberalist educational politics have manifested in Finnish universities in two ways. As producers of research and workforce, universities are expected to primarily serve the economy. Universities and their various units are also expected to function more and more as enterprises. To increase profitability, subsidies are granted to so-called centres of excellence and respectively decreased from ordinary units.\textsuperscript{51}

The precise number of university students with disabilities is unknown. It is estimated that they make up about 0.5 per cent of all university students.\textsuperscript{52, 53} Persons with disabilities are thus clearly underrepresented in university education. If polytechnic schools are included, the percentage of students with disabilities increases significantly. For example, the Finnish results in the study Eurostudent III, funded by the European Union and the German Ministry of Education, show that within Finland’s universities and polytechnics, students with disabilities comprised nearly six per cent of the student body.\textsuperscript{54}

\section*{6.2. Phases in Accessibility Work}

The improvement of accessibility in Finland’s institutes of higher education has advanced in three stages. The first phase was mainly made up of attempts by individual university students with disabilities to affect change in the teaching premises and arrangements, so as to be able to participate in the teaching. This began when the first students with disabilities entered universities, and lasted until the 1960s. The second phase began when students with disabilities raised the idea of accessible education in the 1970s. For example, the goal of the Threshold Association, originally an organization for

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{52} The percentage does not include students with some kind of learning difficulties, for example.
\item \textsuperscript{54} The Ministry of Education of Finland, \textit{Euroopan korkeakoulutopiskelijoiden sosiaaliset ja taloudelliset olot} (Political Analyses of the Ministry of Education 2009:1) p. 4.
\end{itemize}
\end{footnotesize}
students with disabilities founded in 1973, was to improve the equality of persons with disabilities in education, particularly in higher education. Even universities were, at the time, very inaccessible places for a student with disabilities. Ramps didn’t exist, stairs were necessary for accessing many of the premises, and the elevators were too small for a wheelchair.55

Since the turn of the century, there has been active dialogue in Finland about accessibility as it pertains to studying in institutes of higher education. This can be described as the third phase in accessibility work. A turning point came in the 1990s, which resulted in persons with disabilities being seen as citizens, students and employees, not merely as individuals with disabilities.56 The amendment of particular significance for accessible studies in institutes of higher education was the new constitution in 1999. This prohibition on discrimination qualifies disability and health as factors by which a person could not be discriminated against. The Equality Act of 2004 pertained first and foremost to the labour market, but it also applied to education and arrangements related to education. The law obligated the actors who arrange training to make reasonable arrangements to ensure, for the person with disabilities, access to education and support for managing in the educational setting.

The new constitution with its prohibition of discrimination furthered the demands of students with disabilities that institutes of higher education be made accessible. A pioneering project called the Accessible University of Turku begun from the initiative of students with disabilities at the University of Turku was the most ambitious and it received the most publicity57. The rector of the university called together a committee at the end of 2001 to investigate the situation of students with disabilities at the University of Turku. First, physical barriers to studying were mapped out and removed. Vital to the success of the project was that the different sectors of the university were involved right from the start. Accessibility no longer pertained

56 P. Pietilä, Esteetön opiskelu (Presentation at NeuroExpo on 16 September 2005, Turku Fair Centre).
57 In Finnish: Esteetön UTU.
only to studying. It also involved administration, communications, physical spaces and the strategy of the whole university.\textsuperscript{58}

In 2003, disability organizations and student interest groups presented the Minister of Education with the Accessible Education Belongs to Everyone –memorandum.\textsuperscript{59} In this memorandum, organizations demanded practical measures to ensure accessibility for students with disabilities in institutes of higher education. It also gave concrete examples of the barriers to education which different disability groups had encountered, and gave recommendations on further procedures for future collaboration.

Research, which approached accessibility from the standpoint of the personal experiences of students with disabilities studying in institutes of higher education, initiated and hastened dialogue pertaining to accessibility in education. Research by Hanna-Sofia Poussu-Olli dealt with the experiences of students with disabilities studying in a university.\textsuperscript{60} In her thesis, Susanna Haapala investigated the experiences of students with disabilities at institutes of higher education.\textsuperscript{61} A project by the Federation of Hard of Hearing examined the experiences of hard of hearing students at institutes of higher education.\textsuperscript{62} Eija Pääkkölä researched the University of Jyväskylä’s students’ views on accessibility in their study environment.\textsuperscript{63} All the research mentioned clearly showed that at institutes of higher education, students with disabilities encountered many obstacles in their studies.

6.3. Report for the Ministry of Education

In 2004, the Ministry of Education requested a report from Otus, an independent foundation which researches matters concerning

\begin{itemize}
\item J. Kumpuvuori, ‘Yliopisto esteettömäksi kaikille’, Aurora 1/2003.
\item In Finnish: Esteetön opiskelu kuuluu kaikille.
\item Poussu-Olli, supra note 53.
\item S. Haapala, Vammaisen yliopisto-opiskelijan identiteetti (Suomen ylioppilas-kuntien liitto ry, 1/2001).
\item E. Pääkkölä, Kohti esteetöntä yliopistoa. Opiskelijoiden kokemuksia Jyväskylän yliopiston opiskeluympäristöstä (Erityispedagogiikan pro gradu-tutkielma, University of Jyväskylä, 2004).
\end{itemize}
students in higher education, to determine how equality, and accessibility in particular, are realized at universities. Accessibility in this report was defined as the physical, mental and social environment that manifests equality regardless of individuals’ characteristics. The target group consisted of disabled students and diverse learners. Diverse learners are persons who can not perform to their fullest capacity in a study environment due to reading or writing difficulties, for example, or difficulties in mathematical perception, coordination, and spatial perception or to differences in the brain’s capacity to process information. The investigation was carried out in 2004 in the form of a questionnaire given to universities’ administrations. Administrative representatives were asked to assess the realization of accessibility, particularly from the point of view of diverse learners and students with disabilities. The questionnaire was divided into five parts: study-related matters, spatial arrangements, personnel training, planning activities, and communications.64

Laaksonen’s report showed significant deficiencies in university accessibility in all the aforementioned areas. Clearly, most attention had been paid to accessibility in physical spaces. The enquiries and plans made by the universities had mainly pertained to the built environment. Additionally, inaccessibility due to physical barriers was seen as the primary problem – accessibility had mostly to do with educational premises. Only a few universities had attempted to actively develop accessibility in course work-related matters and communications. Personnel training and planning services are key issues for promoting accessibility, but according to the investigation, personnel training within universities rarely addressed accessibility issues. Accessibility mapping and planning had already been done in a few universities, and many others are beginning the process. However, wide-spread cooperation with disability organizations, for example, had not been done.65

The conclusions made it evident that universities had not adequately pursued accessibility in their activities, and that the development of accessibility was necessary in all areas of activity. To systematically promote accessibility in coursework related matters, physical space arrangements and communications, universities

64 E. Laaksonen, Esteetön opiskelu yliopistoissa (Opetusministeriön julkaisuja 2005:6).
65 Ibid.
should develop comprehensive accessibility evaluations and plans of action. They should also include accessibility in strategic plans and personnel training. It was proposed that each university have an official responsible for coordinating issues pertaining to accessibility. To support development in this area, universities need information, models and assistive devices. Additionally, it would be beneficial to form a development committee comprising of representatives of the Ministry of Education, institutes of higher education and interest groups.  

6.4. Accessible Study in Institutes of Higher Education -project

After the publication of the report for the Ministry of Education, much work has been done in Finland’s universities and polytechnics to develop accessibility in education and in services acquisition. A significant portion of this work has been done within the framework of the Accessible Study in Institutes of Higher Education –project, funded by the Ministry of Education and coordinated by the University of Jyväskylä during the years 2006-2009.  

The aim of this project has been to promote the removal of barriers to education in universities and polytechnics for all who study or work in institutes of higher education, especially for those who have some kind of impairment, are diverse learners, are aging or belong to a language or cultural minority. This is being done according to the recommendations of the Ministry of Education. The project has aimed to support the accessibility work of institutes of higher education by activating cooperation and networking, by organizing training, spreading good practices and producing recommendations. The project organization has included 10 pilot institutes of higher education and 20 interest groups or organizations.

As this is being written, the Accessible Study in Institutes of Higher Education -project is still underway. As such, a comprehensive view of the results remains to be seen. It is still too early to evaluate if the pilot institutes participating in the study are more accessible now than they were when the project started, for example. It has become

66 Ibid.
67 Ibid.
68 In Finnish: Esteetön opiskelu korkea-asteen oppilaitoksissa.
evident during this project, however, that in institutes of higher education, students with disabilities and students who are hard of hearing make up only a small fraction of students who need accessibility arrangements. For example, out of the students who have used the services of the University of Turku’s Adviser of Disability Issues in 2007, half had some kind of learning difficulty, such as a difficulty in the areas of reading or writing.\(^6^9\) Thus, it is not surprising that in accessibility work, the focus has shifted from barriers pertaining to physical mobility, sight and hearing to those having to do with social and mental barriers. So in part, development has proceeded to follow the same pattern as it did in comprehensive education.\(^7^0\)

6.5. Finland Lagging Behind?

Some countries, Sweden and England for example, have participated in accessibility development work for longer than Finland has. In 2001, a law was passed in Sweden which prohibits, in universities, discrimination based on disability.\(^7^1\) Further, a Government Ordinance on the responsibility of the state authorities for implementation of disability policy was adopted in 2001.\(^7^2\) The implementation of these statutes is done, in addition to obliging institutes of higher education to develop their own accessibility plans and other means, by budgetary means. In fact, budgetary implementation has been in existence even before the statutes mentioned but with varying percentages. Within the 2009 budget of the Swedish Government, institutes of higher education were obligated to reserve a 0.30 per cent portion of their budgets to services aimed at students with disabilities.\(^7^3\) Unlike in Finland, universities in Sweden are responsible for the activities related to furthering accessibility and for providing

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70  Werner-Putnam, *supra* note 25.
71  Lag (2001:1286) om likabehandling av studenter i högskolan.
the supportive services necessary for study, such as renovation of spaces, assistive devices, assistants and interpretation services.\textsuperscript{74}

In England, the realization of equal rights for students with disabilities in higher education has progressed from a general ethical responsibility (and individual development projects) to detailed guidelines and binding legislation.\textsuperscript{75} Institutes of higher education have acquired new responsibilities, such as the development and publishing of Disability Equality Plans (DEPs). The educational opportunities of persons with disabilities in England are evaluated also as a part of the quality assurance of institutes of higher education. Guidelines for this purpose were published for the first time already in 1997. A revised version of the guidelines will be published in the summer of 2009. It differs from the earlier version in two ways. First, it calls attention to the connection between the guidelines and legislation. In question is the actualisation of rights mandated by law, not merely the observance of the needs of students with disabilities. Second, the revision of the guidelines emphasizes the role and responsibility of senior staff in the accessibility of higher education institutes.\textsuperscript{76}

It is evident that in Finland, accessibility work is carried out in more of a project-style than elsewhere. Also the development of good policies is taking place in only some of the institutes of higher education.\textsuperscript{77} There are also indications that accessibility among polytechnics is even more varied than that among universities.\textsuperscript{78} Continual funding, permanent responsible persons and a national network are not available for accessibility work in Finland’s institutes of higher education. Neither have separate resources been allocated to research pertaining to accessibility, nor to the assessment of accessibility. Additionally, in England and Sweden, accessibility

\textsuperscript{75} SENDA 2001 and DDA 2004.
\textsuperscript{77} Pietilä, supra note 69, p. 29.
\textsuperscript{78} A. Urhonen, Presentation at ‘Esteettömyys koskettaa jokaista’ –Seminar in Helsinki on 6-7 May 2009.
has been a quality criterion for institutes of higher education, much more so than in Finland.\textsuperscript{79}

\section*{7. Challenges Posed to Education by the UN Convention on the Rights of People with Disabilities}

From a sociological perspective, the establishment of formal education has been connected to industrialisation and increasingly complex division of labour. This has presupposed the development of specialized institutions to support the acquisition of technical and social skills necessary for working life, as well as the selecting and allocating of young people for various levels of schooling.\textsuperscript{80} Historically, children and youth with disabilities have been socialised to have low expectations with respect to education and working life. Educational opportunities have been dictated by the notion of “special needs” and separate schooling arrangements. Although the ideology of inclusion has progressed, still all forms of special education coexist in Finland. The UN Convention on the Rights of People with Disabilities aims to question this setup by emphasising the member states’ commitment to an inclusive educational system. Article 24 of the agreement, which addresses education, states:

"...States Parties shall ensure an inclusive education system at all levels and lifelong learning..."

"...Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability..."


“...Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live...”

The text in this agreement thus emphasizes the right of a pupil with disabilities to education on an equal basis with others in his/her age group, in the community in which the pupil lives, right from the start. This is not only a pedagogical recommendation; it is also a significant social and societal stance. When we talk about over one-hundred-year-old special schools, we are not only talking about one way of arranging teaching. We are also speaking about how children and youth with disabilities are isolated and excluded from the rest of society. Inclusive education does not only open doors for a more multifaceted, better quality education. It also furthers the formation of friendships between children with disabilities and non-disabled children. As such, it lays the foundation for the development of social networks necessary later in life. Simultaneously, it can prevent ignorance and the development of stereotypes. Participation in society as an equal member can also result in increased self-confidence and self-esteem. 81

Although much work has been done in the 21st century in Finland’s institutes of higher education to further accessibility, the realization of an inclusive higher education that doesn’t discriminate against students or employees with disabilities still requires more effort. Specifically, the challenge lies in getting accessibility development work to be an established part of all higher education institutions’ normal activities. Thus far, accessibility development work has proceeded in different ways at different institutes of higher education, as well as within the schools themselves in their various departments. The perspective on accessibility in institutes of higher education has, over the past years, expanded. In terms of the study environments, there has been a shift from removing thresholds and stairs to considering ways to improve social and mental accessibility. According to Paula Pietilä, the Adviser of Disability Issues of the University of Turku, it is essential to the realization of social and mental accessibility that issues related to disability and learning disor-

ders are openly discussed.\textsuperscript{82} On the other hand, practical tools for the realization of accessibility in teaching are also needed. For example, how is a student with needs due to an autism spectrum disorder accommodated in a large lecture? How are the exam answers of a student with difficulties in language conceptualisation and perception evaluated? Answers for these types of questions can already be found in comprehensive school, but they cannot necessarily be implemented as such in the teaching of higher education institutes. One of the greatest challenges faced in the development of accessibility in institutes of higher education is finding the tools and practices needed for the realization of social and teaching accessibility.\textsuperscript{83}

Article 24 of the UN Convention on the Rights of People with Disabilities also mentions the right of persons with disabilities to lifelong learning. This poses challenges for adult education accessibility as well. There may also be a need to consider what all inclusivity may encompass in the area of adult education. Are the activities of adult educational institutions which specialise in special education in line with the UN Convention on the Rights of People with Disabilities? Even with providers of adult education, the question is not only about education and the arrangement of education. It may also be a question of removing students with disabilities from the rest of society. It is evident that in institutional living (such as in boarding schools), power dynamics may become unfavourable for students with disabilities. Even if the students with disabilities are of age, they are still the objects of activities, not full-fledged citizens. This kind of situation, combined with employee recruitment problems and deficiencies in institutional monitoring can, at its worst, lead to the death of a student with disabilities, as happened at the Lehtimäki folk high school in 2007.\textsuperscript{84}

Article 8 of the UN Convention on the Rights of People with Disabilities states that all levels of the educational system – this includes in all children from an early age – are to foster an attitude

\textsuperscript{82} Pietilä, \textit{supra} note 69, p. 24.

\textsuperscript{83} Ibid.

\textsuperscript{84} 20.11.2008 The Vaasa Court of Appeal imposed a six-year imprisonment on two night nurses who had been found guilty of bodily injury and involuntary manslaughter in the insulin poisoning death of a pupil with disabilities in a hall of residence at the Lehtimäki folk high school (Vaasan hovioikeuden lehdistötiedote 20.11.2008).
of respect for the rights of persons with disabilities. This presents a
challenge for the development of human rights education which has
not achieved the same kind of foothold in Finland as, for example,
environmental education or sustainable development education
has. The responsibility for human rights education has traditionally
belonged first and foremost to civic organizations. Disability organi-
zations have also provided human rights education. This has already
been taking place for decades, although human rights education
activity has been described using other terminology. Article 8, which
addresses the need for increasing people’s awareness regarding
persons with disabilities, also contains the rejection of negative
stereotypes and predispositions. This statement highlights the
need for more research-based information pertaining to the role of
schools, and the education given in schools, in maintaining or abol-
ishing disability-related stereotypes. There is, for example, a need
for research which investigates the kind of image of persons with
disabilities current teaching materials, such as text books, present.
Do modern text book pictures and texts present persons with disa-
bilities as active citizens or do they maintain stereotypical views of
disability?

A critical question for the future of education is what direction the
development of the Finnish school system will take. An atmosphere
that emphasises excellence and competition can be hard to reconcile
with the demands of the UN Convention on the Rights of People with
Disabilities. There is a danger that the articles pertaining to educa-
tion in the UN Convention on the Rights of People with Disabilities
will become empty promises if their realization is not monitored.
Chapter 5:

Teachers’ and Students’ Awareness of and Attitudes towards the Concept of Inclusion Exemplified in Article 24 of the UN CRPD

Jeyaprathaban Sujathamalini

1. Introduction

Education is the process of helping the individual adjusts to this changing world. A quotation by Swami Vivekananda, a famous Indian spiritual leader, points out that “education is the manifestation of the perfection already in man”.¹ His quotation implies that education is a key factor that helps every individual adjusts to this changing world. The Indian Education Commission (1964 – 66) says that education ought to be related to the lives, needs, and aspirations of the people, and is thereby made to be a powerful instrument of social, economic and cultural transformation.² Mahatma Gandhi (1937) says, “By education I mean an all-round drawing out of the best in child and man – body, mind and spirit”.³ To achieve all of the above objectives, every nation is bound to provide quality education to their citizens. Hence every country tries to furnish such a quality education for their citizens. Each individual differs in their strengths and weaknesses. Thus the educational system of a nation should meet the diversified needs of the individual. To serve a heterogeneous group of individuals, education is provided in different ways with different designations, such as regular education, segregated education, integration, mainstreaming and now inclusion.

³ M. Gandhi, All men are brothers: Autobiographical Reflection by Gandhi (Krishna Kripalani, Harijan, 138 pp., 1937).
The concept of inclusion gained thrust when everyone realized that a quality education for all children irrespective of their abilities and disabilities was advantageous. A high quality education is given to each child based on equality and empowerment. Equal access to education is a matter of right, not privilege. Inclusive education leads to equality in access to education for children with and without disabilities. It is mandatory to meet the diversified needs of children within the classroom set up. The federal Individuals with Disabilities Education Act (IDEA) and its 1997 amendments make it clear that schools have a duty to educate children with disabilities in general education classrooms. It further states that “each State must establish procedures to assure that children with disabilities are included in schools to the maximum extent possible alongside children who are not disabled and that of special education, separate schooling, or removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily”. The paradigm shift from special schools, special classes, and residential institutions to regular schools alongside another group of children derived from the constitutional concept of equalisation of opportunities for individuals with disabilities. All children should have the right to attend school in their home community in inclusive classes and to participate in a quality education that is meaningful for them.4

The concept of inclusion promotes individualised, independent and cooperative management skills among children with special needs. It is a concept which embraces the diversity in children within the classroom. Article 7 of the UN CRPD also emphasizes the need to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. Further, article 24 defines that in realizing this right, States Parties shall ensure that:

"a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

c) Reasonable accommodation of the individual's requirements is provided;

d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion”.

Article 24 of the UN CRPD has made the concept of inclusion mandatory and considers inclusion to be a basic right of every child with disabilities. However, Article 24 will be effectively implemented only when the teachers and students in inclusive schools possess a greater awareness and positive attitudes towards the importance of the concept of inclusion for children with disabilities. This is why the UN CRPD had stressed raising awareness under Article 8. School administrators, managers, teachers, etc. do not have a uniform and common understanding of the term inclusion. Present classroom practises vary greatly, and inclusive practise is undergoing gradual development. In order to assist in the development of good classroom practises, the key factors for inclusive education are to ensure that in the academic, social and cultural spheres, all pupils experience good peer and teacher relationships, a sense of belonging, participation and influence, and good conditions for working together.

Anupreza Chadha brings up certain obstacles for practising inclusion in India. They are: i) a lack of resources for equipping teachers with specialised skills/competencies, making curricula disability-sensitive, or addressing the prejudices of children; ii) only partial integration has been achieved. Most disabled children are

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integrated only for social activities, not in academic areas; iii) disability is described as a problem, not a priority. Building access and accommodations for the handicapped are not prevalent; and iv) not all regular education teachers have the attitude that they are responsible for all children assigned to them, regardless of the handicap.\textsuperscript{6} These obstacles are also often encountered internationally leading to inclusion in education not being implemented. The lack of awareness of and a positive attitude towards the concept of inclusion is one of the challenges for functional inclusion. If the teachers do not possess knowledge about the concept of inclusion, then the children with disabilities will just remain in the classroom without any remedial instruction. On the other hand, Article 24 of the UN CRPD will remain unimplemented as long as children with disabilities are not accepted by their fellow students without disabilities. Hence the first step for successful inclusion is to assess the awareness of and attitudes towards the concept of inclusion of the present practising and prospective teachers and of students without disabilities, and to promote awareness and attitudinal building programmes for better understanding and acceptance.\textsuperscript{7} The present article focuses its attention on the existing awareness of and attitudes towards inclusion of practising and prospective teachers and regular school students.

2. Objectives of the study and Methodology

The objectives of the study are to study the awareness of and attitudes towards inclusion of practising teachers; to study the awareness of and attitudes towards inclusion of prospective teachers; and to study the awareness of and attitudes towards inclusion of students without disabilities.

The survey method was adopted for the present article. Samples were selected by a simple random sampling technique. The inves-

tigator went through the literature and developed an individualised questionnaire to collect data from the sample. The reliability (0.84) and validity (0.92) of the tool has been estimated, and it was found to be reliable and valid. The data were collected personally after maintaining a good rapport with teachers and students. The raw scores were analysed and tabulated for interpretation. Qualitative analysis was also performed by conducting unstructured interviews with the practising teachers to understand the problems and prospects they face in an inclusive educational system. The results of the quantitative data were presented in tabular form. The results of the quantitative and qualitative data were also interpreted.

3. Results and Discussion

The data are analyzed, tabulated and interpreted in three parts. Part I deals with the descriptive analysis to analyse the awareness of and attitudes towards inclusion of practising teachers, prospective teachers and students without disabilities. Part II deals with the qualitative analysis of practising working teachers in an inclusive system to ascertain their perceptions towards inclusion.

4. Quantitative Analysis

A descriptive analysis of prospective teachers’ awareness of and attitudes towards inclusion of children with disabilities is dealt with next.

The major objective of the study is to assess the practising teachers’, prospective teachers’ and normal students’ awareness of and attitudes towards the concept of inclusion. To accomplish this, the mean, standard deviation (SD) and number and percentage from raw score have been calculated. By using the mean ± 1 SD, the awareness and attitude levels of practising teachers, prospective teachers and normal students towards the concept of inclusion have each been divided into three groups, namely 1. High Awareness (HA), 2. Moderate Awareness (MA), 3. Low Awareness (LA). The total number of response of ‘Yes’ in the attitude questionnaire is
considered as positive attitude and ‘No’ response as negative attitude. The attitude of practising teachers, prospective teachers and students without disabilities with respect to item wise were calculated, tabulated and interpreted. The obtained results are presented in the form of tables and discussed in detail.

Table I: Practising teachers’, prospective teachers’ and general school students’ mean score and level of awareness of the concept of inclusion for children with disabilities

<table>
<thead>
<tr>
<th>S.No</th>
<th>Statements</th>
<th>Practising Teachers</th>
<th>Prospective Teachers</th>
<th>Regular School Students</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score of Awareness Level of Awareness</td>
<td>Mean Score of Awareness Level of Awareness</td>
<td>Mean Score of Awareness Level of Awareness</td>
<td>Mean Score of Awareness Level of Awareness</td>
</tr>
<tr>
<td>1</td>
<td>Inclusive school is a place to learn to live together rather than to live together to learn</td>
<td>3.00 HA</td>
<td>2.95 HA</td>
<td>2.49 MA</td>
</tr>
<tr>
<td>2</td>
<td>Inclusive education is based on children’s individual differences with appropriate methods of instruction benefiting all children</td>
<td>2.95 HA</td>
<td>2.67 MA</td>
<td>2.45 MA</td>
</tr>
<tr>
<td>3</td>
<td>Inclusive education gives children without disabilities the opportunity to understand children with disabilities</td>
<td>2.99 HA</td>
<td>2.68 MA</td>
<td>2.44 MA</td>
</tr>
<tr>
<td>4</td>
<td>Inclusive education helps children without disabilities to interact with children with disabilities</td>
<td>2.77 MA</td>
<td>2.81 MA</td>
<td>2.70 MA</td>
</tr>
<tr>
<td></td>
<td><strong>Inclusive education promotes competence among children with disabilities</strong></td>
<td>2.98</td>
<td>HA</td>
<td>2.48</td>
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<td>---</td>
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</tr>
<tr>
<td>6</td>
<td><strong>Disabled children lose their self-confidence in an inclusive system</strong></td>
<td>2.93</td>
<td>HA</td>
<td>2.29</td>
</tr>
<tr>
<td>7</td>
<td><strong>Sometime children with disabilities have to undergo comments and disturbances from children without disabilities</strong></td>
<td>2.69</td>
<td>MA</td>
<td>2.81</td>
</tr>
<tr>
<td>8</td>
<td><strong>Disabled children are psychologically affected by inclusive education</strong></td>
<td>1.98</td>
<td>LA</td>
<td>2.78</td>
</tr>
<tr>
<td>9</td>
<td><strong>Lack of facilities in regular school affects the learning process of disabled children</strong></td>
<td>2.90</td>
<td>HA</td>
<td>2.70</td>
</tr>
<tr>
<td>10</td>
<td><strong>We cannot offer education to all children with disabilities in our nation through inclusive education</strong></td>
<td>2.50</td>
<td>MA</td>
<td>2.71</td>
</tr>
<tr>
<td>11</td>
<td><strong>Through inclusive education disabled students have an equal opportunity in classroom activities</strong></td>
<td>2.36</td>
<td>LA</td>
<td>2.45</td>
</tr>
<tr>
<td>12</td>
<td><strong>Necessary equipment /devices for special children in inclusive classrooms have a greater learning impact in learning activities</strong></td>
<td>2.87</td>
<td>HA</td>
<td>2.52</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Score 1</td>
<td>Score 2</td>
<td>Score 3</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>13</td>
<td>Successful engagement of diverse students in inclusive classrooms requires diverse instructional methodology, curriculum materials, and assessment methods</td>
<td>2.89</td>
<td>HA</td>
<td>2.61</td>
</tr>
<tr>
<td>14</td>
<td>Common rules and regulations for all students are good in inclusive schools</td>
<td>2.88</td>
<td>HA</td>
<td>2.90</td>
</tr>
<tr>
<td>15</td>
<td>Special transport and architectural modification are required for disabled students in inclusive education</td>
<td>2.59</td>
<td>MA</td>
<td>2.79</td>
</tr>
<tr>
<td>16</td>
<td>An inclusive classroom situation helps the disabled compete and develop alongside their classmates without disabilities</td>
<td>2.87</td>
<td>HA</td>
<td>2.72</td>
</tr>
<tr>
<td>17</td>
<td>Inclusive education promotes psychological and physical problems among children without disabilities</td>
<td>2.82</td>
<td>MA</td>
<td>2.57</td>
</tr>
<tr>
<td>18</td>
<td>Inclusive education paves the way for peer guidance and peer tutoring</td>
<td>2.52</td>
<td>MA</td>
<td>2.49</td>
</tr>
<tr>
<td>19</td>
<td>Common instructional methods followed by the teachers satisfy children with disabilities in inclusive education</td>
<td>2.96</td>
<td>HA</td>
<td>2.90</td>
</tr>
<tr>
<td>No.</td>
<td>Statement</td>
<td>Score</td>
<td>Group</td>
<td>Score</td>
</tr>
<tr>
<td>-----</td>
<td>----------------------------------------------------------------------------------------------------</td>
<td>-------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>20</td>
<td>Special evaluation techniques for disabled children are essential during examination</td>
<td>2.90</td>
<td>HA</td>
<td>2.50</td>
</tr>
<tr>
<td>21</td>
<td>Counselling for the parents of both students with and without disabilities is important in inclusive schools</td>
<td>2.99</td>
<td>HA</td>
<td>2.42</td>
</tr>
<tr>
<td>22</td>
<td>Training for the regular classroom teacher is important in inclusive education</td>
<td>2.96</td>
<td>HA</td>
<td>2.35</td>
</tr>
<tr>
<td>23</td>
<td>Effective inclusive education is based on a multidisciplinary approach, which requires regular teachers, special teachers and other professionals</td>
<td>2.96</td>
<td>HA</td>
<td>2.38</td>
</tr>
<tr>
<td>24</td>
<td>A high level of teacher expertise, infrastructural facilities and materials play vital roles for inclusion</td>
<td>2.85</td>
<td>MA</td>
<td>2.09</td>
</tr>
<tr>
<td>25</td>
<td>An inclusive curriculum involves collaboration with colleagues for effective instruction for students with diverse needs</td>
<td>2.93</td>
<td>HA</td>
<td>2.25</td>
</tr>
<tr>
<td>26</td>
<td>Teachers can teach successfully if they have multilevel instruction of students in inclusive classrooms</td>
<td>2.90</td>
<td>HA</td>
<td>2.30</td>
</tr>
</tbody>
</table>
Peer group guidance and counselling by the teacher develops positive attitudes and peer acceptance towards children with disabilities.

| 27 | Peer group guidance and counselling by the teacher develops positive attitudes and peer acceptance towards children with disabilities. | 2.93 | HA | 2.45 | MA | 2.42 | MA |

Parent-teacher meetings encourage proper understanding among parents of both students with and without disabilities.

| 28 | Parent-teacher meetings encourage proper understanding among parents of both students with and without disabilities. | 2.96 | HA | 2.74 | MA | 2.01 | LA |

The result showed that the practising teachers possess a high awareness of almost all the statements, whereas prospective teachers demonstrated only a moderate awareness of the concept of inclusion. At the other extreme the students in regular schools generally evinced a low awareness of most of the statements. The mean score reveals that practising teachers' awareness is better than prospective teachers' followed by non-disabled students'. This result shows that there is a pressing need to promote awareness-building programmes about inclusion for the prospective teachers' in the teacher preparation curriculum so that they are well trained to meet the needs of the diversified classrooms in future. The awareness programme for the students studying in regular schools can help them to understand the concept of inclusion in a more clear and concrete manner and extend a helping hand to their classmates with disabilities to function effectively. Their awareness and attitudes develop peer acceptance, which in turn promotes peer guidance and peer tutoring in an inclusive educational system.
Table II: Attitudes of the practising teachers, prospective teachers and general school students towards the concept of inclusion for children with disabilities

<table>
<thead>
<tr>
<th>S.No</th>
<th>Statements</th>
<th>Practising Teachers</th>
<th>Prospective Teachers</th>
<th>General School Students</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Positive Attitude</td>
<td>Negative Attitude</td>
<td>Positive Attitude</td>
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<tr>
<td></td>
<td></td>
<td>Practising Teachers</td>
<td>Prospective Teachers</td>
<td>General School Students</td>
</tr>
<tr>
<td>1</td>
<td>Inclusive school helps children with disabilities learn to live together rather than live together to learn</td>
<td>89</td>
<td>11</td>
<td>72</td>
</tr>
<tr>
<td>2</td>
<td>Inclusive education should be based on students’ individual differences with appropriate methods of instruction benefiting all children</td>
<td>91</td>
<td>9</td>
<td>90</td>
</tr>
<tr>
<td>3</td>
<td>Inclusive education offers a good opportunity to children without disabilities to understand children with disabilities</td>
<td>65</td>
<td>35</td>
<td>76</td>
</tr>
<tr>
<td>4</td>
<td>Interaction with children with disabilities sometimes helps children without disabilities to learn more effectively</td>
<td>33</td>
<td>67</td>
<td>54</td>
</tr>
<tr>
<td>5</td>
<td>Inclusive education promotes competence among children with disabilities</td>
<td>89</td>
<td>11</td>
<td>75</td>
</tr>
<tr>
<td>6</td>
<td>Disabled children lose their self-confidence in an inclusive system</td>
<td>78</td>
<td>22</td>
<td>67</td>
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<tr>
<td>7</td>
<td>Comments and disturbances from children without disabilities affect children with disabilities</td>
<td>55</td>
<td>45</td>
<td>56</td>
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<tr>
<td>8</td>
<td>Disabled children are psychologically affected by inclusive education</td>
<td>56</td>
<td>44</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td><strong>Adaptive facilities in regular schools promote the learning process of disabled children</strong></td>
<td>100</td>
<td>0</td>
<td>93</td>
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</tr>
<tr>
<td>10</td>
<td>We can offer education to all children with disabilities in our nation through inclusive education</td>
<td>55</td>
<td>45</td>
<td>45</td>
</tr>
<tr>
<td>11</td>
<td>Through inclusive education disabled students have an equal opportunity in classroom activities</td>
<td>76</td>
<td>24</td>
<td>63</td>
</tr>
<tr>
<td>12</td>
<td>Necessary equipment/devices for disabled children have a greater learning impact in learning activities</td>
<td>84</td>
<td>16</td>
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</tr>
<tr>
<td>13</td>
<td>Successful engagement of diverse students in inclusive classrooms requires diverse instructional methodology, curriculum materials and assessment methods</td>
<td>95</td>
<td>5</td>
<td>93</td>
</tr>
<tr>
<td>14</td>
<td>Common rules and regulations for all students are good in inclusive schools</td>
<td>37</td>
<td>63</td>
<td>46</td>
</tr>
<tr>
<td>15</td>
<td>Special transport and architectural modification are required for disabled students in inclusive education</td>
<td>86</td>
<td>14</td>
<td>73</td>
</tr>
<tr>
<td>16</td>
<td>An inclusive classroom situation helps disabled children compete and develop alongside their classmates without disabilities</td>
<td>100</td>
<td>0</td>
<td>94</td>
</tr>
<tr>
<td>17</td>
<td>Inclusive education promotes psychological and physical problems among children without disabilities</td>
<td>67</td>
<td>33</td>
<td>73</td>
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<tr>
<td>18</td>
<td>Inclusive education paves the way for peer guidance and peer tutoring</td>
<td>83</td>
<td>17</td>
<td>75</td>
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<tr>
<td>19</td>
<td>Common instructional methods followed by the teachers do not satisfy children with disabilities in inclusive education</td>
<td>94</td>
<td>6</td>
<td>86</td>
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<tr>
<td>20</td>
<td>Special evaluation techniques for disabled children are essential during examination</td>
<td>97</td>
<td>3</td>
<td>84</td>
</tr>
<tr>
<td>21</td>
<td>Counselling for the parents of both students with and without disabilities is important in inclusive schools</td>
<td>93</td>
<td>7</td>
<td>87</td>
</tr>
<tr>
<td>22</td>
<td>Training for the regular classroom teachers is important in inclusive education</td>
<td>96</td>
<td>4</td>
<td>100</td>
</tr>
<tr>
<td>23</td>
<td>A multidisciplinary approach is difficult to follow in inclusive education</td>
<td>80</td>
<td>20</td>
<td>89</td>
</tr>
<tr>
<td>24</td>
<td>A high level of teacher expertise, infrastructural facilities and materials play vital roles for inclusion</td>
<td>100</td>
<td>0</td>
<td>94</td>
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<tr>
<td>25</td>
<td>An inclusive curriculum involves collaboration with colleagues for effective instruction for students with diverse needs</td>
<td>94</td>
<td>6</td>
<td>96</td>
</tr>
<tr>
<td>26</td>
<td>Teachers can teach successfully if they have multilevel instruction of students in inclusive classrooms</td>
<td>88</td>
<td>12</td>
<td>92</td>
</tr>
<tr>
<td>27</td>
<td>Peer group guidance and counselling by the teacher develops positive attitudes and peer acceptance towards children with disabilities.</td>
<td>85</td>
<td>15</td>
<td>89</td>
</tr>
<tr>
<td>28</td>
<td>Parent-teacher meetings encourage proper understanding among parents of both students with and without disabilities.</td>
<td>83</td>
<td>17</td>
<td>85</td>
</tr>
</tbody>
</table>
Positive attitudes were demonstrated by the practising teachers, prospective teachers and students in almost all of the statements towards the concept of inclusion. The attitude of practising teachers is better than those of the prospective teachers and students without disabilities. The result indicates the need for an attitudinal building programme for the prospective teachers and students without disabilities for better understanding of the concept of inclusion for children with disabilities. This programme will certainly help the prospective teachers realize their responsibilities and help students without disabilities accept children with disabilities.

5. Qualitative Analysis

Qualitative analysis was accomplished via unstructured interviews with practising teachers. The teachers’ opinions about inclusion and the problems faced by them in inclusive classrooms were analysed and interpreted. Teachers feel that inclusion is a good concept, but that it has a long way to go. They have to face many challenges and accept a great deal of responsibility, of which they are naturally apprehensive. They fear that they will not be able to understand the real meaning of inclusion. They are frustrated because, although accountable, they don’t know what they have to do. Similar findings were also published by Jack Pearpoint and Marsha Forest. According to them, the views that surface are: “But, we don’t have enough money! But, we haven’t been trained to take care of those! But, I didn’t choose special education! But, I don’t have special curriculum guidelines, and I don’t have time to create a special program for ‘them’! The other children will suffer!” Similar responses have been expressed by most of the teachers. Although there is no negative perception towards inclusion in general, there still exist certain conflicts within the teachers themselves about what they must do or not do. Some teachers also responded pertaining to certain teaching approaches/teaching competencies. The interviewee in Tamilnadu (January, 2008) stated that

“The teacher should possess the ability to recognize each child’s inner strengths and weakness and adapt curriculum and assign-

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ments according to their needs, interest and abilities. They should know the significance of co-operative learning, peer tutoring & play way techniques, demonstrative teaching and skill training. An inclusive teacher should also adapt flexibility in evaluation where standard evaluation will not work with all the children. Infrastructural modifications, adaptive device procurement for the child's physical adaptations and community involvement will certainly work effectively in an inclusive educational set up."

The qualitative analysis was accomplished via unstructured interviews with practising teachers and prospective teachers working in regular schools. Their opinions were analyzed and interpreted accordingly. The discussion above showed that the practising teachers possess a better awareness and more positive attitude towards the concept of inclusion. Inclusion will be successful only if the teachers and regular school students welcome students with disabilities and treat them as if they are one among them. Only then will the concept of inclusion function; otherwise it will remain on a policy level and its implementation will not truly occur.

6. Implications of the Study

This article indicates the need to organize a need-based training programme for the teachers to face the challenges of an inclusive educational set up. The qualitative analysis revealed that they are uncertain of their responsibilities. The article emphasises that it is the duty of the National Council of Teacher Education in India and other National Level Educational Bodies to conduct an orientation programme to inclusive school teachers to explain their roles and responsibilities and to train them to face the challenges in the inclusive educational system. It is also important to develop a positive attitude among the students without disabilities, as the study evoked only a negative attitude in certain statements among the students without disabilities. Development of a positive attitude will certainly promote peer acceptance, which in turn facilitates peer guidance and peer tutoring. Collaborative and co-operative learning in the inclusive educational system will encourage children with disabilities.

The present study pinpoints the necessary steps to be undertaken for building sensitization and positive attitudinal change among the teachers and students towards the acceptance of children with
disabilities for full inclusion. UN CRPD Article 24 on the concept of inclusion will be functional only when the practising and prospective teachers understand the concept of inclusion and possess competencies to handle children with disabilities. If the teachers possess knowledge about inclusion, a positive attitude towards the concept of inclusion and the skill to handle children with disabilities in inclusive classes then the students with disabilities in the inclusive educational system will certainly benefit from inclusion. This in turn facilitates the students without disabilities to understand the concept of inclusion and promote peer acceptance which promotes peer collaboration and peer guidance in an inclusive learning situation.

This article concludes that the concept of inclusion will be functional when the teachers and students in regular schools value the individuality of other children irrespective of their abilities and disabilities.
Chapter 6:

The Right to “Decent Work” of Persons with Disabilities: Article 27 of the Convention and the Case of Uganda

Edson Ngirabakunzi and Hisayo Katsui

1. Introduction

In general, persons with disabilities (PWDs) in any country are disproportionately unemployed or not in “decent employment” compared with peers without a disability. The unemployment rate among PWDs tends to be at least twice or three times that of peers without a disability. Furthermore, PWDs are disproportionately working at lowly paid jobs. In times of economic distress they are usually the first to be discharged and yet last to be hired. The denial of equal employment opportunities to PWDs forms one of the root causes of poverty and exclusion among this group. Therefore, decent work is fundamental to counteracting such negative consequences. Although employment is only one aspect of life, and many other aspects such as health, family and education are as important, employment has become central in the lives of persons with and without disabilities due to the general trend of capitalism. The Director General of the International Labour Organization (ILO), Juan Somavia states:

“Everyday we are reminded that, for everybody, work is a defining feature of human existence. It is the means of sustaining life and of meeting basic needs. But it is also an activity through which individuals affirm their own identity, both to themselves and to those around

2 Ibid., p. 73.
4 Ibid.
them. It is crucial to individual choice, to the welfare of families and to the stability of societies." 5

The ILO has promoted the concept of “decent work” for the last decade. This refers to work in terms of freedom, equity, safety/security and human dignity. 6 That is, ethical aspects of work and labour rights are paid special attention to. This paper focuses on the right to work stipulated in Article 27 of the Convention as follows:

“Article 27 Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

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(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(g) Employ persons with disabilities in the public sector;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.”

This paper focuses on the right to decent work of PWDs with a case study from Uganda. First, different forms of statutory legal provisions in Uganda are reviewed. These legal provisions have not benefited Ugandan PWDs to a significant extent. Following this, the next section examines the life story of a Ugandan woman with a disability. Her story powerfully describes various challenges regarding the right to decent work. Based on these, the interplay between discrimination against and self-esteem of PWDs will be analysed. Subsequently three thematic discussions concerning reasonable accommodation in 1) the job application process, 2) the work environment and accessibility, and 3) equal benefits are presented. The paper concludes with implications for attaining the right to decent work for PWDs, especially in the Ugandan context but also beyond.
2. Different Forms of Statutory Legal Provisions in Uganda

The following statutory legal obligations are analysed in relation to employment of PWDs in Uganda and lay a firm foundation for the discussion of decent employment for PWDs.

The Ugandan 1995 Constitution recognizes the rights of PWDs and provides for non-discrimination on the basis of disability. It forms the foundation of all the subsequent pertinent laws. This provides a green light on the importance the government attaches to disability and disability issues such as employment, for example. A number of legislations have legal provisions that have a direct bearing on disability in Uganda. However, constitutional provisions on their own often have limited impact because they frequently do not grant substantive rights, so they cannot be invoked in court; they tend to be broad and do not contain precise definitions. Judgments based on these will be discretionary and place obligations on the state and state entities rather than on the private sector.7

However, a number of laws have been enacted in Uganda with provisions on employment of PWDs. A Quota System is provided for under the Persons with Disabilities Act (2006). It provides that the Minister for Labour – with consultation from employers’ organizations – shall determine the quota of PWDs in the workforce. Prior to this there was neither a quota nor modalities. Furthermore, it provides for affirmative action measures, for example by providing tax exemptions to employers for work carried out to make premises accessible (Article 13 b and c) and tax reduction for employing more than 10 persons with disabilities (Article 17). Few employer institutions have taken advantage of this law. Crane Bank and Entebbe Handling Services are two companies that have employed PWDs as a result of these legal provisions.8 Baguwemu et al claim that PWDs are still employed primarily due to acts of philanthropy, and that a

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8 W. Bongomin, Personal Interview at Makerere University, Kampala, on 14 May 2009.
quota system is an important policy mechanism enabling PWDs to obtain employment.⁹

Support Employment refers to the employment exchange service within the Ministry of Gender, Labour and Social Development which facilitates the work placement of PWDs.¹⁰ It also provides vocational rehabilitation and resettlement services, and operates sheltered workshops. However, it has been observed that rehabilitation centres are receiving inadequate resources and hence working below capacity. In early 2000 there was a Youth Entrepreneurship Scheme (YES) programme through the Ministry in charge of labour, where PWDs were given seed capital. However, this programme is no longer functional.

Recently the government has announced plans to pay unemployed persons, including PWDs, between 150,000-200,000 Uganda Shillings monthly (60-80 Euros).¹¹ There is hope that this programme will contribute towards improving the dignity of unemployed PWDs.

The Employment Act (2006) recognizes disability as protected ground with respect to discrimination. Section 6 (discrimination in employment) provides for promotion of equality of opportunities with the view of eliminating all discrimination in employment. The Act defines discrimination as any distinction, exclusion or preference made on the basis of race, colour, gender, religion, political opinion, national extraction or social origin, HIV status, a disability having the effect of nullifying or impairing the treatment of a person in employment or occupation or of preventing an employee from obtaining any benefit under a contract of service.

Also under Sec. 21; the Labour Advisory Board (LAB) was established and among its members is a representative of PWDs. Sec. 34 provides that the Minister, on recommendation of the LAB, can create

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¹⁰ International Labour Organisation, Uganda Country Profile. Employment of PWDs: The impact of Legislations, East Africa (ILO InFocus Programme on Skills, Knowledge and Employability in the Framework of Project Funded by Development cooperation, Ireland DCI, 2004).
regulations governing the employment of categories of employees in need of special protection under the law. Among these are PWDs. However, in view of the above, situations where discrimination occurs only when persons are already in employment would exclude what happens at the recruitment level where PWDs have typically been obstructed. Further, Sec. 6 (4) sanctions exclusion or preference at the employer’s discretion based on the inherent requirements of a job. An employer, based on his/her bias or misinformation, could easily abuse the above provision. This is not uncommon where there are still prevalent negative attitudes and barriers in society.\textsuperscript{12} Furthermore, although there is provision for PWDs on the LAB, the board is not yet functional. There is also no provision concerning how the representatives are to be chosen. The new Act has been disseminated primarily in the formal sector, yet the informal sector is the biggest employer.

The Trade Union Act (2006) is one of the laws that govern the relationship between employees and employers. It is particularly instrumental in fighting for the rights of employees. It regulates the establishment, registration and management of labour unions. Whereas PWDs are part of the labour force, it does not mention or provide mechanisms for how to address disability issues at the workplace. The National Organization of Trade Unions (NOTU) is independent of the government but has little influence in the economy since it claims only about 5 per cent of the workforce. It is important to note that labour unions have not grown large enough to significantly help the situation of vulnerable employees, even less so for PWDs. Contrary to the spirit of affirmative action enshrined in the constitution, there are no PWD representatives in NOTU. Therefore, it is doubtful whether they have the strength and/or ability to champion the rights of employees with disabilities.

Whereas laws and policies provide for these provisions that would give full effect to affirmative action in employment, there is more to be done on the ground. The provisions still largely lack enforcement.\textsuperscript{13} To give full effect to disability laws, the Ministry of Gender,


Labour and Social Development is currently developing regulations and a plan of action. This will contribute to the operationalisation of the laws. It is not enough for clauses to merely exist in laws; their implementation and enforcement determine their effectiveness.\footnote{A. I. Linda, \textit{Ugandan Laws Relevant to Education and Employment of Persons with Disabilities: An Audit on their Compliance with International Labour Standards}; \textit{A report to the National Union of Disabled persons of Uganda (NUDIPU) and International Labour Office} (ILO, 2008).}

3. Life Story of Prossy Nanyunja

The life story of a Ugandan woman with disability in the following illustrates the manifestation of discrimination against and the self-esteem of PWDs. The following life story was written by Prossy Nanyunja.\footnote{The life story was electronically published at our research project website, <http://disability-uganda.blogspot.com/>, on 14 April 2009.} Her life story powerfully presents various challenges in her life in Uganda, while it elucidates how her employment has been an important turning point both for her and for those close to her.

“I am Nanyunja Prossy. I work with the National Union of Disabled Persons of Uganda (NUDIPU) as an accounts assistant. I am a person with a physical disability who has gone through all the stages of primary, secondary and higher institutions of learning. I got this disability at the age of three. My mum told me that one afternoon I got a high fever and was rushed to the hospital. There I was immediately given an injection. In a few hours the fever had cleared, but my legs became very weak. Since then, for the past 28 years, I’ve been a person with a disability.

So this story is all about the challenges I have encountered as a person with disability from the age of three when I was a child, and the opportunities I got on the way to where I am now. But the challenges seem not to stop or diminish because at each stage of life, they become totally different. The fact is I will continue to have the disability for as long as I am alive. I have come to terms with that.

As I was growing up, my mum did her best to see me go to school. I did my primary level for seven years, after which I had to go to another school for the ordinary level. That is where the problems having to do with being a person with disability started. First, my real
father disagreed with my mum, telling her that she shouldn’t bother herself with me because after all, no employer would ever give a job to a person like me, even if I studied hard. He then advised her to take me to a vocational school to learn tailoring. My mum cried over it but later decided to continue with her struggle to educate me with the little earnings she could get. By then my parents had even separated, and my mum was working in one of the big markets in the city centre selling green vegetables.

To my mum’s and my disappointment, I was again denied admission to two boarding schools. The denial was followed by the explanation that being a person with disability, I would not be able to cope with the school environment and that they didn’t have special facilities for such people. This is the time when I started realizing that I was different from other people. In my former school, where I completed my primary, we were all disabled children so I didn’t see myself any different from others. I believed I had the potential to do what they could do. People always say that persons with disabilities are different because they are not physically able. But what is able? For sure, they know the definition of “able” from a cultural point of view, but they do not know what it means for an individual. Surprising! So I ended up joining a day school. This made my class attendance irregular because I had to walk four kilometres every day from home to school. And whenever it rained in the mornings, to me it would mean not going to school. The school buildings were all multi-storied, so I always reached my class tired because going up the stair cases everyday was not anywhere near my idea of adventure. I studied there for one year and later joined a boarding school.

I persevered and managed to complete my secondary levels, but with a lot of psychological torture because of the negative attitude that surrounded me from all sides: first, from the school administrators, then from fellow schoolmates, relatives at home and the community. At home, as a child growing up, I was seen as an extra economic burden. I needed crutches and callipers to enable me cope with my physical limitations, and they were very expensive. My siblings were also against me because our mum always protected me from doing any chores at home. They could not be taken to boarding schools; it always had to be me just because of my disability.

I finished both my ordinary and advanced levels and then looked forward to joining a higher institution of learning where I graduated with a diploma in business studies. After getting my diploma, everyone started doubting whether I would be able to get a job. I remember a friend of my mum telling her, “Nowadays employers, especially men, want to first sleep with these young girls after which they give them jobs. But there is no man in his right thinking capacity
who can sleep with a person with disability.” She even asked my mum why she bothered to waste her time and money to take me to school. It really demoralized me. I had been listening to their conversation - the fact that they were talking about me made me listen attentively. Unfortunately, I couldn’t even participate in their conversation to defend myself.

While I was looking for any possible employment opportunity to come my way, I used to do handwork. I used to weave mats, table mats and table clothes from which I got money to facilitate transport and the photocopying of my academic transcripts so I could leave copies wherever I went to look for a job. Fortunately, I got a job after two years of serious searching. I got to know of a job advertisement in the NUDIPU through a person I studied with in primary school, and that I had the qualifications required for the job. So I decided to put in my application, was short listed and interviewed, and passed. I interviewed with four people, two of whom were persons with disabilities and the other two were not. I came in first and took up the position. It is now six years down the road and I am still working there happily. Getting a job was a turning point for me. It came as a surprise to everyone as many people didn’t expect to see it happen.

But that was not the end of my problems brought about by disability. Now others have started looking at me as someone who was overgrown, and expecting me to find a man just to help me get a child to look after me in my old age, saying, “After all, she has a job and is getting enough money that she can use to look after her child even if the father of the child doesn’t take up full responsibility.” Even now, I am being told that crap. Can you imagine, even by my own mother? It really bothers me a lot when it also comes from my mother because I always saw her as a person who knew and believed that I had the potential to do and achieve whatever I wanted to do without the word disability being fronted.

Being a woman with a disability is a very big challenge here in my country. You are not expected to get married because no man will be willing to genuinely fall in love with you because of the fear of being seen with a cripple. And you are always expected to give in to any proposal offered by whoever comes to you, because he would just be helping you to sleep with him. I remember in the year 2007 there is a man who proposed to me for more than seven months. I remember asking him why he was insisting on me when I had already told him that I was not willing to start a relationship with him. It still sounds fresh in my ears as if it were yesterday when that man replied to me saying, “It is because YOU ARE NEGLECTED”. Neglected, meaning that no man can, has or ever will love me. So he was just going to help me. Awful, is it not? I hated myself for that.
Most times I try to put everything behind me so that I can continue with my life minus what people say about me, but sometimes I lose out and end up being weak and emotionally touched. It really gets me worked up when I am walking down the street and people start looking at me in a strange and inhumane way. Then they start talking about me, not even minding how I feel about their comments regarding my disability. Living with a disability is such a big challenge that I wouldn’t wish even for my worst enemy to become disabled.

To me, the worst challenge in living with a disability is having to depend on other people financially. Being very poor, without any income generating activity to rely on can really complicate the life of a PWD (person with disabilities) completely. You are looked at differently when you are a PWD with money, compared to another PWD who is in absolute poverty. Personally, I am not rich but at least what I earn makes me able to cover most of my needs. And the way my siblings and other relatives look at me now is totally different from the picture they had of me ten years back. I can even support our mother financially, which some of them cannot do.

Working with the NUDIPU has helped me a lot to build my self-esteem and to look at things and myself positively: first, because some of my workmates are PWDs. Second, the NUDIPU being a membership organization is comprised of Disabled People’s Organizations with different categories of disabilities. Looking at all these people in their different capacities, how they have struggled with life to sustain their families makes me proud of myself because most of them didn’t even attain the education that I got.

With my earnings I’ve even managed to sponsor myself and go back for further studies to supplement the Diploma that I’ve always had. I am now pursuing a Degree in Business Administration majoring in Accounts, and I am to complete it in May of this year (thus becoming a full accountant). I am also paying the secondary school fees of one of my siblings, and am always supporting my relatives financially where possible.”

There is an epilogue for her life story. Her employment at the NUDIPU was terminated in spring 2009 when one of the major donors (a Northern DPO) completed its project. Much of the staff at the NUDIPU became unemployed as a result. The board members of the NUDIPU decided to terminate the employment of a number of staff at an earlier stage on very short notice. A few Northern DPOs intervened so that the NUDIPU could extend their employment for a few more months due to labour rights considerations. It was not
the employees of the NUDIPU but the Northern counterparts who appealed and ensured the rights of the employees. That is, labour rights for both employers and employees are not yet clearly recognized even in the formal sector, which is supposed to be better in legally binding provisions of employees’ rights. In reality, even formal sector employment is often not a permanent job. Moreover, even where labour rights are recognized, it would involve legal costs which employees may not be able to afford if they opted for a court settlement. Nevertheless, Nanyunja is still hopeful to complete her studies and find another employment opportunity in the near future.

4. Analysis on Discrimination against and Self-esteem of Persons with Disabilities

Based both on statutory legal provisions and Nanyunja’s life story, we shall analyse the interplay between discrimination and the self-esteem of PWDs.

4.1. Discrimination

In the latest report of the Ugandan Ministry of Finance, it was pointed out that attributing disability to the curse of supernatural powers such as God and witches is common in Uganda.\(^{16}\) This “traditional model of disability”\(^ {17}\) is deeply related to discrimination against PWDs in Uganda today. For instance, Nanyunja’s life was full of encounters with discrimination during her education even before employment. People in society in general think equal educational opportunities for children with disabilities is a waste, because they would not get decent jobs, especially for women with disabilities. Her father had internalised the low expectations of society and did not pay equal attention to her education. Without her mother, she would not have received an education. Even with the positive attitude of the mother, Nanyunja is still hopeful to complete her studies and find another employment opportunity in the near future.


she encountered physical inaccessibility in her schools. This forced her to the choice of a boarding school, which is far more expensive than going to a mainstream school nearby. When given the equal opportunity of education, other siblings were unhappy because the limited resources of the family are allocated to her, even though many of the extra costs were incurred not only because of her impairment but also because of the discrimination in society.

Discrimination took different forms, such as direct (ex. denial of equal education opportunity), indirect (ex. proposal of learning tailoring) and lack of reasonable accommodation (ex. inaccessible schools). Despite of a number of human rights-based legal provisions and a vigorous disability movement in Uganda, the discrimination at the grassroots level has not been remedied. Since discrimination is deeply rooted to the local understanding of disability as curse, it is challenging to change the common perception.

The affirmative action policy of the Ugandan government began to promote employment of PWDs particularly in the central and local government structure as representatives of PWDs (please see Chapter 7 of the book), while DPOs advocate for the right to employment. Positive changes started to take place slowly but surely. A long-serving Member of Parliament, Baba Diri\textsuperscript{18} asserts:

\begin{quote}
"Actually, this constitution and representation of people with disabilities [in the government structure] have really made disabled people known worldwide for us being conscious about disability even at the national level because you find disabled persons as local councillors. You cannot find a disabled person and say, "This is a helpless disabled person," because he could be better than you because you are not a councillor. So they are respected, though the attitude is still there and not changed completely. But at least, we have gone a long way."
\end{quote}

4.2. Self-esteem of PWDs

The aforementioned negative attitude of society frequently limits equal opportunities and further discourages PWDs to expect equal opportunities. Nanyunja did not give up, which many do when deeply

\textsuperscript{18} M. Baba Diri, Member of Parliament, Personal Interview at Kampala on 19 February 2008.
rooted discrimination is too severe and there is no support around them. In this way, the social discrimination becomes painful experiences and challenges at a personal level. This often expresses itself as “personal problems,” which engenders the internalisation of the negative image.\(^{19}\) “Self-pity”, a lack of self-confidence and a fear of encountering stigmatisation as a result of ubiquitous deeply/rooted discrimination were singled out as reasons that PWDs quickly give up in fighting for their rights.\(^{20}\) The Ministry report connects disability with chronic poverty and asserts that many PWDs “cannot leave their homes,” “speak out for themselves,” and “are simply dependants and therefore not decisive on their fate”.\(^{21}\) The capacity of PWDs, particularly with respect to legal knowledge, to benefit from the existing legal provisions is limited.

Consequently PWDs are predominantly employed or self-employed in the informal sector, ending up as e.g. market vendors or shoe-shiners\(^{22}\) in urban areas or “digging” (agricultural work) in rural areas, depending on the impairment and its severity. Otherwise, they are unemployed and considered to be “a burden”.\(^{23}\) Even when employed, they are often exploited. For instance, many deaf women work as house maids or cleaners for richer families, but are paid little to nothing, as their employers rely on their illiteracy and limited communication skills to prevent them from reporting any maltreatment.\(^{24}\) Some DPOs intervene and take the cases to court\(^{25}\), but most nonetheless remain as painful personal experiences that reinforce the internalised negative image they have of themselves in society. Therefore, the self-esteem of PWDs tends to be low due to the discrimination mechanism affecting personal psychology. Conversely, when a person with a disability such as Nanyunja


\(^{22}\) Ibid., p. 21.

\(^{23}\) Ibid., p. 24.

\(^{24}\) R. Nararome (Chairperson of the United Young Deaf Women Group), Personal Interview at Kampala on 4 February 2008.

\(^{25}\) F. Kinubi (Chairperson of the NUDIPU), Personal Interview at Kampala on 31 January 2008.
manages to overcome discriminating conditions and obtains decent employment, the self-esteem improves dramatically. In Uganda where social services are scarce and inaccessible to a large extent, financial independence and the capacity to financially support family members are great achievements for PWDs.

5. Discussing Reasonable Accommodation in the Context of Employment in Uganda

An interview with the Chairperson of the NUDIPU, Kinubi\textsuperscript{26} illustrates how a case of discrimination by employers fails to ensure reasonable accommodation.

“Many of our people have been thrown out from their employment. PWDs read adverts in a paper, apply for a job, are shortlisted, but the employers don’t know that he is blind or physically impaired. Sudden on the day of the interview, they see a person in a wheelchair entering the interview room and disqualify you before they understand your potential, before they see your abilities. They disqualify you just on seeing you. Those who convince them to go through the interview, one of our brothers called Moses was interviewed and succeeded. His appointment letter was given to him. But when he went to the office to work, they saw him leaping. They realized and looked at one another, “Oh, this guy is disabled! Ah!” In only six hours time, he was given a termination letter. He came in the morning to the office, and by the lunch time, he was given a termination letter. After realizing that he is disabled. We tried to pursue this in court. You see? This is very rampant, very common.”

From this interview, it is evident that discrimination in employment provides little leeway in reasonable accommodation issues. The discussion under this section hinges on reasonable accommodation as described in CRPD Article 2, provided as follows:

“‘Reasonable accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;”

\textsuperscript{26} Ibid.
It is important to note that a clear definition of reasonable accommodation is lacking in Uganda\textsuperscript{27}, yet is very important to allow the full effect on decent work and employment. For instance, in the United States, the obligation to provide reasonable accommodation is found in the Americans with Disabilities Act (1990). Reasonable accommodation is understood to mean any change in the work environment or in the way a job is performed that enables a person with disability to enjoy equal employment opportunities.\textsuperscript{28} There are three categories of reasonable accommodations: changes to the job application process, changes to the work environment or to the way a job is usually performed, and changes that enable an employee with disability to enjoy equal benefits and privileges of employment.\textsuperscript{29} The discussion elucidates the aforementioned three categories of reasonable accommodations: 1) job application process, 2) work environment and accessibility and 3) “equal” benefits. At the end of the chapter, we shall debate over who bears responsibility for provision of reasonable accommodation in terms of employment.

5.1. Job Application Process

Reasonable accommodation can be applied as an affirmative action during the recruitment process in favour of marginalized groups of people. The recruitment criteria would not then only cover ability and competence, but consider potentials of candidates who have been marginalized and have not gained enough ability at the time of recruitment. Their potentials would be developed when employed and they would be given the opportunity to learn necessary skills in due course. The Finnish government financially supports this process.

Another means of affirmative action is the quota employment system. The quota system has the clear objective of quantitatively increasing the employment opportunities of PWDs, and to substan-
tially promote their participation in society.\textsuperscript{30} When the quota system is implemented with widely shared social norms that equal opportunity of PWDs should be ensured, it can be effective. However, it has been pointed out that when such social norms are not shared and when this form of affirmative action is “unreasonable,” PWDs would face stigma as a result and encounter feelings of guilt.\textsuperscript{31} In this regard, discrimination and affirmative action is an analogy of “chicken or the egg” debate: which should be tackled first?

As was mentioned above, discrimination against PWDs is historically and culturally rooted and cannot be changed overnight. Thus multiple approaches including political will and leadership with a top-down approach is relevant. Under the circumstance in which persons without a disability do not enjoy “decent work” defined in a Northern framework, the “decent work” concept itself needs to be re-defined to fit into the Ugandan context. However, to respect the labour rights of employees to benefit all in a society, starting from PWDs is a pioneering experiment to eventually uplift the human rights of all. Therefore, we would argue that “decent work” even in a resource-constrained country should accommodate ethical considerations.

\textbf{5.2. Work Environment and Accessibility}

Reasonable accommodation becomes important in work because disability sometimes affects the ability to carry out a job in the customary way.\textsuperscript{32} Employers have not responded to change the work environment as has been articulated in a number of legislations. For instance, Baguwemu et al\textsuperscript{33} argue that some employers in Uganda have not taken full advantage of existing legislations because they still employ PWDs on philanthropic considerations. This implies that they may not even concern themselves with changing the work environment to accommodate employees with disabilities. Furthermore the laws have also created a lacuna that can be exploited by the employers. For instance, while the Employment Act (2006) prohibits


\textsuperscript{31} Ibid., p. 3.

\textsuperscript{32} ILO, \textit{supra} note 7, p. 30.

\textsuperscript{33} Baguwemu et al, \textit{supra} note 9.
discrimination based on disability, at the same time it allows employers to practice discrimination on the pretext of the inherent nature of the job (section 6). In a society where stigma and negative attitudes towards disability and PWDs are still prevalent, getting employers to make changes to work environment to accommodate PWDs may not be amicable. For instance there is a clear lack of any reference in the national legislation – the Constitution and relevant laws including the PWDs Act and the Employment Act (OHCHR, 2008) – concerning the duty to provide reasonable accommodation. The law ought to be more precise.

In their study, Baguwemu et al. highlight that many employers lack information on the potential abilities and needs of PWDs and how they can be integrated. In effect this would negate operational changes to the work environment since the needs of PWDs are unknown to their prospective employers. The study claims that if a blind person is given a job, it is not automatic for him or her to get a guide; s/he must also ask whether or not the employer will get him or her one. S/he must look for a white cane and s/he cannot be afforded the modern technology required to do his/her work. Therefore, these are issues and bottlenecks that would impede practicing reasonable accommodation by employers, because there is neither clear law nor the requisite awareness of the meaning of reasonable accommodation.

Another practical challenge in Uganda is that employers sometimes do not own the premises. They operate from rented premises. They argue that when faced with the challenge of changing the architectural designs of premises, the landlords may not be willing to permit this. Yet non-discrimination legislation increasingly requires employers and others to take into account individuals’ disabilities and make efforts to cater to the needs of workers or job applicants with disabilities to overcome physical and social barriers. The principle itself from the outset contains such words as “undue burden” which can be misconstrued or misinterpreted by employers.

34 Linda, supra note 14.
35 Baguwemu et al, supra note 9 and Richards, supra note 12.
36 Baguwemu et al, supra note 9.
37 Ibid.
38 ILO, supra note 7, p. 30.
ILO\textsuperscript{39} contends that laws should precisely define what is meant by reasonable accommodation so that misinterpretation is avoided and employers clearly understand what they must do. OHCHR\textsuperscript{40} also agrees that the duty to accommodate and the “undue burden” limit should find a clear space in the domestic legislation. While it would be difficult to prescribe what reasonableness would entail given the unique characteristics and needs of various categories of PWDs, it would be important to argue that countries and individuals should be empowered with enough information and knowledge to be able to determine what is reasonable in their specific context.

Reasonable accommodation is gaining momentum in Uganda. There is some level of accommodation of disability issues in the employment area. For instance DPOs are pioneers in encouraging reasonable accommodation so that modifications are made at the level of organizational policy, programme activities and recruitment. At the NUDIPU there were two blind employees who were both afforded personal assistants, while the deaf employee had a sign language interpreter. Members of Parliament representing PWDs are also provided with personal assistants and interpreters. It is important to note that with entry of MPs representing PWDs, the Parliamentary building was modified to accommodate physical access. However, toilet accessibility within the premises has remained a challenging issue. Moreover, accessibility to the premises is not enough when public transportation is inaccessible. Nonetheless, accessibility in all of its forms is fundamental to maximising the effect of reasonable accommodation. Therefore, failure to provide reasonable accommodation to workers and job applicants who face obstacles in the labour market is not merely bad practice but is increasingly perceived as unacceptable discrimination\textsuperscript{41} against human rights, and is furthermore illegal.

5.3. “Equal” Employment Benefits

In Uganda where an estimated 28 million reside, the size of the labour force is estimated at 13.76 million, 82 percent of which are in the agriculture sector, 5 percent in industry, and 13 percent in

\textsuperscript{39} Ibid.
\textsuperscript{40} OHCHR, \textit{supra} note 27.
\textsuperscript{41} ILO 2004, \textit{supra} note 7, p. 30.
services. Since most of the populations are in rural areas, most of the work takes place in rural areas. It is estimated that the informal sector employs 90 per cent of the “non-farm private sector workers.” One of the characteristics of the informal sector is the lack of social protection schemes; farmers are also barely protected by labour rights. Thus, most of the population does not enjoy decent work. As the UN Convention promotes the right to work “on an equal basis with others,” does this situation imply that PWDs in Uganda do not have the right to decent work? Similar questions can be raised about other rights covered under the Convention (please see Chapter 9 of this book for the right to food), if the rights are non-existent in practice when persons without a disability do not enjoy the rights. Who are the “others”?

Furthermore, Shakespeare alerts us that paying little attention to the diversity of PWDs would lead to an exacerbation of inequality among PWDs: “those who are able to compete effectively in a market economy, given certain basic protections and welfare services, flourish in a way impossible for those who cannot work the hours of non-disabled people.” He calls for “a more radical social philosophy” to emancipate all. Along the same line, both reasonable accommodation and the right not to work for those who are, for instance persons with severely disabilities, are relevant discussions in the disability discourse in terms of the right to decent work. Equality is not about equal treatment (please see Chapter 3 of this book for the discussion on equality).

44 Ibid.
46 Ibid., p. 4.
In Uganda, PWDs still do not receive equal employment benefits, even in their simplest forms, such as a salary. Baguwemu et al. affirmed that PWDs who are denied employment due to disability are victims of unjustified prejudices from employers. Some PWDs are paid less than what their non-disabled counterparts get for the same work. Therefore it is important that the concept of reasonable accommodation is an essential part of the definition of discrimination in the context of disability in Uganda.

5.4. Who Bears the Responsibility?

In view of all of the above, it is now time to answer the question of who is responsible for reasonable accommodation. This question is both simple and complex. It is simple because stakeholders in this sector are well known, but complex because we are not so sure how effectively they can reasonably accommodate the issues of PWDs. This is partly because there are many areas, spaces and concerns that will require reasonable accommodation to take full effect as stakeholders themselves. For instance there are legislations that govern relations between employers and employees; there are those, such as the informal sector, whose sector’s relations are not well anchored in the law. There are also government agencies that create the law and those charged with its implementation. All these stakeholders need to be in harmony with each other as far as the employment of PWDs is concerned, because employment is only one aspect of life which cannot be easily and clearly distinguished from its other aspects. Amidst all of these matters, reasonable accommodation is therefore the responsibility of everybody. It is the responsibility of a person with disability, persons without disability, employees, employers, policy makers, policy implementers and the general public.

6. Concluding Remarks

This paper concentrated on the right to work by paying attention to the ethical aspects surrounding it, namely the right to “decent
work”. Work has become an important part of life for persons with and without disabilities due to various issues including self-esteem and income. This is not to imply that employment and work ability are essential for human beings. However, the tendency to highly value employment has increased, which has further marginalized many PWDs without employment. Throughout this paper, therefore, we were careful not to overvalue the significance of employment in one’s life. Conversely, the paper reviewed the right in the Ugandan context and reassured that work is only part of life: mere employment opportunity, especially without reasonable accommodation, does not change the deeply-rooted discrimination against PWDs. The life story of Nanyunja strongly spoke to the interconnection of employment to different aspects of life as well as the significance of decent employment. Unfortunately “others” are also not enjoying “decent work” either. Therefore, we came to the following concluding remarks, which we think have great implications to the right to work in other countries beyond Uganda even though the arguments are based on the Ugandan context.

Firstly, we are all responsible since all the stakeholders are not fully aware of the right to work of PWDs, particularly in terms of reasonable accommodation. Obviously, the primary responsible party is the state, which is responsible for proper legal provisions and their operationalisation. However, as the employment sector involves various other stakeholders, including people in the informal sector, and thus any person at the grassroots level, raising the awareness of all stakeholders becomes essential.

Secondly, the Convention stipulates the right to work “on an equal basis with others.” When “others” mean persons without a disability in the same country, and when they also do not enjoy “decent work” at present, beginning with PWDs becomes important. As PWDs are recognized as one of the most marginalized groups of people, and as human rights start from the most marginalized, for applicants and employees with disabilities taking the ethical aspects of work seriously has important implications, which infer that in the future, the right will be applied also to “others”.

Thirdly, an “equal” right to work is not exclusively about employment with individually-tailored reasonable accommodation. We think that the reasonable accommodation concept should include the right
not to work for those who are not capable of working due to their more severe impairments. Reasonable accommodation for those people should be also included into the discussion on the right to work of PWDs.

Hence, a serious commitment from all of us is required for PWDs’ right to work to be operationalized in practice.
PART III: PARTICIPATION OF PERSONS WITH DISABILITIES
Chapter 7:
Towards Participation of Persons with Disabilities from the South: Implications of Article 32 of the Convention

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1. Introduction

The Convention allows us to consider how we can benefit from it. The focus, however, tends to remain on our own countries or smaller units. Less attention, if any at all, is paid to considering how to use this Convention to benefit others and other countries. Therefore, this chapter elaborates upon the Convention by focusing on aspects of international cooperation and in so doing tries to include persons with disabilities in the South.

Article 32 of the Convention stipulates as follows:

"Article 32 International cooperation

1. States Parties recognize the importance of international cooperation and its present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:
(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

(c) Facilitating cooperation in research and access to scientific and technical knowledge;

(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention."

From the global perspective, one important remark to make about the Convention is that “International Cooperation” was included as a stand-alone provision\(^1\), which was not the case for the Conventions for the rights of women and children. That is, transnational obligation is stipulated. This Article has various implications, particularly towards participation of persons with disabilities from the South, which will be elaborated in this contribution. In this paper, “South” or “Southern countries” are so-called “developing countries” and “transitional countries” or recipient countries of development cooperation. However, I wanted to problematise the concept of “development” as quantifiable and measurable changes in terms of free market economy, and thus chose North-South terminology instead. Throughout the paper, I try to answer the question, “Why do persons with disabilities in the South need to be included in international cooperation?” For that, this paper starts by debating the relevance of international cooperation to all countries. The importance of international cooperation is widely acknowledged among stakeholders in the field of disability. However, the hierarchy of rights tends to benefit already powerful actors more than others in the existing

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power structure. This general weakness of the human rights-based approach is introduced and discussed. Subsequently, the heterogeneity of persons with disability is presented as an important aspect of disability. This heterogeneity leads to questioning the relevance of development cooperation, which has not adequately paid attention to mainstreaming of disability to development, let alone the participation of persons with disabilities. On the basis of these arguments, the possibilities and challenges in the implementation of transnational obligations are pointed out. Finally, the concluding chapter touches upon future visions towards equality. The paper uses examples from Finland and Uganda to contextualise the arguments and facilitate the understanding of readers.

2. Relevance of International Cooperation

Presently the proportion of persons with disabilities from the total world population is estimated to be between 10-12 per cent.² This is a significant number and demonstrates the importance of inclusion of persons with disabilities in all of the countries in the world. There is no evidence that any single country has achieved equality for and non-discrimination of persons with disabilities. As a matter of fact, the concept of “development” is multidimensional, so countries cannot fit into a simple dichotomy between “developed” and “developing” countries. Many “developed countries” are not necessarily "developed" from a human rights perspective. For instance, the first countries to acknowledge sign language as an important language for deaf people in Constitutions were the Slovak Republic, Uganda, and Finland in 1995, the Czech Republic in 1998, and Thailand and Venezuela in 1999, demonstrating that when human rights of persons with disabilities are taken into account, the dichotomy easily fails.³ In other words, when a human rights-based approach (HRBA)

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to disability is applied, all countries are developing countries. A HRBA, therefore, deconstructs and problematises “development” merely as an objectively quantifiable phenomenon. For instance, discrimination cannot be measured well enough with the enrolment rate of children in primary education when children with disabilities have not even been registered as part of the population or when they do not receive suitable and/or necessary assistance in the school environment. Hence, this article technically uses “North” and “South” to distinguish donor countries and recipient countries without the connotation that North is better or more developed in terms of the human rights of persons with disabilities. The underpinning concept here is that international cooperation, particularly concerning the inclusion of persons with disabilities, involves reciprocity from which the involved countries mutually benefit.

The following examples are from Finland and Uganda. They eloquently speak to the necessity for international cooperation to learn from one another:

Experience of My Finnish Friend:

My Finnish friend described his experience in a conference on human rights in Finland. He is a wheelchair user. When the participants were invited to a coffee break on the second floor in the building where there was no elevator, he was left alone on the ground floor when everybody else went upstairs to enjoy their coffee. The conference organizer knew that there was a wheelchair user in attendance. Nobody paid attention to him, although the other participants were researchers in the field of human rights.

Experience of My Ugandan Housemate:

One day, my housemate in Uganda came home very exhausted. She uses a crutch for walking. She said she could not have lunch in her university because the classroom was located on the second floor and there was no elevator. It was difficult and took her a long time to get to the second floor for the lecture, which continued after the lunch break for 30 minutes. With only a 30-minute break, she did not have

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time to go down and find a restaurant, eat, and make it back up to the second floor. So she decided not to eat lunch.

These two incidents, occurring both in Finland and Uganda, took place during the same month in 2008. Finland and Uganda are considered to be disability sensitive countries at least in legal terms. Yet the realities on the ground are so similar. People with physical disabilities are quite a few among persons with disabilities. When their reality is as described above, it is easy to imagine how challenging the lives of people with other impairments such as impaired hearing and/or vision, learning difficulties, cognitive impairment or multiple impairments must be. In this regard, the disability movement has been actively asserting the rights of persons with disabilities beyond different types of single impairments. Moreover, persons with disabilities are always a minority within a country. Thus international cooperation is one of the important strategies that strengthen the disability movement in each country to make their voices louder and more easily heard. International cooperation is relevant for all countries. It allows them to learn from each others’ good practices and experiences, as there is vast room for improvement in terms of fulfilling human rights of persons with disabilities in all countries. The capacity of improvement in all states through international cooperation is thus pertinent.

3. Hierarchy of Rights: Weakness of Human Rights-Based Approach

The importance of international cooperation is rather straightforward to understand. However, when it is taken into practice, Southern persons with disabilities are too frequently left behind. For instance, it has not been long since many Northern countries enjoyed the visibility of disability during the UN Year of Persons with disabilities in 1981 and the UN Decade between 1983 and 1992. The series of UN events stimulated many individuals and organizations to start new activities and networks around the world. However, later it was regretted that the impact was felt mainly in Northern countries but

rather little in Southern countries during that period. This was why
the Asia and Pacific Decade of Disabled Persons between 1993 and
2002 was launched, to focus on disability and development in that
region. What can explain this phenomenon that the South so often
lags behind? Why is the priority given to the North?

Where human rights are concerned, in principle, “the priority must
be given to the most marginalized.” All rights are equally important,
whereas “the principle of ‘progressive realization’ recognizes that
some rights may have to be given priority over others, because not
all rights can be fulfilled at the same time.” This argument is particu-
larly valid in the context of a resource-constrained Southern country.
In reality, “trade-offs” at the expense of the less-privileged often take
place. Human rights systems have historically benefited the well-
off, because human rights depend very significantly on the power
relations that exist within the society or the group and between
countries. Frostell indicates that the male-dominant or gender-
neutral understanding of human rights is the norm, while Seppänen
points out the states’ legal power over people. That is, powerful
actors already have the possibility to misuse a human rights-based
approach. These priority making processes and outcomes, if based
on existing power relationships, have the potential to reinforce status
quo because the most vulnerable people or countries are out of reach
of the activities of the HRBA.

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6 Ibid.
7 OHCHR, Frequently Asked Questions on a Human Rights-Based Approach
to Development Cooperation, 2006, p. 24, <http://ohchr.org/english/about/publica-
8 Ibid, p.12.
9 D. Kennedy, The Dark Sides of Virtue: Reassessing International Humanitarianism
and Development Debate Seen Through the Lens of the Millennium Development
12 S. Seppänen, Possibilities and Challenges of the Human Rights-Based
Approach to Development (Hakapaino, Helsinki, 2005) p. 93.
13 Alston, supra note 10, p. 767.
4. Heterogeneity of Persons with Disabilities between and within Countries

The aforementioned hierarchy of rights is valid in the context of disability due to the heterogeneity of “persons with disabilities” between and within countries. To elaborate this contextual background, this part describes in more detail the aforementioned two close friends of mine from Finland and Uganda:

The Finnish friend was provided with his wheelchair and personal assistant costs by his municipality. They are his entitlements as a Finnish citizen. This situation is applicable to all Finns with disabilities, though many are dissatisfied with the quality and/or availability of services. Universal education is also commonly understood as a right. Even a university education is free in terms of tuition fee. His preconditions are similar to other Finns with disabilities’ concerning the right to education and its operationalisation.

On the other hand, my Ugandan friend is not typical of Ugandans with disabilities, since she is managing to attend an institute of higher education with her assistive devices. She is not typical firstly because her mother encouraged her to continue studying up through a secondary education, while 50 per cent of persons with disabilities never attend school. Education is not free, so financial status and discrimination interactively affect the decision of parents on their children’s education. Secondly, she is employed, while many are self-employed or unemployed. She pays her high tuition fee from her own salary, while many cannot afford that. Thirdly, she has made foreign friends who subsequently provided her with her assistive devices, while most do not have such contacts. Many persons with disabilities, particularly women with disabilities in Uganda, do not enjoy similar preconditions. In general, “human rights” is an obscure concept for persons with disabilities in rural Uganda.

Hence, various discrepancies certainly exist between countries and even within countries. Resource constraints are often the excuse of duty-bearers for not implementing laws and human rights principles, particularly for persons with disabilities. Persons with disabilities are not prioritised in the budget planning to a great extent in many countries. As no country has achieved non-discrimination, all countries must commit more resources to disability issues. When a human rights-based approach is applied in line with this Convention, the resources allocated to disability issues are an inherent right, not charity.

In reality, however, application of a human rights-based approach to disability in international cooperation is complicated when the non-discrimination principle is also applied to marginalized groups of persons with disabilities.\textsuperscript{16} For instance, few deaf women in Uganda fully benefit from mainstream and/or disability-specific prerogatives. Most of the Ugandan deaf women are illiterate without opportunities for a proper education. Consequently they do not have a means to communicate because they often use local signs rather than the established Ugandan sign language, or even home signs/gestures rather than the local signs. This is reflected in the fact that there is currently not a single deaf woman among the 47,000 Ugandan disability councillors.\textsuperscript{17} As a result any activity involving deaf women often needs to start with the instruction of basic sign language skills. When one deaf woman in Uganda was interviewed and asked what she had learned from a training course on HIV/AIDS organized by a DPO, she answered as follows:

"Onion, tomato, orange, banana, matooke (one kind of banana), cassava, greens. Those (signs) are what I remember. I remember so well. Others are clothes, suits, shoes, blouse, skirts. That's all."\textsuperscript{18}


\textsuperscript{17} Chairperson of UNAD, Personal Communication by e-mail on 13 June 2008.

\textsuperscript{18} Deaf Women E, Personal Interview at Kampala on 17 February 2008.
fundamental that they are one of the prerequisites to learning of one’s innate human rights. Various preconditions for rural persons with disabilities, especially those in marginalized groups such as deaf women, are often undermined in international cooperation activities. The next interview segment captures this issue:

“You have to keep the topic of awareness to the side and begin with basic sign language training first. Maybe for two weeks, one week, what is this about the language, first of all. So it costs a lot. Always spending and spending at the level of basic sign language training. When we are lucky enough to finish the training, we move on to awareness training. This also requires more time than with the blind and physically disabled. Awareness needs more time, because they are not yet fluent and the language is not easy to master. You keep repeating. Some of them are using lip reading while talking. Some of them cannot understand what rights are. We keep on teaching them the language. (...) they don’t understand what it is. So you just get tired. You get tired and say, “Let me do this and carry out activities because you don’t understand the word.” Sometimes you train and train, but they don’t understand it. So if you want to do something with them, sign language is the first step (emphasis added).”

The discrimination against persons with disabilities has been too deeply rooted to tackle by any single actor within a single international cooperation intervention.

Pertaining to the deeply rooted culture, “the poor help each other.” In one study on the poorest 20 per cent of the population concerning their “horizontal philanthropy” in four Southern African countries20, “Persons with disabilities (specifically the visually, physically and mentally impaired)” are categorised into “the vulnerable” and recipients of help.21 This study revealed that poor friends, neighbours and family as givers do not expect reciprocity from persons with disabilities, but consider them as mere objects of altruism, though mutuality and reciprocity are found to be the first motivational drivers for the majority of their other help.22 When both governmental and international interventions are absent or too scarce, such “horizontal” help

19  Deaf Member of Parliament, Executive Director of UNAD, Personal Interview at Kampala on 28 January 2008.
21  Ibid., p. 42.
22  Ibid., p. 70.
is more than necessary for the survival of many persons with disabilities in the South. At the same time, such a culture in which people voluntarily give without expecting any return is valuable. However, the idea that persons with disabilities are objects in their daily lives rather than deserving peers from whom reciprocity is expected is reinforced. This is too frequently the starting point for persons with disabilities in the South. Therefore, without a proper understanding of the reality of persons with disabilities, including their preconditions and living environment, particularly those of marginalized groups, international cooperation frequently ends up using a charity-based approach, as expressed in the above interview.

Another important aspect to be addressed in terms of heterogeneity is the identity of persons with disabilities. The definition of disability is evolving and differs from one culture to another. Even if national and international laws and policies began to take a HRBA seriously, common people continue to perceive disability as a charity, as a health or medical issue, and/or as a curse from supernatural powers.\textsuperscript{23} The series of negative consequences and the negative connotation of disability lead some persons with disabilities not to identify themselves as such, although they are technically categorised so. Alternatively, were they to be treated in a positive manner, some of these persons would accept the identity of persons with disabilities. For instance, when Ugandan persons with disabilities were granted affirmative action to get into institutions of higher education, they willingly identified themselves as persons with disabilities. On the contrary, when they are perceived negatively, some refuse this identity:

“You also have to look at the disability fraternity (=movement) internally. How do we think about ourselves? For me, I was in a motor accident. I’m not a polio victim. At some times, when they (people in the disability movement) heat up, they say, “You, you came to the disability fraternity via the shortcut. You weren’t born with a disability.” I didn’t have polio, so they don’t even count me as one of them. That is very worrying (…) You find very few disabled graduates taking leadership roles in local areas on issues of disability, because they don’t want to associate with disabled persons. You see a disabled person walking on the streets, and see another disabled person coming. The

chances are that they’ll avoid since he does not want to see himself in the second disabled person. He is more comfortable alone than within ourselves. So within ourselves, as disabled persons, we have a great challenge.”

Similar identity issues have also been raised in Northern countries. Furthermore, even those who recognize themselves as persons with disabilities, either negatively or positively, also change their identity depending on time, place and occasions. The divide of identity among persons with disabilities has not been articulated in the Convention, but is nevertheless important to take into account because it is a fundamental question: who is this Convention concerned with?

Without comprehending one of the essential aspects of disability, namely heterogeneity of persons with disabilities, the Convention would again end up benefiting only those persons with disabilities who have been more empowered and vocal rather than those who are marginalized. Hence, representation of “persons with disabilities” requires careful attention, while empowerment of persons with disabilities, particularly the marginalized, is needed in combination with mainstreaming activities.

5. Creation of Article 32

When the heterogeneity of “persons with disabilities” is taken into account, legitimate participation of Southern representatives becomes essential in making important decisions on disability and development. Therefore, it was a natural matter of course that Southern representatives participated in the development of the Convention. Their participation is clearly evident, particularly in the existence of Article 32.

24 Project Officer of NUDIPU, Personal Interview at Kampala on 1 February 2008.
The idea of including an independent article of international cooperation was introduced during the ad hoc committee sessions, which were followed by the 8th and last session of the committee during which the article was finally included under the consensus. Southern countries vigorously supported the idea and pushed it through into the Convention. In order to reach consensus, there was a heated discussion among the states, particularly between the South and Northern countries – such as those from the EU and Japan – that had been anxious about this idea during the 7th session (JDF Convention Secretariat, 2006). A Ugandan delegation representative in the ad hoc committee recalls as follows:

"I recall clearly that there were a number of developed countries, particularly the major donor countries, which initially were apprehensive about the inclusion of Article 32 in the Convention. Many of them argued that the inclusion of that Article would put an undue burden on them to provide funding to developing countries to implement the Convention. If no funds were provided, those countries would not implement the Convention giving the excuse that donor countries had not made funds available for implementation. This, it was felt, would undermine the initiative of developing countries to implement the Convention. We, from the developing countries, were strongly in favour of that Article and decided to re-draft it in such a way that International Cooperation would include not only donor funding but also exchange of information, research etc. After re-packaging the Article it became more acceptable and even popular."

One of the controversial points was to what extent the aspect of development cooperation would be highlighted in the theme of international cooperation by articulating transnational obligation without undermining the primary duty of each country. Development cooperation can be defined as “the practical work that is undertaken with the aim of improving the position of developing countries. It is implemented as country- and region-specific cooperation and multilateral cooperation”. That is, the dichotomy of so-called “developed” and “developing” countries is the underpinning presumption in which “developed countries” and “developing countries” implement “practical works” for the betterment of the latter countries. International

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27 Ugandan Delegation Representative in the ad hoc Committee. Personal Communication by E-mail on 10 June 2008.
cooperation, on the other hand, is not limited to the relationship between “developed” and “developing” countries. It is a common effort of involved countries to achieve a shared goal. The ad-hoc committee came to a consensus to include international cooperation as a standalone provision and highlighted the development cooperation dimension of international cooperation under this Article. Southern countries claimed that it was “essential to complement national efforts,” while Northern countries associated this article with an obligation to development cooperation and economic assistance. The availability of resources from the North to the South, therefore, was implicitly negotiated with the understanding that not only money but also information and experiences are to be shared amongst the various stakeholders. In a human rights-based approach to disability in development, transnational obligations are one of the strengths. In the Convention, these obligations were embedded into this Article.

6. Relevance of Development Cooperation

Why is development cooperation relevant? It is because 80 per cent of the world’s persons with disabilities are estimated to live in the South. Despite the significant number in the South, only 4 per cent receive some kind of support. This clarifies the following statistic: 17 per cent of the poor have some sort of disability according to the World Bank. In other words, persons with disabilities in the South are largely ignored both by the governments and international communities. Thus, if the Convention is to cover not only the minority of persons with disabilities in the North but also majority of those in the South, then both empowerment- and mainstream-oriented interventions must be adequately increased in the South.

Uganda has put in place an affirmative action policy and quota system for representatives with disabilities in the decision-making structure at different levels from the Parliament to villages. Altogether 47,000 disability councillors are working in the structure after the enactment of the Local Government Act of 1997. Nevertheless, even in Uganda, persons with disabilities are not yet adequately prioritised. After the election in 2006, at least seven members of parliament (MPs) have disabilities: five MPs were elected due to the quota system and two without it. This is a noteworthy achievement for the Ugandan disability movement. Nevertheless, they are only 2 per cent of the MPs after all and thus it is sometimes difficult to make their voices heard. Moreover, “there is a tendency (in Uganda) to look at disability issues as donor responsibility” in spite of all the human rights-based laws and the representation structures. That is, a human rights-based approach is observed in the political space, but not as significant elsewhere in Ugandan society, particularly in terms of law implementation. In fact, only the Ministry of Education and Sports explicitly admits that it uses a human rights-based approach. It is easy to imagine the reality in other countries without a human rights-based legal and/or affirmative action policy, when the situation in Uganda as a relatively disability-sensitive country is as described above.

Resource constraints are often pointed out as one of the major barriers to implementation. Uganda and many other countries in the South are highly dependent on Northern assistance in terms of national budget. For instance, more than half of the Ugandan national budget was from donor support in 2005. This figure indicates that development cooperation is a very relevant aspect in disability in the South. Budget support, in which donors contribute to the national

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budget of a Southern country with no strings attached, requires that the donors also prioritise mainstreaming disability to the same extent as the Southern country in question. Hence, on the one hand, donors must co-operate to mainstream disability. On the other hand, the Southern country concerned must also of its own initiative exert its political will to prioritise disability in national negotiations. Uganda is one of the few Southern countries to have a specific focal point in the government structure responsible for persons with disabilities: the Department for Disability and Elderly Affairs was established under the Ministry of Gender, Labour and Social Development in 1998. This is once again a great achievement for the disability movement. However, the Ministry is one of the most under-resourced in the government. In this way, the human rights-based approach in Ugandan politics is often in practice watered down, particularly in the grassroots. Consequently, disability as a topic evaporates either during the negotiation process with donors and/or within the Southern governmental structures. Therefore, development cooperation itself is a relevant aspect, while international cooperation within development cooperation is also an indispensable aspect towards mainstreaming disability in development.

Concerning Northern countries on the donor side of the development cooperation equation, their contribution to development cooperation has been limited. At present, Northern countries allocate 0.25 per cent of their Gross National Income (GNI) to development cooperation, which lags far behind the UN target of 0.7 per cent allocation agreed upon in 1970 in the UN General Assembly. Moreover, the quality of development cooperation has also been in question. For instance, contributions to the disability sector have been minimal. One of the most disability-sensitive countries, Finland, allocates only 5 per cent of its official development aid to disability, which amounted to 32 million Euros between 1991 and 2002. Finland is said to be one of the few Northern countries to allocate a relatively

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large ratio of funds out of its budget to disability projects. However, this number is presently decreasing and too small considering that 10-12 per cent of the world population is estimated to be disabled lacking major prerequisites for participation in mainstream development activities. Moreover, at present, disability-specific projects and programmes have been implemented, while mainstreaming disability into other projects and programmes has not been adequately promoted. Consequently, development cooperation activities have too frequently focused on enlarging the gaps between people with and without disabilities by favouring the latter.

In summary, both South and North have failed to secure participation of persons with disabilities in the South to the extent that they can fully benefit from existing policies and practices of development cooperation. In this regard, development cooperation is also a relevant sector for the Convention, especially when development cooperation activities are one of the few accessible and available supports for many persons with disabilities in the South.

7. Implementing Transnational Obligation in Reality

As has become clear, the existence of this Article itself has great implications because the participation of Southern representatives in the creation of the article is evident in its content. What this Article also indicates is that the Convention aims to benefit persons with disabilities in all countries, both North and South, despite the different priorities amongst the nations comprising them. Yet, the previous chapters imply challenges in implementing this transnational obligation in reality when the Convention entered into force. Incidentally, “donor support has virtually dried up, since it [a rights-based approach] is considered too slow and hard to measure.” It is important to remind ourselves that the Convention and a human rights-based approach are not a panacea. Operationalization proc-

esses require a long-term commitment with a nuanced approach that suits the concerned context and people. With this in mind, this section attempts to investigate possibilities and challenges in implementing this transnational obligation in reality.

We’ll begin with the possibilities. First of all, the transnational obligation is one of the most important operational values of this Article. Northern organizations of persons with disabilities (DPOs) can pressure their governments to contribute properly to disability in international cooperation including development cooperation, both to disability-specific and mainstreaming programmes, in terms of both quality and quantity. That is, DPOs can advocate to their governments to mainstream disability in their programmes and increase disability-specific programmes aimed at empowerment (known as a “twin-track approach”). In both types of activities, sensitivity to the heterogeneity of disability and to fulfilling the prerequisites of different persons with disabilities are required, so that they are capable of full participation in activities beyond the mere representation of a few. Towards that end, more time, money and energy must be allocated. The Northern contribution is stipulated in the Article in paragraph (a) and (d), which countries have promised to fulfil by ratifying the Convention. As the relevance of the North to Southern persons with disabilities was elaborated above, more action must follow to support the fulfilment of the transnational obligation pertaining to the human rights of persons with disabilities in the South.

Second, disability-specific policy-making in development and its implementation monitoring are to be operationalized. There has been a trend toward producing clear policies on disability within development cooperation. For instance, DFID, USAID and JICA prepared such a policy. If a policy has not been implemented, DPOs can pressure their governments to create one in collaboration with them. Implementation of such policies is limited even for those countries that have one already. For instance, in Finland humanitarian aid as well as planning and activities in multilateral and much of bilateral cooperation seldom include the disability component. Therefore, DPOs or a designated organ are to monitor their governments to

meet the set policy guideline. In this way, Southern countries can benefit from this Article in cooperation with the North.

In Southern countries, DPOs can lobby their governments to include disability in the development agenda. Without this initiative, persons with disabilities continue to be omitted from the mainstream development. For instance, in Uganda, the Poverty Eradication Action Program, which is equivalent to a Poverty Reduction Strategy Paper, initially did not include a disability aspect. Only after vigorous disability activism was disability included. Mainstreaming disability is not automatic and requires continuous efforts from diverse actors. This Convention has brought and continues to bring positive effects in increasing international awareness of and interest in disability in development. DPOs can make use of this trend of putting disability in their national agenda in cooperation with actors from different countries. In a national context, persons with disabilities always remain in the minority, and their voices tend not to be heard. Therefore, international cooperation is essential in bringing this field to the forefront. This Article shall be one useful instrument for such change.

As for challenges in implementation, it is possible that this Article is viewed as a voluntary aspiration rather than a binding law. First and foremost, the operational guidance of this Article is not clear, as is often the case in international human rights treaties. Pertinent questions urging implementation such as the following remain unanswered: “To what extent are countries expected to allocate resources to international cooperation and/or development cooperation?”; “Who could account for their practices and to whom?”; “At what point are countries to be legally punished for failing to adequately implement?”; “If not only money but other resources are concerned, is it possible to measure how much is reasonable?” As stated, context-specificity has to be carefully taken into account for implementation. This conversely means that each country and actor can set its own objectives and indicators for their international cooperation. This grey zone requires great pressure, both nationally and internation-

43 Ibid.
ally, as well as for the Northern and Southern disability movements to articulate their prioritisation of the most vulnerable people. The lessons learned from the recent past concerning the UN Decade must be repeatedly brought to the fore.

Another concern of careless international cooperation is an increase in or even acceleration of Northern control over Southern countries. The North has a considerable transnational obligation due to the resource gap and the consequences of its position as a stakeholder of resources. However, “does this mean that the North is imposing conditionality on the South, thereby infringing upon the self-determination and sovereignty of the South?” Inclusion of persons with disabilities is an added value to mainstream development, just as the exclusion of such a significant group of people would not enable any country to achieve poverty eradication. This notion has to be understood properly beyond national borders to avoid making human rights a mere conditionality of international cooperation. DPOs and the disability movement, therefore, still need to work hard for the implementation of this Convention in collaboration with other actors.

8. Future Vision towards Equality: Concluding Remarks

This article scrutinised international cooperation as called for in the Convention. International cooperation is necessary to the disability sector because no country has yet achieved equality and all have to learn from each other to strive towards this goal. Moreover, persons with disabilities are a minority in every country, and thus international cooperation is an important strategy to allow their voices to be heard. Development cooperation, which is an important part of international cooperation, requires that both donor countries and recipient countries increase their capacities to deal with the human rights of persons with disabilities. Northern countries are deeply involved in and responsible for persons with disabilities in Southern countries. This concept has not yet been properly understood, as demonstrated by the low commitment to development cooperation in terms of both quality and quantity. Southern countries are also generally failing to mainstream a disability into their development
agenda. Resource constraints are often cited as the reason for not prioritising the human rights of persons with disabilities. The discussion during the ad hoc committee sessions in the process of writing the Convention clarified some gap between North and South: the North stressed international cooperation and the South development cooperation. When taking a closer look at the contexts between and within countries, their priority gap indicates that the Convention and this specific Article would benefit only more empowered persons with disabilities, if not enough attention is paid to the heterogeneity of persons with disabilities and their different preconditions. The proper attention is crucial in operationalizing this Article both in the North and South. On the basis of these arguments and discussions, the operational values of this Article were listed. Both Northern and Southern nations must ensure mutual benefits so as to not repeat the same mistake of the UN International Year of Persons with Disabilities and the following Decade benefiting primarily the North.

Experiences in Finland and Uganda illuminated the above discussion and contextualised this specific Article. Each context is different and needs elaboration, needless to say. In every country, challenges are multitudinous due to their distinct systems that have not been sufficiently disability-sensitive. This is the starting point. All actors and thus every single one of us need to build more capacity for dealing with both mainstreaming and empowerment activities on disability. International cooperation is needed because operational guidelines are not clear in the Convention regarding each context, as has been the case in other existing international human rights treaties. The Convention stresses the implementation and monitoring of the Convention especially by involving persons with disabilities (Article 33), while each actor has to materialise a suitable solution for its own context in collaboration with other stakeholders. Hence, we need to learn from each other’s good practices and lessons learned. These are all answers to the key question, “Why do persons with disabilities of the South need to be included in international cooperation?”

Equality is not the exclusive domain of persons with disabilities.\textsuperscript{45} A human rights-based approach to disability carries with it an implicit vision of building more capacity to deal with the rights of any other marginalized people as well, while existing international human rights treaties also continue to include persons with disabilities. For

instance, persons with disabilities would not feel equal if they were discriminated against because of their other characteristics such as sex, age and/or ethnic origins, while responsible persons with disabilities should likewise not discriminate against others. At the same time, the disability movement can also network with other marginalized groups and work towards an equal society for all. The gender approach, for instance, is insightful and has much to offer the disability actors. The Article and the whole Convention are primarily for promoting the human rights of persons with disabilities. However, we should not forget that discrimination exists elsewhere as well, which necessitates international cooperation and development cooperation. Furthermore, we should also not forget that the human rights analysis must be implemented more widely in other areas such as in globalisation and the free market, both of which have much larger implications than development cooperation with the existing power structure. Towards equality, securing inclusion and participation for persons with disabilities from the South to international cooperation is one of the first steps forward.
Chapter 8:

Barriers to the Inclusion of Disabled People in Disability Policy-Making in Seven African Countries

Raymond Lang and Ambrose Murangira

1. Introduction

The United Nations Convention of the Rights of Persons with Disabilities came into force in May, 2008, this being the first human rights treaty to be enacted in the 21st century. It was negotiated over a five-year period, where UN agencies, national sovereign states, and representatives from civil society institutions, (particularly disabled people’s organizations), actively engaged and collaborated with each other during the negotiation process. The UN Convention has the potential to create a seismic paradigm shift in the manner by which disability policy is framed and implemented. However, notwithstanding the historic importance that is rightfully ascribed to the UN Convention, it is argued here that such a paradigm shift is by no means a foregone conclusion. By drawing upon original empirical research undertaken by the authors in seven African countries in four separate studies between 2007 and 2009, this chapter will delineate and analyse some of those critical factors that significantly militate against the effective execution of disability policy and practice.

At the outset, it should be acknowledged that the difficulties in implementing progressive, human rights-based social and economic policy is not unique to the disability sector, but rather reflect difficulties with generic governance issues such as representation, accountability, decentralisation, implementation modalities and the lack of robust statistical data that is necessary for effective and efficient service delivery. Indeed, it is argued in this chapter that governance, defined in its broadest sense, is the single most important factor in the furtherance of progressive disability policy and practice. Following the analysis of the particular challenges in implementing disability policy and practice, reference will be made to contempo-
rary debates within the political science and development studies literature to illustrate this. This will enable the findings and inferences emanating from these studies to be contextualised within a broader framework.

Despite the fact that all seven countries had different political, social and economic profiles, in concert with significantly contrasting development trajectories, it was nevertheless the case that some key strategic issues were addressed in all studies. These included:

1. To undertake a review of existing disability policy and practice;
2. To assess the extent to which each country’s policy and practice were in alignment with the principles of the UN Convention on the Rights of Persons with Disabilities;
3. To analyse political and policy-making environments and processes by which social and economic policy is developed within the country, with specific reference to disability issues;
4. To assess to what extent disability policy had been mainstreamed in each of the seven designated countries; and
5. To provide an assessment of to what extent disabled people’s organizations have been effective and been engaged in the policy-making process with regard to disability issues.

2. Disability Policy Research Methodology

At this juncture, it will be instructive to describe the methodology that was employed in undertaking the disability policy research in the seven countries. A total of four separate studies were undertaken between 2007 and 2009. These were: ‘Disability Scoping Study for DFID Zimbabwe (2007)’, ‘Disability Scoping Study for DFID Nigeria (2008)’ ‘Disability Policy Audit in Namibia, Swaziland, Mozambique

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and Malawi’ (commissioned by the Southern African Federation of the Deaf, 2008)\textsuperscript{3} and 'Disability Scoping Study for DFID Uganda (2009).\textsuperscript{4}

In all four studies, a comprehensive literature review of all relevant documents regarding disability issues was undertaken. This comprised a review of relevant academic articles, as well as reports and other forms of “grey” literature produced by disabled people’s organizations (DPOs), reports by relevant government ministries and other civil society institutions working within the disability sector. In addition, where appropriate, the Department for International Development (DFID) made available unpublished concept notes regarding their future strategies, thereby enabling strategic recommendations to be made regarding how DFID can mainstream disability issues within their core activities.

Furthermore, in all four studies, a concerted effort was made to engage with disabled people’s organizations and leaders of the disability movement through a series of in-depth interviews and discussions, in order to evaluate to what extent they have been successful in engaging and influencing policy-makers in their respective countries. Additionally, focus group discussions with disability activists were held in the majority of countries included in these studies. However, for logistical and time constraints, it was not possible to conduct such discussions in Namibia, Malawi and Mozambique. However, in Zimbabwe, Nigeria and Uganda, focus group discussions were held in the capital cities, as well as in other strategic places, such as rural areas and refugee camps, so that a more nuanced understanding of the issues encountered by people with disabilities could be gleaned.

For example, in the case of Uganda, it was considered imperative to conduct the focus group discussions in the Northern region of Uganda, which has been subjected to war and civil strife over the past two decades. This was thought to be essential, in the belief that


the experience of people with disabilities, and the assistance that they require, (provided by the Ugandan Government, civil society institutions or donor agencies), will be different from those living in areas where there have been comparative social, political and economic stability over a sustained period.

Where it was possible to undertake focus group discussions, a portfolio of key issues were identified, which sought to elucidate the following:

- What are the main challenges faced by DPOs?
- How have DPOs been lobbying their respective governments and how effective have these lobbying efforts been?
- How have DPOs been working in collaboration with other NGOs and INGOs and how effectively?
- What needs to change to make the lives of people with disabilities better?

In addition, key informant interviews were undertaken with a wide range of stakeholders working within the disability sector in each country. These included senior civil servants working in key ministries (particularly those with specific responsibility for disability issues), politicians, leaders of the disability movement, academics, bilateral and multilateral donor agencies, (including DFID, the EU, USAID, and UNICEF), as well as representatives of disability-specific and mainstream NGOs working in the disability sector. By undertaking these interviews, it was possible to some extent to gain an in-depth understanding of the current status of disability policy and practice in each country, as well as to identify those strategic areas where more progress needed to take place.

All studies utilized the “Stepping Stool to Inclusion”, originally designed by Phillipa Thomas, (Social Development Advisor at DFID Zimbabwe), as an analytical tool to assess the relative strengths of the respective roles played by the State, service providers and DPOs with regard to the inclusion of people with disabilities within a given society. This model assumes that each of these components must be in equilibrium and interact with each other in mutually supportive and reinforcing ways, otherwise the Stepping Stool to Inclusion will be unbalanced or the legs may splay outwards causing the stool to collapse. The strength of each component or ‘leg’ in a country can be
assessed by finding the answers to few simple questions. Then the Stepping Stool to Inclusion can be drawn to visually represent the basic status of disability issues within a country.

Finally, all studies utilized a Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis of the contemporary position of the disability sector in each country. Such an analysis provides an instructive insight and basis for making specific, strategic recommendations to DFID Uganda in supporting people with disabilities and their representative organizations in taking forward a rights-based agenda to disability issues, but which nevertheless takes into account the political realities and operational modalities.

3. Substantive Findings and Inferences of the Research

3.1. Legal and Constitutional Status of People with Disabilities

Space precludes a detailed, comprehensive analysis of disability policy and practice in each of the seven countries. Therefore, this section seeks to address some of the key strategic and generic issues that were common in all the studies outlined above. Where appropriate, examples will be given to illustrate the arguments that are being made, and by so doing, highlight issues that work against the formulation and implementation of progressive disability policy and practice. As already highlighted, many of the issues that will be discussed are not unique to policy-making in the disability sector, but are also found in the development of social and economic policy throughout Africa, and indeed, throughout the developing world.

Firstly, it should be recognized that the legal and constitutional status of people with disabilities in each of the countries is recognized in their written respective constitutions. Therefore, at a fundamental level, people with disabilities have the same inherent human rights and responsibilities as all other citizens within their own countries. Furthermore, with the exception of Zimbabwe, all countries have signed the UN Convention, and Uganda and Namibia have also ratified it. It should also be noted that all countries involved are
signatories to other international human rights treaties, such as the 1948 Universal Declaration of Human Rights, the 1976 International Covenant on Civil and Political Rights, the 1990 Convention on the Rights of the Child and the 1997 Mine Ban Treaty. However, as will be demonstrated below, these fundamental human rights are invariably honoured in the breach. Notwithstanding the existence of progressive human right-based legislation and international treaties, people with disabilities throughout Africa encounter systemic institutional, attitudinal and environmental discrimination, in concert with high levels of social exclusion and, in some instances, unmitigated oppression.

Therefore it is reasonable to conclude that, ostensibly, all the Governments are committed to a rights-based agenda for disability policy and practice. However, from the evidence gathered during the course of these four research studies, it has become abundantly clear that many politicians and senior civil servants do not have a clear and nuanced comprehension of the implications of implementing a rights-based agenda to disability. For example, Namibia has ratified the UN Convention, but it is clear that existing domestic legislation is not in alignment with the fundamental tenets that underpinned the Convention, and are therefore in need of substantial overhaul and revision. It should also be noted that even when there is a rhetorical commitment to implementing a rights-based approach to disability, the fact of the matter remains that many Governments do not really have the political will to take this forward, with several of the Governments still having what is essentially a medical understanding of disability. Consequently, at least for those countries included within these studies, Government officials did not demonstrate an in-depth understanding of the importance and ramifications of basing their policies and services on the principles of the social model of disability.

This can be demonstrated by considering some specific examples taken from the four research studies. The Nigerian Government signed the UN Convention of the Rights of Persons with Disabilities in March 2007. In addition, it has also ratified human rights treaties, such as the 1948 Universal Declaration of Human Rights and the 1966 International Covenant on Civil and Political Rights. The Ministry of Women and Social Affairs is the lead government agency with principal responsibility for disability issues. However, from the
key informant interviews undertaken with officials from the Ministry, it was very apparent that it was totally under-resourced, both in terms of financial and human resources, which inevitably resulted in disability issues being given an extremely low priority. The Ministry has primary responsibility for the provision of prosthetics and orthotic devices, to assist people with disabilities with mobility difficulties. However, the administrative procedures for obtaining such assistance were so bureaucratic that the large majority of people with disabilities did not benefit from this scheme whatsoever. Furthermore, such appliances are too expensive for the vast majority of disabled people to ever really benefit from such provisions. Also, demand far outstrips supply for such appliances, which means that, even if they were affordable, only a very tiny proportion of disabled people would be able to benefit.

In Nigeria there is a lack of political will among politicians and senior civil servants to ascribe to disability issues a sufficient level of importance to ensure real progress in terms of disability rights. In March 2008 two separate disability bills were introduced into the National Assembly, but both failed to be enacted. Moreover, as both of these bills progressed through the legislative process, their substantive content was so diluted as to make them meaningless in promoting disability rights, even if they were to have become passed. Subsequently, initiatives have been undertaken to introduce another disability rights bill, but due to the apparent lack of unity within the disability movement together with the reticence of parliamentarians to implement such legislation, to date little substantive progress has been achieved.

Another example that illustrates the lack of political impetus to implement progressive human rights-based disability legislation is from Namibia, which ratified the UN Convention in December, 2007. In 1997, the Ministry of Lands, Resettlement and Rehabilitation produced a National Policy on Disability which was subsequently adopted by the National Assembly in July of that year. This document endorses the principles of the social model of disability as a basis for the formulation and implementation of disability policy and practice. The underpinning principles upon which this National Policy is premised are the equalization of opportunities, inclusion and inte-

5 Government of Namibia, National Policy on Disability (Windhoek, Namibia, 1997).
gration. Moreover, it states that disability issues are inherently linked to the advancement of human rights and inextricably linked to human development. Once again, it can be legitimately argued that Namibia has progressive disability policies. However, it very clear that these are being honoured in the breach.

The National Disability Council Act of Namibia (2004) makes provision for the establishment of an advisory body to provide strategic and expert advice on disability issues to the Government of Namibia. Under the provisions of the Act, the membership of the Council will comprise a total of 13 members. Seven members are to be representatives from disabled people’s organizations, which include a broad range of different impairments; one representative from an employer working in the private sector; three representatives from organizations working in the field of rehabilitation, integration or education; one representative from the trade unions; and one member “who has special knowledge of, or interest in disability or any issues relating to disability”. The majority of the Council must be comprised of disabled people.\(^6\)

The ostensible mandate and powers of the National Disability Council are far reaching, which include monitoring the implementation of the National Policy on Disability; identifying other legislation that conflict with the National Policy; consulting with disabled people’s organizations and other civil society institutions regarding the implementation of the National Policy, and proposing amendments to the National Policy in order to ensure that it takes account of changing circumstances. Furthermore, the National Disability Council has the legal authority to summon any individual or organization to give evidence before its proceedings.

The National Disability Council ostensibly has the potential to be an effective watchdog to ensure that disability rights are indeed upheld and to hold the Government accountable for the effective delivery of disability services. It also has the potential to be very inclusive in terms of its own membership, encompassing representatives from disabled people’s organizations, service providers, the private sector and quasi-governmental agencies. However, despite the fact that this legislation was passed by the National Assembly in 2004,\(^6\) Government of Namibia, *National Disability Council Act* (Windhoek, Namibia, 2004).
the National Disability Council has never been constituted, and has never held its first meeting. At the present time, the Disability Unit within the Prime Minister’s Office is trying to provide some impetus and momentum to establish the Council. However, the disability movement in Namibia is somewhat circumspect regarding how effective any established Council will be, particularly given the lack of political will to take a rights-based approach to disability issues seriously.

A possible explanatory factor in understanding this lack of political will and reticence in developing genuinely inclusive disability policy, is that all Governments are facing huge developmental challenges, of which disability is but one. These include dealing with chronic levels of poverty which characterises the majority of the populations; the detrimental effects of the HIV/AIDS pandemic; gross inequalities in income distribution; political corruption; and the incapacity to provide effective public services. For example, Namibia has the highest levels of income inequalities in the world, with a Gini coefficient of 0.70. In addition, many of the countries have very high levels of HIV/AIDS, (for example, Namibia 24 per cent and Swaziland 41 per cent), which significantly hampers any sustained, long-term social and economic development within such countries. This is not to provide an excuse for not advocating for the development and implementation of a rights-based agenda to disability; merely it is an attempt to understand why it is so hard to perceive sustained progress within this field.

3.2. Governance and Implementation Infrastructure

One of the most deeply entrenched factors militating against the sustained development and implementation of disability policy concerns “governance” and “accountability”. This is arguably the most important single factor working against human right-based disability policy being effectively implemented. Poor governance and accountability mechanisms are not the sole preserve of public institutions, but are also fundamental to the management and engagement of civil society institutions, and within this context, particularly DPOs. Over the course of the last decade, there has been increasing recognition of the importance of addressing govern-
ance issues in the political science literature. Adejumobi identifies five key components of governance, all of which are pertinent to the foregoing discussion. These are i) the means by which governments are selected, monitored and replaced; ii) constitutionalism and the rule of law; iii) the capacity to formulate and implement sound policies and deliver public services; iv) the respect of citizens and the state for institutions that go along economic and social interactions; and iv) citizens and civil society and empowerment. This section explores these issues with regard to disability policy-making.

Three key issues warrant discussion vis-à-vis the interface between governance and disability policy-making. These are:

- ineffective and inefficient administrative infrastructures for disability services
- the apparent dominance of a charity/welfare approach to disability issues, even where human rights-based legislation is being enacted; and
- the lack of co-operation with regard to disability policy-making within the disability movement itself.

One of the most striking findings emanating from these studies is that in none of the countries was there an effective and efficient administrative infrastructure for the provision of disability services. This is not just exclusively the case in the field of disability, but affects every area of public service provision. Public sector reform is high on the agenda of many developing countries in Africa, some of which have a history of political patronage, nepotism and corruption. It is entirely feasible for countries to have the most advanced and forward-looking disability legislation and requisite policy and to have ratified the UN Convention; but without an effective administrative infrastructure to implement such policies, they are all but worthless. In the absence of an effective administrative infrastructure, disabled people will continue to face social exclusion and marginali-
sation, manifested by people with disabilities unable to benefit from receiving appropriate education, unable to secure long-term sustainable employment who thus remain in a state of poverty.

However, it must be recognized that in many cases, and given the particular history of some countries, public sector reforms will inevitably be a long-term process. Therefore it is incumbent upon those working within the disability sector to work with Governments to ensure that, in the long-term, an effective administrative infrastructure is built. This last point is closely related to the debate regarding the need for robust disability statistics outlined in section 3.4 below. A further issue regarding implementation is that in many countries, there is little inter-departmental collaboration on crosscutting issues such as disability. For example, the Government of Uganda has made a firm commitment to implement inclusive education policies, thereby ensuring that children with disabilities are able to attend mainstream schools within their local community. However, the Disability Scoping Study for DFID Uganda found that the Ministry of Education and Sports did not have any meetings with the Ministry of Transport and Works. As a result, in the vast majority of instances, primary schools were totally inaccessible to children with disabilities. This is just one example where inter-departmental collaboration could potentially result in a significant advance of disability rights.

Furthermore, a further significant challenge is that, even in countries where progressive disability legislation and internationally recognized human rights treaties have been enacted, the fundamental raison d’être to policy-making is premised on deeply entrenched and deeply seated notions of charity and welfare. A classic example of this was found in Nigeria, where notional adherence was given to human rights legislation, but where in practice, the vast majority of public administration and governance is based on patronage and nepotism, and where the underlying premise of social and economic policy is founded upon charity and welfare.

This charity/welfare approach to disability issues was manifested in a multiplicity of ways. Firstly, there is no national anti-discrimination legislation in Nigeria, although recently initiatives have been undertaken to address this. Secondly, as was already mentioned, the Ministry of Women and Social Affairs, which is the lead government department for disability issues, is totally under-resourced and had
little understanding of the principles of the social model of disability. Furthermore, notwithstanding attempts by the Nigerian Government to provide basic rehabilitation services, demand far outstrips supply, particularly for those living in rural areas.

This is further compounded by the fact that civil society institutions, including some DPOs, have themselves imbibed the prevailing culture of charity and welfare. There are a plethora of DPOs that exist in Nigeria, that operate at the national, state and local levels. However, with only a few notable exceptions, the vast majority of DPOs have themselves adopted a charity/welfare approach to disability issues, and have little understanding of a rights-based agenda or the principles of the social model of disability. Furthermore, within Nigeria there are two national umbrella DPOs (the Joint National Association of Persons with Disabilities (JONAWPD), and the Association for the Comprehensive Empowerment of Nigerians with Disabilities (ASCEND), each of which perceives itself to be the authentic and representative voice of disabled people. However, there is a great deal of conflict between these two organizations, which has a serious negative impact upon their ability to effectively lobby the Nigerian Government to implement a rights-based agenda to disability issues. In addition, the vast majority of the leaders of the disability movement are based in urban areas, and have little comprehension of the issues encountered why disabled people living in rural communities.

Finally, it must be acknowledged that there are significant governance issues within the disability movement itself, which has profound implications for policy-making. Hitherto, few have been willing to openly discuss these important issues, and when they have been, these discussions have been highly personalised in nature. Nevertheless, if progressive human rights-based disability policies and practice is to advance, then the governance of disabled people’s organizations will have to be addressed. At the international level, it must be, first and foremost, acknowledged that disabled people’s organizations have been at the very forefront of prosecuting a human rights agenda for disability issues. Without this impetus, it is very doubtful whether the UN Convention would have come into being. However, it is timely for the disability movement, particularly at the

10 Lang and Upah, supra note 2, p. 6.
11 Ibid.
national level, to critically appraise its governance and democratic credentials, combined with its ability to realistically engage and influence the policy context in which it finds itself. Moreover the inherent challenges that national umbrella DPOs face is to what extent they truly represent the needs of all impairment groups. All too often, national umbrella DPOs only represent a minority of impairments. Historically, the leaders of the disability movement had been populated by “elites”, drawn primarily from wheelchair users or those with visual or hearing impairments. Indeed, one may argue that there is a “social hierarchy of impairment” within the disability movement itself.\textsuperscript{12} An analogous related issue is that, in terms of policy-making, the same individuals are invariably invited to be “consulted” and “participate” in the policy-making dialogue. Consequently, in many developing countries, single impairment disabled people’s organizations exist, in the belief that they are best able to represent their own particular needs.

From the evidence gathered from the four disabilities studies, is very evident that the disability movements in these countries often do not have the capacity to effectively engage in policy dialogue. This can be partially attributed to the fact that frequently they do not understand the dynamics and constraints within the policy-making process within their own countries. Also, it has to be readily acknowledged that policy-makers themselves do not have a nuanced understanding of disability issues. Nevertheless, there is strong anecdotal evidence to suggest that even national umbrella disabled people’s organizations routinely lack the inherent organizational capacity to engage with policy-makers. Furthermore, in the past, umbrella disabled people’s organizations have received funding from bilateral and multilateral donor agencies. However, lack of follow up as to effectiveness and impact of the programmes funded have led to donors in many cases discontinuing their funding of these organizations.

3.3. Access to Mainstream Services

A related issue is that people with disabilities invariably do not have access to mainstream services, either provided by the public sector or by national or international NGOs. For example, from the

evidence gathered for the Disability Scoping Study in Zimbabwe, it was evident that while non-governmental organizations stated that people with disabilities were a key target group for NGOs providing relief under the DFID-funded first phase of the Protracted Relief Programme (PRP), operational between 2004 and 2007. From the key informant interviews that it was very apparent that people with disabilities received no substantial support from this programme whatsoever.

This state of affairs can be explained by a multiplicity of factors. At the community level, due to negative social attitudes, disabled people were often hidden, and are not encouraged to attend community meetings to speak publicly of their needs and opinions. This is compounded by the fact that disabled people were almost invariably neglected at the household and community levels, where community leaders discourage their involvement and participation in communal village meetings. Consequently, disabled people were invisible, with NGOs finding it very difficult to identify them. Furthermore, this state of affairs compounds the difficulties of PRP partners in effectively targeting the most vulnerable, including disabled people, thereby ensuring that those who are in the greatest need of assistance in fact receive it.

Another difficulty is that NGOs did not have sufficient knowledge and experience in disability issues to effectively incorporate disability into their core activities. This can be partially explained by the fact that NGOs, in common with other stakeholders, have a misconception that “disability” is a specialist area. PRP partners recognized the fact that they needed to make a more concerted effort to include disabled people. However, it was openly acknowledged that this is by no means easy. One of the problems is that no outcome indicators had been developed, in any true sense that analyses the extent to which disabled people have genuinely benefited from PRP programme activities. UNICEF is particularly aware of the problem and is very keen to work with other stakeholders to develop meaningful, pertinent and quantifiable outcome indicators that genuinely reflect sustained improvements in the quality of life of disabled people, following programme interventions.\textsuperscript{13} This raises questions

\textsuperscript{13} Lang and Chadowa, \textit{supra} note 1, p. 23.
regarding the efficacy of participatory approaches to development, which is discussed in the next section.

3.4. Statistical Data

Another serious impediment to the implementation of disability policy is the paucity of reliable statistical data. During the last 20 years, Namibia, Swaziland, Malawi and Mozambique have all included questions on disability within their National Census. However, it is highly questionable how robust these data are, and to what extent such statistics provide an accurate analysis of the social, political and economic situation of disabled people. Internationally there has been a great deal of debate regarding the validity and use of statistical data on disability issues. However, it is highly likely that any of statistical data on disability issues in sub-Saharan African countries underestimate the number of disabled people. This is due to a number of complex and interrelated factors, which include stigma and negative social attitudes regarding disabled people, particularly in rural areas. There are also issues regarding the way such census questions are phrased, and this may well lead to different statistics being generated. The Washington Group on Disability Statistics, which was established following the United Nations Seminar on Measurement of Disability held in June, 2001 has undertaken a great deal of work regarding these complex a methodological and ethical issues.¹⁴

Notwithstanding the complexities and difficulties outlined above, it is nevertheless argued here that it is imperative to produce robust and useful statistical data on disability. This is not least because once countries have ratified the UN Convention, it will be essential for them to demonstrate the extent to which their countries have implemented specific Articles, especially in the fields of education, employment and rehabilitation. At a fundamental level, the absence of robust statistical data creates a “democratic deficit”, in-as-much that civil society institutions (particularly disabled people’s organizations) have no means to hold their respective governments to account vis-à-vis human rights commitments, not least within the field of disability. Furthermore, if governments are to provide genu

inely inclusive public services, then it is essential that statistical data regarding disability is available at regional and local government level. In the absence of such statistics, it is difficult to foresee how governments will be able to effectively design, implement and monitor the provision of disability services, and to what extent disability has been effectively included in mainstream public services. A further reason for the generation of disability statistics is that as “disability” moves up the development agenda, bilateral and multilateral donor agencies still need to be convinced of the economic case for including disability within their core activities. It is often said that there is a mutually self-reinforcing negative cycle of disability and poverty, and that disabled people are one of the most socially excluded, marginalized and discriminated groups within any society. However, to date, a great deal of the evidence regarding disability and poverty is of an anecdotal nature, which does not hold much credence with economists working in development agencies.

3.5. Involvement of Disabled People’s Organizations in the Policy-Making Process

One of the most protracted and entrenched barriers to the implementation of human rights-based disability policy and practice is that policy-makers on the one hand, and disabled people’s organizations on the other, do not understand each other’s “world view”. Consequently, politicians and senior civil servants, with few notable exceptions, have little or no comprehension of the principles of the social model of disability. Hence, they perceive disability as a “specialist issue”, and invariably perceive people with disabilities in a negative and indeed, pejorative manner. Conversely, DPOs do not understand the complexity of policy-making. For example, in Uganda, under the Constitution, there are six elected MPs with disabilities. However, from the fieldwork conducted for the Disability Scoping Study in February 2009, it was very clear that there was almost no collaboration between the leaders of the disability movement and the MPs with disabilities. This resulted in a rift in terms of developing genuinely inclusive policies. There is also strong anecdotal evidence to suggest that some disability organizations in Uganda feel that the

national umbrella DPO, the National Union of Disabled Persons of Uganda (NUDIPU), do not adequately represent the needs of all impairment groups. Some single impairment and disabled people organizations reported they feel they have been excluded from influencing the national policy agenda, primarily because the NUDIPU had not been fully receptive to their inputs.

A further pertinent example is taken from Namibia, where a Disability Unit was established in the Prime Minister’s Office in 2002. In recent years, this Unit has represented the Government of Namibia at the negotiations on the UN Convention on the Rights of Persons with Disabilities, attending the Ad Hoc Committee meetings which were held in New York. During 2008, the Unit was in the process of writing a “layman’s guide” to the UN Convention. It is also in the process of establishing focal points within each of the respective line Ministries, (such as Education, Transport etc), who will take primary responsibility for ensuring that all existing domestic legislation is updated and amended so that it is in alignment with the obligations that the Namibian Government has as a signatory to the UN Convention. Each line Ministry is expected to ensure that the sufficient human and human resources are made available to ensure that these obligations and commitments are upheld, through the development and implementation of Disability Action Plans, which must include a timeline and budget. At the time of writing, 11 focal points have been identified and 17 Disability Action Plans have been drafted.

At the time when the Disability Unit in the Prime Minister’s Office was established, it was originally envisaged that it would work in close collaboration with the National Federation of People with Disabilities in Namibia (NFPDN), as well as providing a coordination role between itself and the other line ministries. However, key informant interviews with the leaders of the disability movement in Namibia suggest that currently the collaboration between the Disability Unit and the National Federation is not working well. This is somewhat surprising, since it was the National Federation that spearheaded the initiative to establish the Disability Unit and made recommendations regarding its personnel. The Disability Unit itself duly acknowledges that it is under-resourced, and lacks sufficient capacity to carry out its designated functions.
One area of policy-making that has received considerable attention is the involvement of DPOs in developing poverty reduction strategies.\textsuperscript{16} There is strong anecdotal evidence to suggest that poverty is both a cause and consequence of disability. Hence, if one has a disability, then there is a greater possibility that they will be poor, given that the vast majority of people with disabilities do not complete formal primary education and consequently, find it extremely difficult to secure long-term, sustainable employment. Conversely, there is a greater likelihood that the chronically poor will also have a disability, due to lack of access to adequate health care provision, satisfactory housing conditions and clean water. However, the evidence for this symbiotic relationship between disability and poverty is primarily anecdotal in nature. What is known is that people with disabilities find it extremely difficult to access micro-finance\textsuperscript{17}, and with some notable exceptions, throughout the developing world there are no designated social protection programmes for people with disabilities.\textsuperscript{18}

Some attempts have been made to include people with disabilities in poverty reduction strategies in Uganda. The Poverty Eradication Action Plan (PEAP) is an overall planning framework for guiding public action on development/poverty reduction. It has been implemented on a three-year basis through its translation into expenditure actions in the 3-Year Medium Term Expenditure Framework (MTEF). The PEAP, which started in 1997 in Uganda, has been revised every 3 years with an aim of incorporating emerging lessons and issues. The latest version of the PEAP was formulated in 2004 and thus expired in 2008. Currently a 5-Year National Development Plan (NDP) is being developed to become the successor plan to the PEAP.

Unfortunately active participation of DPOs in the PEAP has been largely absent. The first submission by the Ugandan disability movement was made during a third review of the PEAP, which only took place in 2004. It was made by the NUDIPU under the auspices of the Uganda NGO forum, with no other DPOs being involved in the process. It is apparent that the NUDIPU has not been involved in implementation, monitoring and evaluation of PEAP, meaning that the involvement of DPOs ended at the consultation/planning level. All DPOs agree that, to date, DPO involvement in the PEAP planning process has been tokenistic.

With reference to the Ugandan context, Sam Hickey has argued that, even where there is constitutional provision for the representation of marginalized groups (including people with disabilities), within Parliament, it nevertheless remains the case that they have been ineffective in influencing and shaping poverty reduction initiatives.\(^{19}\) Notwithstanding their constitutional status, it may well be the case that to policy-makers may perceive people with disabilities in Uganda as constituting the “undeserving poor”, who ultimately are an economic burden.\(^{20}\)

4. Participatory Human Rights-Based Development: A Critique

Thus far in this chapter the emphasis has been on analysing the difficulties and challenges involved in specifically implementing a rights-based disability policy and practice. Within contemporary discourse in disability studies, there is an apparent inherent tendency, with perhaps the exception of sociology, to not engage with other mainstream academic disciplines. In this section, an attempt is made to contextualise some of the challenges described above within the broad context of international development, by drawing on current debates in mainstream political science and development studies. It is not the intention of this section to provide a comprehensive

critique of “participation” and the efficacy of a “rights-based agenda to development”, but solely to raise awareness that these debates in development studies and political science discourses are ongoing.

The clarion call of the international disability movement has been “nothing about us without us”, in the belief that people with disabilities and their representative organizations should be at the very forefront of disability policy making. To some extent, it can be argued that the ideological hegemony of disability policy-making has indeed embraced this premise, underpinned by the principles of the social model of disability. A good example is that during the five-year negotiation of the UN Convention, civil society institutions, particularly disabled people’s organizations, actively engaged with UN agencies and government representatives during this process. Some would even go as far as to claim that this changed the manner by which future human rights treaties will be developed.21 Such an approach to policy-making, that explicitly recognizes the inherent efficacy of a rights-based approach to development, is predicated on the notions of participation, accountability, inequality, non-discrimination, transparency and empowerment.22 As Peter Uvin has aptly stated the essence of a rights-based approach to development constitutes “promoting human dignity through the claims that seek to empower excluded groups and that seek to create socially guaranteed improvements in policy, including but not limited to legal frameworks”.23

While acknowledging that there is indeed a great deal of utility in adopting a rights-based approach, the claims of the advantages claimed by the rights-based approach to development, in combination with its fundamental values, has been subject to criticism from development practitioners and academics in the recent past.24 Indeed, many scholars would argue that such terms as “empower-

ment” “participation” and “rights-based approaches” have become the sacred cows in the development lexicon, with some even going further by saying that “participation” has now become a “tyranny”. Other scholars and development practitioners are questioning whether the current aid modalities are actually benefiting the poor and whether they will actually make any significant progress in achieving the Millennium Development Goals.

The intellectual heritage for participatory approaches to development began in the 1970s and 1980s, pioneered by Robert Chambers at the Institute of Development Studies at the University of Sussex. Through his work on participatory rural appraisal, Chambers has consistently challenged top-down power relations between donor agencies and beneficiaries. This critique is premised on the belief that long-term sustainable development could only be achieved when local knowledge, in collaboration with local “ownership” of development initiatives was achieved. Therefore, it is incumbent on bilateral and multilateral donor agencies to develop aid modalities and planning processes which actively engage with project beneficiares. It is also maintained that the very act of “participating” in development initiatives is by its very nature empowering to hitherto socially excluded and marginalized groups.

Subsequently, the concept of participation has been subject to severe critique. There is strong evidence to suggest that participatory approaches as they have been used by development practitioners have been done in a somewhat technocratic manner, as means by which to access donor funding. Furthermore, many would argue that this tendency has “depoliticised” the original objective of participation, which was not primarily concerned with poverty alleviation, but with challenging existing power relations within international development, based on the ideology of Paulo Freire and Marx. As originally conceived, empowerment was to ensure the “transformation of the

cultural, political, and economic structures that reproduce poverty and marginalisation".28

The experience of the DFID-funded Protracted Relief Programme in Zimbabwe cited above is just one example of this. In addition, the concept of “local communities” has been somewhat romanticised and unproblematicised, failing to take into account existing patriarchal and hierarchical power relations. In addition, there is strong evidence to suggest that, where participatory approaches to development had been used, it is invariably the local elites that have been involved in such initiatives. Frances Cleaver has cogently argued that “participation” has become an act of faith by development practitioners, in the belief that it is inherently a “good thing”.29

It is not intended here to provide a comprehensive critique of participation. Nevertheless, many of the criticisms that have been outlined above resonate with the experiences of the authors. The systemic exclusion of people with disabilities within policy-making processes is well-documented. Even where DPOs have been included, routinely their participation has been tokenistic in nature, more akin to consultation than meaningful and effective dialogue. In addition, as already mentioned, DPOs tend to be populated by “elites” who do not represent all impairment groups.

Prominent disability activists have consistently argued that people with disabilities, who constitute the poorest, most marginalized and most socially excluded groups within any society, should be actively engaged in development on poverty reduction initiatives, such as the PRSP process. Furthermore, increased resources should be made available to DPOs to ensure that they participate in such initiatives more effectively.30 It is also becoming increasingly recognized that multi-dimensional poverty, participation and social exclusion are inexorably linked. Social exclusion is essentially a process by which individuals and groups are systemically excluded from participating in their own societies, which includes the inability to be informed in

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30 Dube, supra note 16.
the policy-making process. Moreover, de Haan and Maxwell maintain that social exclusion has three critical dimensions: the inability to exercise human, civic and bureaucratic rights; the inability to access human and social capital; and the depletion of family and relational bonds. Therefore, social exclusion as defined in such writings is highly relevant to the development of aid modalities and poverty reduction strategies. Yet notwithstanding the increasing recognition that there is an inherent nexus between poverty, participation and social exclusion, which is highly relevant to disability policy and practice, current evidence suggests that the PRSP process is not as inclusive as it was originally intended to be.

The PRSP process was initiated in 1999 as a reaction to detrimental effects on the Structural Adjustment Process, spearheaded by the IMF and World Bank. Underpinning the whole process was the belief that poverty reduction strategy papers (PRSPs) will be “owned” by their respective countries and that they should be developed with a high level of engagement and input from civil society institutions.

However, there is a substantial body of evidence to suggest that the participatory credentials of the PRSP process are highly questionable. Said Adejumobi, within the African context, has provided a critique of the governance structures and processes for PRSPs. His underlying premise is that poverty, inequality and governance are inexplicably linked. Given that there is now widespread acknowledgement that poverty is a multidimensional phenomenon, (that encompass both financial and non-financial facets), it can be argued that effective governance underpins the “institutional, legal and political framework not only for the design of poverty reduction policies but also for the enhancement of the capacity of the poor to

deal positively with and improve their conditions".  

It is therefore recognized that building the capacity of those who are most marginalized and socially excluded to engage with and participate in the democratic processes within their country has a direct positive correlation with poverty reduction. Hence, the PRSP initiative is not solely concerned with the production of a poverty reduction strategy, but it is also equally concerned with the process by which it is achieved.

Hence, the ostensible participatory nature of PRSPs has several implications in terms of governance. First, there is the desire to move away from the technocratic and bureaucratic production of top-down poverty reduction strategies, to one that actively embraces and encourages the voices of poor and marginalized groups to be heard in its development. Secondly, PRSPs seek to foster the principles of democratic accountability and responsibility in the design of poverty reduction initiatives. Thirdly, as already had been mentioned, the raison d’etre of PRSPs is that they should be “owned” by government. David Booth has argued that the PRSP initiative has the potential to produce a “new poverty contract” between bilateral and multilateral donor agencies, governments and civil society.

Notwithstanding these laudable ideals, Adejumobi has argued that the participatory credentials of PRSPs have not been achieved. In reality, civil society institutions are consulted after the poverty reduction strategy paper has been produced by the IMF and World Bank in collaboration with the government. Hence, it is somewhat of a false claim to suggest that civil society is engaged in meaningful ‘participation’ in the process. Moreover, even though there has been a degree of consultation, with the notable exceptions of Ghana and Uganda, the involvement of civil society has been largely tokenistic. There is also evidence to indicate that only local NGOs that are sympathetic and in agreement with the prevailing ideology of the ruling political party have been consulted. A further contributing factor is that in many African countries, the democratic legitimacy and capacity of NGOs to engage in policy dialogue is extremely weak. Thus, the apparent lack of capacity of DPOs to engage in policy-making is not unique, but

rather commonplace throughout civil society. Also, drawing upon the experience of developing PRSPs in Tanzania, Kinsella and Brehony argued that civil society institutions that have either participated or been consulted are urban based, and result in the voices of those living in rural areas being ignored.\textsuperscript{36} Adejumobi rather pessimistically concludes that the underlying ideological foundations from which the PRSP process is based have not fundamentally changed since the structural adjustment policies of the 1990 that were underpinned by the so-called “Washington Consensus”.

5. Conclusion

The objective of this chapter has been to critically evaluate the extent to which the United Nations Convention on the Rights of Persons with Disabilities, which came into force in May 2008, will create a paradigm shift in the manner in which disability policy and practice will be formulated and implemented in the future, based on findings from these four research studies. Analysing disability policy in Zimbabwe, Nigeria, Uganda, Namibia, Swaziland, Malawi and Mozambique, we have discussed some of the entrenched challenges that need to be overcome in order for a truly inclusive and rights-based approach to disability policy and practice to move beyond the rhetorical statement and become a reality. Notwithstanding the acknowledged historic importance of the UN convention, it is too early to determine whether such a paradigm shift will take place.

The challenges that are ahead in achieving this paradigm shift are considerable, and there are no easy solutions. The authors are not questioning the validity of a human rights-based approach to disability policy and practice, but are rather seeking to raise critical issues that will inevitably need to be addressed. First and foremost, it is imperative that the difficulties surrounding governance issues, defined in their broadest sense, are addressed. Public sector reform, encapsulating good governance and accountability, is high on the agenda of bilateral and multilateral donor agencies. It is imperative that solutions are found to ensure that social and economic policies in developing countries, not least within the disability sector,

are developed so that people with disabilities are able to access mainstream public services, in concert with exercising their inherently endowed human rights. Furthermore, it is vitally important that robust statistical data vis-à-vis disability is generated and utilized by government and civil society institutions. In the absence of such data, a “democratic deficit” will continue to exist, whereby people with disabilities will not have the benchmarks and evidence to hold their respective governments to account for commitments to human rights-based disability policy and practice.

But the challenge lies not only with governments and donor agencies. From the evidence gathered from the research studies described in this chapter, it is very apparent that neither governments nor disabled people’s organizations understand each other’s “world view”. Therefore, there is a significant challenge for disabled people’s organizations to make a concerted effort to understand the policy-making process in their own respective countries, including comprehending the constraints that are faced by many governments throughout the developing world, where there are competing claims for significant but finite human and financial resources in addressing difficult political, social and economic challenges and realities.
PART IV: NEW TRENDS IN DISABILITY RIGHTS
Chapter 9:

Realizing the Right to Adequate Food for People with Disabilities in Uganda

Emmanuel K. Kanyemibwa

1. Introduction

In Uganda People with Disabilities (PWDs) are faced with challenges of exclusion from the political, social and economic life of their country. This affects the realization of their human rights, especially the Right to Adequate Food (RTF). The right to food for people with disability is a special area of concern because it is interrelated with the realization of other rights necessary for the well being of PWDs as spelt out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2007. This is because access to food is crucial for a meaningful livelihood. Besides, it is an area which has not yet attracted adequate attention from disability activists. As a result of missing out on the RTF, the lives of PWDs are characterised by inadequate nutrition, ill health and other conditions resulting from the violation of the right to adequate food. However, since the 1980s efforts have been taken to attempt to rectify this situation to ensure the full realization of human rights for PWDs. These rights are enshrined in the Universal Declaration of Human Rights (1948) and the Convention on the Rights of Persons with Disabilities (2007) among others. In spite of these efforts the struggle for the fulfilment of the RTF for PWDs is far from over and the problem appears to be persistent. This article investigates efforts to protect and promote the right to adequate food for PWDs in Uganda. It seeks to establish the extent of the realization of the right to adequate food for individual PWDs in Uganda and highlight the constraints involved. The study covers the period from 1990 to the present, because this was the period during which major policy measures were put in place to assist vulnerable people.
2. The Right to Adequate Food

The right to adequate food is defined as the entitlement of individuals alone or in a community to enjoy physical and economic access to food or the means to procure it.\(^1\) Basically it means the empowerment of individuals to access adequate food but not food handouts. For individuals to realize this right, food should be available in sufficient quantity and quality to satisfy dietary needs in culturally acceptable forms; and accessibility to food should not interfere with the enjoyment of other rights.

Availability implies that individuals should be able to access food directly from their activities or the presence of a well co-ordinated system where it is possible to access food without any obstacle. Accessibility is both physical and economic. Physically, food must be accessible to all; most especially to vulnerable groups such PWDs. The right to adequate food also implies that food must be safe and that there is minimum risk of missing out on food at all times.\(^2\) It is the obligation of states parties to international and regional instruments to promote the fulfilment of this right. The government of Uganda has made efforts to promote the RTF for PWDs, but the fulfilment is still lacking. The liberalisation of Uganda’s economy since the 1990s and the recent rise in the prices of food and fuel have further complicated accessibility and availability of adequate food for the vulnerable poor, particularly PWDs. This has made it difficult for PWDs to cope with the situation. As a result of missing out on the RTF the realization of other human rights is threatened.

3. Human Rights for PWDs

There has been a resurgence in the promotion of human rights for PWDs following the ratification of the Convention on the Rights of People with Disabilities (CRPD) (2007). Efforts to promote the human rights of PWDs have also been reinforced by the need to achieve the targets of the Millennium Development Goals (MDGs),

\(^1\) United Nations High Commissioner for Human Rights (1999), General Comment 12, The Right to Adequate Food.
\(^2\) Ibid.
a strategy to transform lives by 2015 through poverty eradication.\textsuperscript{3} This necessitated the need to address the human rights of PWDs by removing the marginalisation and discrimination, which are largely responsible for perpetuating poverty among PWDs.

Prior to the ratification of the CRPD, recognition of the human rights of PWDs was lacking as the law seemed not to offer adequate protection.\textsuperscript{4} Following this ratification efforts have been made to mainstream the human rights of PWDs by states parties. Efforts to improve the livelihoods of PWDs must ensure equality and non-discrimination. This would entail efforts to help PWDs realize their full human rights through effective and efficient development strategies that are inclusive of PWDs. To transform the lives of PWDs, it is important to note that human rights are interrelated and interdependent. In this case, the right to adequate food for PWDs would have to be promoted to achieve this target. According to the social model of disability, disability is a creation of society whereby attitudinal barriers exclude PWDs from full enjoyment of their human rights, as a result of which they suffer from want of various needs.\textsuperscript{5} These include sufficient, adequate, safe and culturally acceptable food.

4. Disability and the Right to Adequate Food

Disability is a human rights issue which is mainly manifested in poverty and social exclusion. This causes PWDs to miss out on education among other things, which may lead to a lack of access to meaningful livelihoods. This has wider implications for the human rights of PWDs, particularly concerning the right to adequate food. There have been renewed efforts towards the struggle for equality between disabled and non-disabled persons since the ratification of the CRPD by the majority members of the United Nations. However,

\textsuperscript{4} Ibid.
\textsuperscript{5} H. Katsui, Downside of the Human-Rights-Based Approach to Disability in Development (Working Paper 2/08, Institute of Development Studies, University of Helsinki, 2008).
the ratification of the UNCRPD is yet to have an impact on the RTF for PWDs.

In Uganda, the nutritional status of the population, particularly women and children, is poor and a major health issue. Those responsible in Uganda have embarked on a programme of sensitisation and training of the populace, but this remains a major challenge. Poor maternal nutrition and undernutrition in the first two years of childhood affect brain and physical development where the damage is irreversible. This is likely to affect physical ability not only in childhood but throughout life. This issue points to the need to ensure the realization of the RTF for pregnant mothers and young children so as to minimize the dangers of disability. Unfortunately, various impediments constrain efforts to alleviate this problem.

The situation of people with disability in Uganda is further aggravated by poverty. As a result of poverty people with disability may not have access to adequate resources to support their needs in education, housing, health and clean environment, and this may constrain the realization of the right to adequate food. Failure to access adequate food further aggravates the disability of a person. Households headed by people with disabilities are likely to experience poor living conditions. Families with PWDs also face constraints of health care, foregoing other activities to look after the disabled. Because of cultural factors, PWDs are often feared and considered subhuman.

Disability is viewed by all societies as an accomplished fact; an unavoidable burden to be accepted – as our forefathers accepted all disease – as an act of fate or of some malevolent demon.

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7 Kikafunda, J.K(2009), The Double Burden of Hunger and Obesity in Relation to the Right to Adequate Food in Sub-Saharan Africa, in *African Journal of Ethics and Human Rights* Vol 2, Department of Philosophy, Makerere
Efforts to alleviate poverty and improve the livelihoods of PWDs in Uganda seem to be lacking.\textsuperscript{10} This makes it difficult for PWDs to realize their human rights in full. The RTF for PWDs is particularly violated because of the inequalities perpetuated by attitudinal barriers that exclude PWDs from enjoying human rights. This is made worse by the gaps in poverty eradication, the rising food prices and the recession which has hit the global market.

The rights of PWDs are protected by Uganda’s legal framework and government policies. However, it is not clear to what extent the right to adequate food for PWDs is protected. PWDs constitute the largest percentage of the vulnerable poor who cannot enjoy an adequate standard of living. Because of their unique situation, PWDs face challenges which require specific interventions tailored to suit their needs in order for them to realize the right to adequate food. The UNCRPD and other regional instruments protect the RTF of PWDs. In spite of this, PWDs in Uganda seem to be missing out on their RTF and it would be of interest to know how this problem can be alleviated.

The RTF of PWDs faces a high risk of violation because of the marginalisation PWDs face in society. As a result they face unequal access to resources. They risk hunger and malnutrition because of low incomes and limited mobility.\textsuperscript{11} This is why interventions have to be made by those in power to stop the oppression of PWDs so that they can realize the RTF.

The promotion of the RTF is particularly emphasised in guidelines to support the realization of the RTF.\textsuperscript{12} The strengthening of partnerships and capacity-building are emphasised. However, disability issues are not highlighted. As the World Bank observes\textsuperscript{13}, unless


\textsuperscript{13} Op Cit.
disability rights are specifically emphasised, they are likely to be ignored.

The right to food is an entitlement for all individuals. Therefore people have the right to demand that the state provides either an environment that favours the realization of this right or simply adequate food to vulnerable groups in extreme cases. The realization of the RTF is not an act of charity but an obligation of a states party which must be accountable to all of the rights-holders. The state is required to identify the most vulnerable people such that their RTF is protected. It is not clearly known to what extent PWDs, as a vulnerable group, receive particular focus in the realization of the RTF.

The rise in food prices in Uganda and around the world is bound to have an impact on the livelihoods of the vulnerable poor beyond the year 2015. This is said to be a result of the increase in oil prices and in the use of food for bio-fuel. This is exacerbated by the economic recession which hit western economies in 2008 and is spreading to developing countries. It has been estimated that the vulnerable poor spend about 80 per cent of their income on food. This situation poses a serious threat to the RTF, especially for PWDs. However, literature on these crises does not adequately focus on the impact of the global crises on the RTF for PWDs. This raises questions about the mainstreaming of the rights of PWDs, particularly the RTF.

According to the Food and Agricultural Organization of the United Nations- FAO (2004) the realization of the RTF can be achieved by encouraging states parties to end food insecurity and by helping to empower the most vulnerable groups. More information is needed on how disabled people can be empowered so as to realize the RTF. It is particularly important to note that PWDs have a varying range of

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17 FAO (2004), Voluntary Guidelines to support the progressive realization of the right to adequate food in the national context of national food security, Rome, FAO.
18 FAO, supra note 14.
impairments which would require various strategies to address the needs of each category of PWDs in order to realize their RTF.

FAO\textsuperscript{19} reveals that women with impairments are even more vulnerable to missing out on their RTF although the human rights framework protects their RTF. This is because they suffer the double burden of discrimination based on gender and disability. This in turn is likely to affect the health and nutritional status of mothers whose children have disabilities. There is a need to shed light on how the RTF for women with disabilities is being promoted given that they are an extremely vulnerable group.

In Uganda the RTF is protected both by international and domestic human rights instruments. However, there are gaps in accountability mechanisms with regard to the RTF for PWDs as a strategy to improve the realization of this right. It is important to address such challenges so to empower PWDs.

5. Legal Framework for the Right to Adequate Food in Uganda

The Convention on the Rights of Persons with Disabilities, Article 25 provides for access to health services, and food without discrimination while Article 28 provides for adequate standard of living, including food, clothing and housing, clean water, affordable services without discrimination. The United Nations Convention on the Rights of People with Disabilities recognizes the right to a standard of living for PWDs. Among other things, this includes adequate food, housing and other rights. States parties have the obligation to promote the rights of PWDs without discrimination. On 30 March 2007 Uganda signed the CRPD and the Optional Protocol. This is a very significant step towards improving the lives of PWDs. It is hoped that this will strengthen the promotion of the RTF for PWDs in Uganda.

\textsuperscript{19} Ibid.
The human rights approach to disability has led to the demand for a legal framework that favours the needs of PWDs in Uganda. It was partly because of this that the Persons with Disabilities Act (2007) was passed by the Parliament of Uganda. The legal framework ensures that the entitlements of PWDs are respected as rights and not just privileges. As a result of this development, efforts have been made to improve the lives of PWDs, although such efforts are constrained by poverty. The ratification of the UNCRPD is likely to strengthen efforts to design policies that favour mainstreaming of the rights of PWDs. This is because it has encouraged PWDs to demand improvement and operationalisation of the Disability Act (2007).

The Constitution of Uganda (1995) Article 25 protects the rights of PWDs:

“Persons with disabilities have a right to respect and human dignity and the State and society shall take appropriate measures to ensure that they realize their full mental and physical potential.”

Based on this, other laws and policies on PWDs have been designed. They include the National Council on Disability Act (2003), the Disability Act (2007), the Equal Opportunities Act (2006) and the National Disability Policy and the Local Government Act (1997). However, despite these provisions, PWDs seem not to be satisfied with measures to improve their livelihoods, particularly the right to adequate food.

Although legal framework in Uganda protects PWDs against discrimination and provides for efforts to enable them to realize their right to a livelihood, this is yet to be fully implemented.

6. Efforts to Promote the Realization of the RTF for PWDs in Uganda

The realization of the RTF for PWDs requires the existence of conditions that totally favour access to food for people with different types of disabilities. These include the harmonisation of political, social and economic conditions in the country. The fulfilment of the RTF for PWDs is the duty of government, although civil society is playing a significant role in creating conditions necessary for the empowerment of PWDs to realize the RTF.

6.1. Sectoral Policies and the RTF for PWDs

In Uganda, PWDs appear to be socially, politically and economically marginalized, because disability issues are not adequately streamlined in government policies. As a result, specific needs of PWDs are not addressed. This is because policy-makers may not value the contribution of PWDs, and this undermines efforts to realize their right to adequate food.

Poverty reduction policies have not succeeded in empowering PWDs in their efforts to access adequate food, because more often than not they are not inclusive and this weakens their implementation. Policy makers do not realize that disabled people as rights-holders are mainly dependent and unable to provide for their own needs.

Without inclusive development which integrates the needs of PWDs in development policies, the livelihoods of PWDs may not improve. Inclusive policies for PWDs would target income generation and employment opportunities in various sectors, mitigating physical accessibility challenges providing appropriate technology. This would provide a strong base for efforts to realize the RTF for PWDs.21

Poverty is the major cause of the failure of PWDs to realize their human rights, especially the RTF. In the face of limited resources, PWDs may not be considered a priority in their families. This causes neglect of their essential needs, especially access to adequate food. In Uganda governments efforts to eradicate poverty are guided by the Poverty Eradication Action Plan (PEAP) 2004. However, the PEAP is not designed according to the Human Rights Based Approach to Development (HRBAD). Therefore there are weaknesses in this policy which do not strengthen efforts for the realization of the RTF for PWDs.

6.2. Education

While efforts have been made by the government of Uganda to provide education to PWDs, this is still lacking. There is very serious under funding, which makes it difficult to implement special education programmes for PWDs; hence the policies remain on paper. Oloya\textsuperscript{22} observes that school children with disabilities “are considered non-citizens as far as Uganda Ministry of Education is concerned.” In spite of Universal Primary Education (UPE), which is presumed to be free and compulsory, the costs of education in special-needs schools are prohibitive and hence contribute to exclusion.\textsuperscript{23}

All this results in a host of other problems such as lack of equipment and facilities for training specific categories of PWDs according to their needs and abilities. Education for PWDs is further constrained by lack of specialised resource persons for different types of disability.\textsuperscript{24}

Additionally, the physical infrastructure and sanitation facilities in schools may not be user-friendly for PWDs. PWDs may also be excluded from education services because of long distances, lack of specialised devices to assist them such as wheelchairs, hearing devices, etc.

\textsuperscript{23} Ibid.
\textsuperscript{24} Ibid.
6.3. Health

The health service delivery is not adapted to addressing the needs of the various categories of PWDs. For example, health workers are not trained in communication skills for PWDs nor in the treatment of different categories of PWDs. PWDs may also lack guides to accompany them to health centres, stigma and verbal abuse from health workers, long distances and unfriendly physical structures of medical facilities. In addition, it is not common for health centres to stock certain drugs such as those for the mentally ill. Health service delivery in Uganda is generally still poor in terms of accessibility, availability and quality care. This particularly affects the ability of PWDs to realize their right to health as provided for in human rights instruments. The UNCRPD in particular states that:

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation” (Article 25).

The ministry of health in Uganda has made efforts to provide for the fulfilment of the right to health of PWDs as reflected in the ministerial statements and health strategic plans. However, these efforts to promote the rights of PWDs in health service delivery are not yet effective. This is because of limited resources and other weaknesses of service delivery but not deliberate efforts or failure to realize that PWDs need services related to their needs. The poor health conditions nonetheless fail to address the health conditions necessary for the RTF of PWDs.

6.4. Agriculture

Agriculture is the mainstay of Uganda’s economy where the majority of the vulnerable poor eke out a living. According to Lwanga-Ntale,

25 Ugandan Ministry of Health, supra note 6.
the agriculture sector’s policies fail to address the needs of PWDs whereby responsible officials are ignorant of rights of PWDs. Besides, government has thus far not taken steps to support PWDs in agriculture-related work. The Plan for Modernisation of Agriculture (PMA) and National Agricultural Advisory Services (NAADS) are government programmes aimed at increasing incomes and transforming livelihoods. However, they target people who already own property such as land and finance capital. As a result many PWDs are excluded and denied the chance of accessing incomes to facilitate the realization of the RTF.

6.5. Participation in Politics

Article 29 of the CRPD provides for effective and full participation of PWDs in political and public life. Efforts have been made by those responsible in Uganda to empower PWDs to realize their right to participation. The Local Government Act (1997) provides for affirmative action for PWDs in governance. There is legal provision for political representation of PWDs on an affirmative basis. As a result of this, PWDs elect their representatives to various political positions from grassroots to the national parliament. Although this gives an impression of active participation and equality for the PWDs, the reality on the ground is different. This is because of high illiteracy levels and not knowing how to use the power of their positions, especially when making decisions on matters concerning disability. Although efforts have been made to train PWDs political leaders, there is still a long way to go. Various sources, including the Dutch Coalition on Disability and Development27 and Disability World 200328, agree with the view that PWDs representatives do not know what to do in local councils. Since the introduction of Movement Party politics in 1986 and the multiparty system in 2006 in Uganda, politicians seem to have manipulated disability issues to promote their interests. Disability is a human rights issue, and it is important that the political factor should be controlled in order to protect the livelihoods of vulnerable people, especially the RTF for PWDs.

27 Dutch Coalition on Disability and Development, supra note 8.
6.6. Housing for PWDs

As provided for in Article 28 of the CRPD adequate housing is one of the conditions for the full realization of human rights for PWDs. PWDs face serious health risks as a result of the poor housing situation that generally prevails in Uganda. For example, in Kampala city alone housing facilities are scarce and the cost of building or renting a house is unaffordable for the poor. More than 80 per cent of the poor in Kampala do not own the houses where they stay, and the majority of the vulnerable poor lack shelter. Looking at the plight of PWDs, the difficulties in accessing adequate housing arise from the environment in which the public is not sensitised to human rights and the needs of PWDs. Under such disenfranchising conditions it is very difficult for PWDs to realize their RTF.

6.7. The Role of Civil Society Organizations (CSOs)

CSOs have played a significant role in ensuring that PWDs access adequate food. This includes Disability People’s Organizations and CSOs that provide inclusive programmes to PWDs. Although it is the duty of government, civil society comes in to supplement the role of the state, given the constraints faced in developing countries. Civil society in Uganda contributes much in terms of advocacy and sensitisation. However, market forces seem to not favour PWDs because of commercialisation, which denies PWDs the dignity and freedom to make personal choices, limiting the right to adequate food. CSOs have increased participation of citizens in the policy-making process, especially the mobilization of vulnerable groups and advocation of policies on their behalf.

29  'Massive Housing Shortage Looming: 4.8 Million People will Be Homeless in Kampala by 2025', Saturday Vision, July 12 2008.
32  R. Kunnemann and S. Epal-Ratjen, supra note 11.
7. Constraints to the realization of the Right to Adequate Food for PWDs

Constraints to the realization of the RTF for PWDs are highlighted in various literature sources. The major cause of weaknesses in the livelihoods of PWDs is social exclusion.

7.1. Poverty

Poverty is the number one cause of violations of the RTF for PWDs. Poverty and disability are closely linked. It is mentioned that poverty not only causes disability but also makes disability worse. Because most PWDs lack minimum skills for employment and physical assets like land, they may be unable to support their needs or grow their own food. As a result they may not have access to adequate food. The overall framework for poverty alleviation – the Poverty Eradication Action Plan (PEAP) – which guides the major sectoral policies like education, health, agriculture inter alia, has not since its inception in 1997 satisfactorily addressed issues of vulnerability, more particularly the livelihoods of PWDs.

7.2. Social stigma

Social stigma is often the cause for the socio-economic exclusion of PWDs, as a result of which their lives become difficult and their access to the RTF is lessened. PWDs may be considered to be of no use and are therefore discriminated against. This is often a result of ignorance and superstitions whereby PWDs are considered cursed and taboo to associate with.

7.3. Ignorance about interests and rights of PWDs

The promotion of the rights of PWDs appears to be a recent development, mainly as a result of the promulgation of the Constitution of Uganda (1995) which focuses on human rights. Despite this development, the public, including policy-makers, is not well informed about
the rights of PWDs. This negatively affects the realization of the RTF for PWDs as there may be no deliberate effort to empower them.

7.4. Inadequate financing of sectoral policies

In Uganda there is a tendency to ignore adequate allocation of resources to service provision sectors like education and health, leading to gaps in the prioritisation of resource allocation. This constrains service delivery as a result of which PWDs find it difficult to realize adequate living conditions which would favour the realization of the RTF.

7.5. Weaknesses in mainstreaming interests of PWDs

As highlighted by Lwanga-Ntale, sectoral policies do not take into account the fact that there are different categories of PWDs with a range of disabilities and needs, which must be addressed differently. It was noted that this results in exclusion of the more vulnerable cases of PWDs such as women, children, people with extreme cases of mental disability, epilepsy cases, the elderly and youth. It was also found that this problem also affects disabled people’s organizations.

7.6. Marginalization of Women with Disabilities

According to various writers, women PWDs are the most discriminated against of all of the vulnerable people on account of their gender. As a result of exclusion they are more likely to be needy. This is because it is considered a curse to marry a woman who is disabled. For this reason they may not be able to produce children who would subsequently be a source of social security. As a result such women may not be able to acquire property, since in patriarchal communities property is accessed through marriage. Article 6 of the CRPD provides for states parties to ensure empowerment for

33 Lwanga-Natale, supra note 10.
34 Dutch Coalition on Disability and Development, supra note 8; J. Bhekoe, supra note 28; Lwanga-Natale, supra note 10.
women with disabilities. However, this is yet to be effected in Uganda such that women with disabilities can enjoy their RTF.

7.7. Children with Disabilities

Children with disabilities are considered both a curse and a burden by their families.\textsuperscript{35} It is not considered to be of any economic sense to spend money or other resources on such children. They are often confined to their homes under seclusion because of the shame associated with producing children PWDs. In addition they may not be allowed to do any type of work. This denies them the chance to acquire survival skills and condemns them to a life of dependency. As a result many of them do no not go to school and they lack economic and social coping skills. This results in poverty and unemployment in subsequent years. Eventually, it is a difficult task to realize their right to food. Article 6 of the CRPD obligates states parties to ensure that children enjoy their fundamental freedoms. The implementation of these legal provisions would help children enjoy their RTF.

7.8. Gaps in Economic Empowerment

The promotion of efforts that would favour the realization of the right to food for PWDs in Uganda is constrained by a lack of resources to support PWDs.\textsuperscript{36} Limited funding has made it difficult to implement policies and laws made for the purpose of promoting the rights of PWDs. Most developing countries, Uganda included, tend to focus on the general conditions of the economy and ignore social development. As a result vulnerable groups like PWDs are ignored and the scarce resources are allocated elsewhere.

Failure to access job skills as a result of exclusion means that PWDs cannot get employed. This limits their capacity to fulfil their basic needs. This obviously affects food security and the quality and quantity of food accessed. In addition, other needs such as health, shelter and sanitation may also not be addressed, and this may further frustrate efforts to realize the RTF.

\textsuperscript{36} DPOD, supra note 20.
It is difficult for PWDs to participate in income generation activities. This is partly because many of them are often denied credit facilities and may not even join credit associations, because it is presumed that they may fail to pay their loans.\textsuperscript{37} This may affect the RTF in different ways and should therefore be investigated with the goal of improving livelihoods.

7.9. \textit{Inadequate sensitisation strategies}

The disability movement being a recent development, policy makers lack training in disability issues, and hence may not be able to articulate the interests of PWDs. As a result the interventions to empower PWDs may be inadequate. It has been pointed out that the rights of PWDs are not widely understood even among PWDs, CSOs and the general public. This seems to stem from a failure to sensitise communities on human rights instruments. This could explain why advocates of human rights for PWDs and the disabled are not bold enough in demanding practical efforts from the responsible parties to ensure the realization of rights for PWDs.\textsuperscript{38}

7.10. \textit{Challenges Facing Non-Governmental Organizations (NGOs)}

The persistent failure of states to address the needs of vulnerable groups in Africa has led to the relegation of much of the responsibility to improve the livelihoods of the poorest of the poor to CSOs, also variously described as NGOs. This makes it crucial to review the challenges facing CSOs as major actors in the struggle to realize the RTF for PWDs. According to Chiroro\textsuperscript{39} (2008), in African states where democracy is weak, governments do not pursue participatory approaches in the development process and sideline established

\footnotesize{37} Lwanga-Natale, \textit{supra} note 10.
institutions. Such governments have a tendency to mistrust CSOs, viewing them as unrealistic and subversive.

Weaknesses in civil society could explain why PWDs are not enjoying the RTF. Several authors reveal that CSOs in Africa are still young and small.\textsuperscript{40} As a result, they may not be able to use provisions in international law that address food and disability to pressure responsible parties to focus on the promotion and protection of the rights of PWDs, especially the RTF. The National Union of Disabled Persons of Uganda (NUDIPU) blames weak livelihood promotion for PWDs on the failure by CSO management at the district level to mobilise grassroots organizations of PWDs.\textsuperscript{41}

8. Strategies to improve the realization of the RTF for PWDs in Uganda

8.1. Education

The UNCRPD provides for access to education for services for PWDs on the basis of equal opportunity. Education is crucial for the realization of the right to food of PWDs because it equips them with skills for income generation and participation in community activities to ensure that their interests are served. In Uganda the Department of Special Needs Education at the district and national levels ensures inclusion of the right to education for PWDs, but this faces constraints. For example, while teachers for special needs education are trained at the National Institute of Special Education-Kyambogo University, the numbers are still inadequate, and even when they do enter the field, they are poorly facilitated. The policy of free education at the primary and secondary school levels provides for all children, but again this does not adequately serve the needs of Children with Disabilities (CWDs) because of inadequate resources.

\textsuperscript{40} P. Bewan and A. Ssewaya, \textit{Understanding Poverty in Uganda: Holding a Sociological Dimension} (Centre for the Study of African Economies, University of Oxford, 1995) and Barr \textit{et al.}, \textit{supra} note 31.

\textsuperscript{41} National Union of Disabled Persons of Uganda (NUDIPU)/Africa 2000 Network-Uganda Collaboration, Report of the Capacity Building Workshops of the Sub County Leaders of Persons with Disabilities (PWDs) in Arua District (NUDIPU, Kampala, 2006).
Special schools for CWDs do exist but are few and also constrained by inadequate resources.

8.2. Economic Empowerment

For PWDs to realize their RTF it is important that they are empowered to support their basic needs through training, access to public and private service and self-employment. In the course of doing this, effort should be made to create work environments that are friendly to PWDs and allow PWDs to equally access job opportunities with able-bodied people. Economic empowerment goes hand in hand with access to information. For PWDs to improve their livelihoods they need messages adapted to their different categories of disability e.g. learning, hearing or visual difficulties. Stakeholders could consider improvements in funding for education adapted to the needs of PWDs so as to retain specialised teachers and procure relevant resources to support learning.

PWDs need to be economically empowered to access meaningful livelihoods. However, this can only be possible when they can access adequate income. This is not guaranteed for the majority of PWDs in Uganda because of the high poverty levels that affect the country overall. Although UNCRPD Article 27 and Uganda People with Disability Act (2006) Article 12 provide for the right to employment, this may not be easily realized in a developing country like Uganda. It may also be difficult to realize because of cultural settings where PWDs are considered abnormal and unable to work, and are viewed as objects of pity who can only survive on donations. The inclusion policy adopted by the government of Uganda will take a long time to ensure economic empowerment of PWDs, because such programmes demand adequate resources which are hard to come by. Efforts by the Poverty Eradication Action Plan 2004, the National Agricultural Advisory Services and other poverty eradication strategies have so far not benefitted a significant proportion of the population including PWDs.

Worse still, PWDs are restricted from employment or receive inadequate payments. This condemns them to a life of dependency and not having their needs met. Physical barriers in public places such as roads, buildings and transport systems may also deny them
access to basic needs. All this may undermine efforts to realize the right to adequate food.

With the liberalisation of Uganda’s economy and the introduction of Structural Adjustments Policies of the economy in the 1980s the economic landscape has become particularly harsh for vulnerable groups. Before this period the fixing of prices would address the needs of the poor. This period also marked a loss of jobs through restructuring. Since then, Uganda’s economy has been characterised by high levels of unemployment and the lack of a minimum wage policy. All of this has severely undermined the livelihoods of the poor with little or no effective efforts to rectify the situation. This has had a severe impact on PWDs, most of whom are dependent on their communities for their livelihood, particularly in accessing adequate food.

8.3. Independence

PWDs need to make independent decisions in order to overcome the social stigma that is partly responsible for their economic marginalisation. This can be done by assisting them to overcome difficulties resulting from disability that impede their efforts to learn, see, hear, and move among others. They would need support in the form of counselling, technical support, financial support, advocacy and assisting them to access a wide range of opportunities for economic empowerment. To create conditions for independence, there is a need for new legislation, amendments to existing laws and the redesign of sectoral policies to accommodate the interests of PWDs. This should go hand in hand with government efforts to improve service delivery by improving funding particularly aimed at programmes to empower PWDs. There may also be need for efforts to sensitise communities to respect the rights of PWDs. This can be done by fighting discrimination. Through active participation which emphasises inclusiveness, the stigma against PWDs can be removed. This would promote equal participation and access to economic resources by individual PWDs, and hence improve their livelihoods particularly the RTF.
8.4. Improving the role of Civil Society

Considering that Uganda is a country emerging from the problems characteristic of a failed state, it is important that strategies to boost CSOs’ efforts in empowering PWDs to realize their right to food be encouraged. Sensitisation on human rights instruments could help raise the awareness of the RTF for PWDs by educating CSO personnel, PWDs and the general public. This would stimulate the demand for giving PWDs their entitlements, especially the RTF. However, a review of various literature reveals that much of the sensitisation does not focus on the RTF for PWDs. Donors can also help improve the role of CSOs in the promotion of the RTF for PWDs by putting pressure on responsible parties to create a good working environment for CSOs. They can also ensure that the state promotes gender equality, helps identify and support local initiatives and supports CSOs to have capable and accountable management. In addition, donors can ensure that CSOs are participatory, have internal democratic structures and are willing to co-operate with other development actors in addition to providing adequate financing and strengthening of CSOs.42

9. Recommendations

In view of the discussions above it is recommended that the Right to Adequate Food for PWDs be mainstreamed in all efforts to improve the livelihoods of PWDs. This is because the right to adequate food is an essential prerequisite for the realization of all other human rights of PWDs. This would entail the economic empowerment of PWDs to enable them to live independent and dignified lives. To achieve this, major gaps in the legal framework, education, health, housing and poverty-reduction strategies inter alia must be addressed to comprehensively improve the livelihoods of PWDs. In addition, the role of civil society must not only be recognized but improved, to empower PWDs to enjoy the RTF.

10. Conclusion

The RTF for PWDs has not been adequately given the attention it deserves, and yet it is the touchstone of all of the human rights of PWDs. Given the challenge of ensuring proper and adequate nutrition for various categories of PWDs, this right deserves consideration by human rights activists as a premier strategy to improve the livelihoods of PWDs worldwide. This entails revisiting the legal framework for disability rights, ensuring inclusion of disability issues in all development programmes and fighting discrimination of PWDs at all levels. PWDs will not live dignified lives until their right to adequate food occupies the centre stage in the struggle for the human rights of PWDs.
Chapter 10:

Achieving Human Security through Political Advocacy: Linking Ugandan and Finnish DPO Advocacy Work to Article 14 of the UN CRPD

Jukka Kumpuvuori and Hisayo Katsui

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1. Introduction

“Disability is above all a critical human rights issue and respecting these rights is critical for the sake of justice, equality and inclusion. To achieve a genuine development process, DPOs [organizations of persons with disabilities] must address human rights issues too.”

Human rights and disability are inseparable concepts. This article elaborates on these using case studies on the advocacy work of DPOs pertaining to the enactment of the Local Government Act in Uganda and the Personal Assistant System in Finland. The reasons for selecting these cases are four-fold. First, they are both cross-disability advocacies. Second, they are both examples of major changes in laws improving the quality of life of persons with disabilities (PWDs). Third, DPOs were the driving force or part of the driving force influencing the creation of these laws. Fourth, they are both

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recent advocacies which have allowed interviews and communication so that others might learn from the relevant actors involved.

We make an important link between advocacy activities of DPOs and human security, which are tightly bound to Article 14 of the Convention:

"Article 14 Liberty and security of the person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
   (a) Enjoy the right to liberty and security of person;
   (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation."

Firstly, the cases are respectively described. Secondly, different forms of advocacy are analysed with special attention paid to political and legal advocacy. Thirdly, challenges to the advocacy processes are reviewed. Fourthly, the personal experiences of the studied advocacy activities are linked to the concept of human security. The concluding remarks present a few observations from our case studies. The arguments are enriched by interviews conducted during 2008 and 2009 with key stakeholders of the cases in both countries. Disability study is multidisciplinary in nature. This article is written by two scholars from different fields, namely law and social sciences. Hence, the analyses utilized in this article are also multidisciplinary: evidence-based situational analysis combined with legal and theoretical ones. The conclusions drawn in the article are the result of an effective combination of these different methods of analysis.
2. The Ugandan Case: Local Government Act 1997

The Ugandan Local Government Act (1997) legally secured the political representation of PWDs in all local government structures with the introduction of a quota system. The Act was enacted as a series of decentralisation efforts by the ruling political party, the National Resistance Movement (NRM) since 1986. After the military regime of Idi Amin (1971-1979) which centralised power, and the regime of Obote (1980-1985) which did not make any major changes to its structure, there was a vacuum in local government structure. Consequently, the new NRM regime and President Museveni gave high priority to democratic governance. In 1987, right after the regime change, the National Union of Disabled Persons of Uganda (NUDIPU) was established as the umbrella organization of 17 DPOs. The NUDIPU is said to be “one of the strongest national advocacy and lobbying organizations championing the cause of marginalized groups in Uganda”. The ruling political party has morally facilitated the growth of the disability movement. The Affirmative Action Policy (1989), for instance, promoted representation of marginalized groups including PWDs.

In the Constituent Assembly for the formation of the Constitution in 1995, the late Eliphaz Mazima, a disability activist with a physical impairment and the first elected chairperson of the NUDIPU represented PWDs. As a result, the Constitution succeeded in having many clauses related to PWDs. How Mazima managed to convince other delegates, especially other vulnerable groups, has become a legend.

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4 Ibid., p. 17.
5 Ibid.
6 Ibid., p. 23 and B. Kokhauge, Personal Interview at Kampala, Uganda, 30 January 2008.
among present disability activists. Consequently, the Constitution (1995) includes the following clauses, among others:

"Rights of PWDs.

35. (1) PWDs have a right to respect and human dignity and the State and society shall take appropriate measures to ensure that they realize their full mental and physical potential.

(2) Parliament shall enact laws appropriate for the protection of PWDs."

In 1996, five Members of Parliament (MPs) with disabilities were elected to represent PWDs in a national election implementing the affirmative action policy following the Parliamentary Statute (Government of Uganda, 1996). Similarly the Local Government Act resulted in 47,000 disability councillors representing PWDs at different levels of the local government structure, half of whom are women with disabilities. This representation has gradually influenced changes on the grassroots level, as these councillors have become the channel to relevant decision making. Councillors have been improving the quality of life of PWDs at different levels. The Act is referred to as a “top-down initiative” of the NRM, rather than as a movement-oriented bottom-up initiative. An MP, Sekabira, and Mwesigye make mention of the good political will of the President as a positive factor in the creation of the Act. However, including PWDs into the Local Government Act was not automatic. Vigorous advocacy was required for the inclusion of PWDs in the final realization of the Act.

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8 Millward, supra note 7, p. 154.
9 C. Lule, Personal communication by e-mail on 17 April 2009.
11 F. N. Sekabira, Personal communication by e-mail on 17 April 2009.
12 J. Mwesigye, Personal communication by e-mail on 17 April 2009.
3. The Finnish Case: The Personal Assistant System

The Personal Assistant System for PWDs is based on the Act on Services and Support for Persons with Disabilities (law No. 380/1987, later the ‘Disability Service Act’). It provides financial support for PWDs to enable them to hire a personal assistant to assist them in their daily activities.

From the beginning of the enactment of the Disability Service Act, the right to retain a personal assistant has been a discretionary right, allowing the municipality to legitimately deny PWDs from getting this support by claiming the lack of resources. This has led to variation in situations among PWDs needing personal assistance depending on their place of domicile.

The problems inherent in the Personal Assistant System have constitutional dimensions as well, relating to the fact that the Disability Service Act was enacted before the constitutional reform in Finland that took place in 1995. Because of this, the Disability Service Act has not been examined from the point of view of a strong system protecting the fulfilment of the basic rights of individuals. In the context of the Personal Assistant System and PWDs, Section 19 of the Constitution of Finland (Act No. 731/1999) is particularly relevant. It regulates as follows:

“Section 19 - The right to social security

Those who cannot obtain the means necessary for a life of dignity have the right to receive indispensable subsistence and care.”

The right to receive indispensable subsistence and care means that PWDs must be provided personal assistance to enable them to live a life of dignity. Hence, the legislator has an obligation to make laws that guarantee this right, i.e. to make effective laws on the Personal Assistant System.13 Maintaining the right to a personal

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assistant as a discretionary right or a moral obligation can not be seen as effective legislation.

The goal of DPOs has been to promote change in legislation to make the right of PWDs to a personal assistant a subjective right. The pressure from organizations of PWDs to change the Personal Assistant System increased towards the end of Matti Vanhanen’s I Cabinet term (24 June 2003-19 April 2007). In particular, the Association of Employers of Personal Assistants, an organization established to advance this particular advocacy, performed intensive and sophisticated political lobbying – using the latest forms of electronic communication – of decision makers. Decision makers were contacted by telephone and in person. In autumn 2006, when the campaigning for the upcoming Parliament elections of March 2007 was very heated, a demonstration took place on the stairs of the Parliament building on 29 September 2006 to increase pressure on the Government. Another demonstration took place on 6 December 2007 (the Independence Day of Finland) using the slogan, “Independence for PWDs”. As a result of all this advocacy work, 2008 became a groundbreaking year in the development of the Personal Assistant System.

In practice, the same core group that had been active during the whole process described above negotiated intensively with the Government. It is significant that they actually negotiated. There was enough political support for the change because the negotiations were a very valuable source of information and ideas to the Government as well. The Minister for Social Affairs, Paula Risikko, led the process, which resulted in the proposal to change the law in October 2008. The proposal was accepted by the Parliament in December 2008 and the amended law came into force on 1 September 2009.

4. Forms of Advocacy: Political or Legal?

In the context of DPOs, legal advocacy and political advocacy can be distinguished as follows. In legal advocacy, both the arguments and methods used are primarily legal. This means using arguments such as “We PWDs have the constitutional right to X”, and employing
legal methods such as filing complaints to legal bodies. In political advocacy, both the arguments and methods used are primarily political. This means using arguments such as “You politicians should change the law, otherwise your political support from our group will decrease rapidly”, and employing political methods such as negotiations with politicians. The two types of advocacy are not mutually exclusive. The following analysis of the two cases reveals that these two advocacies complement each other.

In the Ugandan case, disability activists recognize the process to be political advocacy. This is due to the inseparable relationship between the NUDIPU and MPs.14 Almost all of the MPs with disabilities have a background as disability activists prior to their political positions. Therefore, even though the ideological background of the advocacy work is largely based on the human rights framework (such as the human rights-based Constitution (1995) and the Affirmative Action Policy (1989)) it is considered to be political, not legal advocacy. The advocacy for the Act did not utilize legal institutions, and thus led to the recognition of political advocacy.

“Multi-party politics” were introduced only in the national election in 2006. To some extent, this began to facilitate legal processes against the ruling party, the NRM. The Act in question was enacted during the time of nation-building, which had minimised confrontation and legal measures, particularly against the NRM. In this way, PWDs were positively included as part of an important constituency with the common goal of democratic nation-building. Only after the enactment of the Persons with Disability Act (2006) could legal advocacy means begin to be used for revealing violations of human rights against PWDs. The NUDIPU and other Ugandan DPOs have been involved in filing court cases based on the Persons with Disability Act. However, the recognition of human rights among PWDs on the grassroots level is too limited despite the NUDIPU’s great sensitisation and awareness-raising.15 Even lawyers working for PWDs try to settle cases without going to court because of resource constraints.16

16 L. Kanushu, Personal interview at Kampala, Uganda, 21 February 2008.
Purely legal advocacy, therefore, is a very recent phenomenon as well as the “last and most expensive choice” in Uganda.

In the Finnish case, DPOs had lobbied before as well to decrease regional inequalities in the implementation of the Disability Service Act, also in terms of other services and support besides the Personal Assistant System. Implementation of societal change had previously been very politically-oriented (mostly non-party). The first sign of an awakening in the field of legal advocacy came in 2005, when a prominent legal scholar Professor Kaarlo Tuori was asked by the Association of Employers of Personal Assistants to write a constitutional analysis of the Personal Assistant System and the grounds for securing a life of dignity for PWDs through that system.\(^\text{17}\) A constitutional analysis from a prominent legal scholar was not a minor event. It was a totally new way of analysing the situation of PWDs beyond the scope of the Personal Assistant System, as there had not been much written on the rights of PWDs, particularly not by professor-level legal scholars. Besides the per se importance of the analysis, the importance of disability activists asking for it was a noteworthy occurrence. It signified a move toward a more legal way of thinking about societal change, toward legal advocacy. The importance of this analysis in the whole process can not be underestimated:

> “During the fight, the analysis of Tuori acted as a cornerstone all the time. In the final stages of the fight, it was not so much marketed because its arguments were well accepted even amongst the preceding Parliament.”\(^\text{18}\)

The analysis of Professor Kaarlo Tuori can also be said to have played an instrumental role in political advocacy, which is an interesting aspect of the relationship of these two types of advocacies. The arguments of the analysis were later used in actions of political advocacy.

Following the demonstrations in 2006, people and organizations supporting the demonstrators started a new human rights-based project. They wrote a complaint to the Chancellor of Justice requesting


\(^{18}\) J. Tiri, Personal communication by e-mail on 17 April 2009.
an investigation into whether or not Matti Vanhanen’s Cabinet had neglected the development of the Personal Assistant System, even though a legal obligation for this development existed. The complaint was signed on 24 October 2006, about a month after the demonstration. Even though the organizations were serious about the legal grounds of the complaint, it was clear that the main purpose for filing the complaint was to apply political pressure on Vanhanen’s Cabinet. Although the result of the complaint was not the one DPOs had hoped for, legal machinery was used to make a change in the political sphere. Again, legal and political advocacy intertwined.

This analysis of these two cases allows us to understand that the concepts of legal and political advocacy are, in practice, intertwined. In particular, legal arguments which revolve around the human rights ideology and are based on existing laws and Constitutions have been utilized in both cases. The use of legal advocacy methods, such as the filing of complaints, is ultimately seen as a “final stage.” Even if methods of legal advocacy are used, they are disguised primarily for the purpose of obtaining additional arguments for political advocacy. Legal advocacy is, however, increasingly emphasised in both countries, particularly for the arguments it presents but also as a means to an end. An increased utilisation of legal advocacy in the future is very likely among DPOs in both countries.

5. Challenges of the Advocacy Process

In both cases, the sought for laws were realized. For the disability movement, law-making is only a process for “correcting things that had gone wrong for decades, if not centuries”. The law-making process, including the implementation of the laws, has involved a number of challenges in both countries. This part sheds light on those challenges so as to highlight the specificity of disability in

19 Mwesigye, supra note 12.
human rights advocacy work: discrimination\textsuperscript{20}, heterogeneity among PWDs\textsuperscript{21} and resource constraints.\textsuperscript{22}

First of all, severe discrimination and ignorance are a common challenge in both Uganda and Finland. In practice, this means that PWDs and DPOs are considered responsible for the needed changes because others are not well aware of their needs and rights. This causes severe stress for disability activists since they must crusade for necessary social changes for the realization of the human rights of PWDs in a discriminatory society. The personal experiences of some disability activists will be elaborated upon more in the following chapter. In the Ugandan case, the enactment of the Act presumed that the NUDIPU had already penetrated all districts to be able to elect disability councillors, which was not the case before the Act. The NUDIPU was a Kampala-based organization at that time. Nevertheless, the NUDIPU viewed this as an opportunity and created the nation-wide structure “in record time”.\textsuperscript{23} This enabled the election of the 47,000 disability councillors in time. Since many of the disability councillors were not qualified, the NUDIPU created an “empowerment package” to allow them to negotiate with others in the decision making processes. Consequently, in practice the PWDs have officially been mainstreamed in the political space; however, the empowerment of PWDs is still lagging behind.\textsuperscript{24} The policy cannot rectify discrimination.\textsuperscript{25} This has been seen to be of the biggest challenges pertaining to this Act.

In the Finnish case, DPOs have trained PWDs to take authority over their personal assistants. Being in charge over someone is not easy. It is especially difficult when one has no experience, which is usually the case when a PWD hires their first personal assistant. The

\textsuperscript{23} B. Kokhauge, Personal interview at Kampala, Uganda, 30 January 2008.
\textsuperscript{24} E. Kyozira, Personal interview at Kampala, Uganda, 7 February 2008.
Threshold Association, a human rights organization of PWDs, began to organize “Boss Training” sessions with the aim of empowering PWDs to take authority. The level of knowledge about the rights and obligations connected to being in authority was very weak in the disability community. Over the decades, the knowledge has spread, but as there are constantly new PWDs hiring personal assistants, so the training is on-going. The training is predominantly organized on a peer-support basis. In both cases, DPOs are assumed to carry a heavy responsibility for the implementation of laws.

Secondly, the human rights advocacy of DPOs means in practice that heterogeneity among PWDs has to be overcome and harmonised into one appeal. In the Ugandan case, the grouping of “PWDs” was not questioned.

“When it came to fighting for our own issues, for the issues of the people whom I’m representing, you know, we could forget those differences, and we can fight for the issues of PWDs. I think also that was very fundamental.”26

When the demographics of the elected 47,000 disability councillors were clarified after the election, the grouping of PWDs was, however, questioned. Among the elected councillors in Uganda, marginalized groups, such as the deaf27, children with disabilities and their parents28 are represented to a very limited extent or are non-existent.

In the Finnish case, many conflicts among different groups of PWDs and their organizations arose during the advocacy process. Conflicts were about disagreements on a number of definitions in the draft laws that were presented by some DPOs and the Government. Few persons with physical impairments had leadership positions in the series of activities. The time frame was too tight to obtain consensus from individual members of the organizations. One interviewee describes this phenomenon:

“I said myself all the time that we can not afford any differing views. (...) To some extent we were forced to make decisions by ourselves, 26 S. Nalule, Personal interview at Kampala, Uganda, 15 February 2008. 27 A. Murangira, Personal communication by e-mail on 13 June 2008. 28 Millward et al, supra note 7, p. 161.
we did not have the possibility to get acceptance to everything from everybody. The time frame was tight and we just needed to get the papers done – we just put a few people to work on them and the core group commented.\[29\]

The ‘civil war’ amongst DPOs and their leaders affected the public image of the whole advocacy campaign. Members of Parliament accused the demonstrators of not having the backing of the whole disability movement in Finland. This caused a lot of frustration among the demonstrators because they actually had the support of the Finnish disability movement. Disagreements that arose, some due to the diverse needs of the disabled community, were settled among a few leaders who had gained each others’ trust.

Every movement must contend with a “plurality of orientations”.\[30\] The diversity of “PWDS” is very challenging to overcome. The “effective leaders” of the disability movement have been widely recognized for moving the agenda forward.\[31\] They are central in transforming individuals from passive recipients of discrimination into agents of change.\[32\] From the aforementioned cases, we can draw the preliminary conclusion that when an advocacy project is ongoing, decisions have to be made quickly. There is no time to negotiate or to get acceptance from the individual members. This has at least three implications. First, the leaders in charge must have strong support from their organizations to withstand the turbulence relating to the advocacy, otherwise they actually lack legitimacy and others can bypass the core group and invalidate their mandate. Alternatively, collective identity formation among leaders and the maintenance of values through the movement have become important today as a form of a new social movement.\[33\] Second, the core group has to be small enough to enable a fast process in drafting and accepting the advocacy papers. This is known as “The Law of Michels’, the Iron

\[29\] M. Heikkonen, Personal communication by e-mail on 17 April 2009.
\[32\] Ibid., p. 342.
\[33\] Dowse, supra note 30, p. 125.
Law of Oligarchisation”.

Third, groups of PWDs that are traditionally in politically strong positions can not advocate successfully only by themselves. They need allies.

The implementation of law is divided into two types of obligations: the moral obligation and the binding obligation. In the Ugandan case, the negative attitude of society has hardly changed as a result of the Act. “Some still feel it is the duty of the donors to come in and help”, especially when resources are limited and when the resources required for changing a historically discriminatory society and for impairments-specific needs are extensive. One of the most essential requirements is more resources. Hence, negotiation with colleagues has been very challenging. Some district disability councillors managed to plan a budget for disability causes, but many others have received little or no resource allocation for any activities for their constituencies with disabilities. Poverty is a great challenge, as well as a good excuse for the responsible public agencies not to fulfill their duties as long as they are perceived to be mere moral obligations. As a result, very few changes have taken place in Uganda and these changes are not even monitored.

In the Finnish case, individual municipalities have implemented the personal assistant system to varying degrees and created inequality among PWDs living in different places. On a small scale, this has led to “domicile-shopping”, which means that PWDs choose their place of domicile based on where they get the best services. Thus in both the Ugandan and Finnish cases, laws are inconsistently understood as moral obligations, using the excuse of resource constraints as the primary cause.

All of these challenges are deeply rooted in the local community where PWDs live. These challenges cannot be easily addressed over a short period of time through the enactment of laws. The analysis of the challenges has made it clear that law-making is important, but it is more of a process than a goal in and of itself. These challenges

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35 Millward et al, supra note 7.
36 Mwesigye, supra note 12.
37 Millward et al, supra note 7
38 Lule, supra note 9 and Mwesigye, supra note 12.
often affect success, and too frequently the failure to implement laws also affects the lives of PWDs in both countries. At the same time, these challenges and structurally rooted causes partly explain why the disability movement must use both political and legal advocacy for making necessary changes today.

6. Personal Experiences and Human Security

Personal experiences are always involved in any type of self-advocacy as a form of social movement. Experiences of PWDs of discrimination are surprisingly similar around the globe, while personal accounts are as important. An interesting phenomenon in both cases was that personal experiences of their advocacy activities were framed very closely by the organizational level and the results of the advocacy project:

“Taking the thing forward was at some points very hectic and also tiring but at the same time also rewarding, because we got our own goals included in the law. It felt like one could actually make an impact on some issues, and that the dialogue with the legislator worked.” 39

“We fought to have a gender balance within the representation. That’s why you see we have one man and one woman at LC-5 and LC-3 [different levels of the local structure]. Those are the districts and sub-counties. Those are the gender rights that we are looking at. Those were the things that we fought for.” 40

The phenomenon described above most likely has to do with the hectic nature of the advocacy activities. People involved in the core group do not necessarily have time to reflect on their own situations and feelings during the activities. This could be very serious because it may endanger the future capabilities of the movements because the members of the core groups are likely to get tired. 41 Besides individuals getting tired, this may have the effect of reinforcing the introverted nature of the core group, because they do not have time

39  J. Keski-Korhonen, Personal communication by e-mail on 17 April 2009.
40  Nalule, supra note 26.
41  E. Akaan-Penttilä, Personal communication by e-mail on 22 April 2009 and Lule, supra note 9.
to listen to other people. On the other hand, achieving a good result from an advocacy activity has tremendous potential for empowering people, which would result in new and better advocacy activities:

“The above approach though peaceful, threatens people’s positions and authority and especially power of the mind plus other benefits associated with it. And that is where fear and insecurity about the disability movement, its activists and those involved arise. It however demands a strong heart, a heart that is guided by faith, belief and commitment to become heroes when the time comes. You possibly need to know that at a personal level commitment, especially over-commitment and over-zealousness, poses a high sense of fear and insecurity in one’s life. That said, when you achieve the intended results that have a wide impact such as has been the case in Uganda, you feel good. The challenge arises from the inability of the Movement itself to sustain the momentum which is required to maximise the benefits. This development, if not checked in time, can lead to failure, frustrations and therefore regret. You come across statements that bring out this feeling from the history of most movements and revolutions, especially when they start missing the mark and doing the unexpected. And this is the worst insecurity at both the personal and organizational level.” 42

Therefore and finally, we want to make an important link to the concept of human security and explore its significance in the context of human rights advocacy of DPOs.

The relationship between human security and human rights is very much ‘under construction’. Oberleitner 43 describes the relationship as similar to ‘porcupines in love’. Jones 44 lists developments that have reshaped the notions of security and conflict resolution and mentions as one of them the shift from a narrow focus on military security in the defence of national sovereignty to consideration of internal sources of instability such as communal strife, ethnic unrest, poverty, unemployment, crime, and terrorism.

Within the context of this article, we see human security as a notion that has to do with individuals, groups formed by individuals

42 Mwesigye, supra note 12.
and their ability and possibility to make a difference in their daily lives, not as a tool for foreign policy-making or an issue of military security. We see the empowerment and participation of persons with disabilities and their organizations as vital to increasing coherence in society, and as an important factor in decreasing conflict within society.

Human security starts from the recognition that people are the most active participants in determining their well-being. In the two cases examined here, it means that to achieve the highest possible level of human security, PWDs and their organizations need to be the key players in changing society with respect to the issues that concern them. Autonomy is also relevant to immediate family members when PWDs have severe impairments and barriers to communicate with others. Including the persons closest to the PWD is an important approach particularly in Uganda where individuals belong to a bigger core unit such as family, clan or community, which differs from the individualistic Western approach. It is common that when discussing the realization of human rights of PWDs, attention turns to the actions and omissions of the state. Almost as commonly, the state successfully pleads a lack of resources. The significance of this dialogue in the sphere of international law has little or nothing to do with individuals with disabilities on the ground. The human security of this group of people is not realized.

Human security is not achieved through multiple and complex international human rights protection mechanisms. Achieving human security is not just protecting people but also empowering people to fend for themselves. Dersso argues further that in achieving human security by empowerment it is critical to enable people to actively defend their freedoms and to develop the capacity to address insecurities.

46 Ibid.
Human security in the context of PWDs and the people closest to them can be impacted through self-advocacy activities. Conversely, this means that advocacy involvement can also jeopardise the human security of the participants and more generally the disability movement, when a set goal is not achieved. “Personal is political,” but also vice versa; “political is personal”. Performing advocacy activities, any type of them, is very much about PWDs and the people closest to them being exposed to the public domain. This has the implication that whatever happens in the public domain, be it a success or a failure, has a direct effect on the person and on the realization of his/her human security.

7. Concluding Remarks

The article has discussed different dimensions of the advocacy activities of DPOs and the connections of those to PWDs in the context of human security. We want to conclude the article with three observations on this topic.

First, the comparative discussion used in this article shows that it is important to learn from good practices and lessons learned in different contexts, because no country has ever achieved equality. By exploring two cases of advocacy activities, both similarities and differences were discovered in the utilisation of different types of advocacy activities. The ways to apply an attitude to different types of advocacy activities were naturally founded on the societal situation in a particular national context. Having said this, one could also claim that while learning from another domain is essential in developing new methodologies, direct assimilation of an idea from a totally different societal environment will most likely lead to difficulties. For example, very right-conflict-oriented types of thinking which tend to utilize pure legal advocacy in the Anglo-American world would not fit in the more consensus-oriented societal atmospheres of Uganda or Finland.

Second, different types of advocacy activities complement each other. Legal, political and any other types of advocacy activities alone do not work very effectively. All types of advocacy are needed to make societal change of this magnitude of disablism. A very
legally-oriented advocacy leaves large gaps on the political sphere, while a very politically-oriented advocacy does the same in the legal sphere. There are many more types of advocacy that bear little or no resemblance to either of the two aforementioned ones. The selected cases revealed a clear trend of DPOs’ advocacy activities to increasingly incorporate legal advocacy arguments and methods into their political advocacy work. The Convention is expected to increase this trend.

Third, we want to establish a solid connection between empowering PWDs and their organizations, utilising different types of advocacy activities, and human security. Human security can not be realized if PWDs or the people closest to them are not given the opportunity to make their own decisions, especially when PWDs have severe impairments and barriers to communicate with others. There are many tools to choose from in pursuing advocacy activities, or even in deciding to not pursue them. The most important implication with regards to achieving human security is that one is empowered to make one’s own decisions. That is an essential aspect of liberty and security.
Chapter 11:

Participatory Justice, the UN Disability Human Rights Convention, and the Right to Participate in Sport, Recreation, and Play

Janet E. Lord and Michael Ashley Stein

1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD, or the Convention),1 together with its Optional Protocol,2 imparts a human rights framework that engages the full spectrum of civil, political, economic, social and cultural rights.3 By so doing, the CRPD aims at remedying the systemic deprivation experienced by persons with disabilities throughout the world4 and seeks to make a reality the concept of participatory justice.5 Accordingly, the Convention recognizes that “individuals cannot flourish without

4 See, e.g., Gerard Quinn & Theresia Degener, Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability 2 (2002) (“People with disabilities were often virtually invisible citizens of many societies” and “have been marginalized in nearly all cultures throughout history.”); Second Annual Report on the Implementation of USAID Disability Policy 2 (2000) (noting that persons with disabilities, while comprising ten percent of the global population, account for twenty percent of the world’s poorest people).
5 “Participatory justice parallels the social model’s assertions that but for the existence of artificial barriers, people with disabilities would play an equal part in society. It also supercedes that model by asserting that a just society not only removes unneeded obstacles, but also makes participation a moral imperative.” Stein, supra note 3 at 102.
their joining with other humans in some sort of collective activities” and acknowledges that “nothing could be more essential to personality, social existence, economic opportunity—in short, to individual well-being and integration into the life of the community—than the physical capacity, the public approval, and the legal right to be abroad in the land.”

This chapter briefly recounts the detrimental exclusion of persons with disabilities from the social right to sport, recreation, leisure and play (SRLP) in human rights practice, provides an analysis of the content of CRPD Article 30(5) equal participation rights, and discusses the implications of SRLP rights for the expressive and socializing affects of the Convention.

2. Disability, SRLP Rights, and Exclusion

The general right to participate in SRLP activities has long been marginalized within international human rights instruments, most frequently as a second class right and adjunct to provisions on

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8 The term "social rights" is used variously in the literature to encompass social rights only, economic and social rights or socio-economic rights, social welfare rights or economic, social and cultural rights more generally. See Malcolm Langford, The Justiciability of Social Rights: From Practice to Theory, in Social Rights Jurisprudence 3, 3 n.1 (2009). As used herein, the term relates specifically to Article 30(5) rights, though the CRPD articulates a full range of social rights provisions (e.g., education, adequate standard of living).
employment. Nevertheless, it is well-established that the isolation of disabled persons—as well as other marginalized groups—from SRLP socialization opportunities serves to reinforce internalized oppression and disconnection from the community.

The CRPD’s drafters recognized these tendencies and responded by grafting onto the text a broad array of interpretive principles and core concepts to be applied across its provisions. In combination, these precepts seek to dismantle intransigent barriers and thereby make possible participation in all aspects of society. Yet it remains the case that the extent of isolation and exclusion of persons with disabilities in their communities is under-reported or simply not acknowledged in human rights practice.

Disability rights reporting organizations in recent years have documented persistent practices of abuse in which both adults and

12 See, e.g., David Hutchinson & Carol Tennyson, Transition to Adulthood: A Curriculum Framework for Students with Severe Disability (Further Education Unit 1986) (discussing disability oppression in the context of childhood).
13 See CRPD, supra note 1 at art. 3.
14 Gerard Quinn makes a similar point in relation to the important revisions to the European Social Charter which substantially revised the disability-related provision (Article 15) and added a non-discrimination provision (Article E). Gerard Quinn, The European Social Charter and EU Anti-discrimination Law in the Field of Disability: Two Gravitational Fields with One Common Purpose, in European Social Rights 279, 285-86 (Grainne de Burca & Bruno de Witte eds., 2005).
children with disabilities who are housed in institutional settings are
denied their rights to access to opportunities for sport, recreation or
play.\textsuperscript{16} The exclusion of children with disabilities from play and more
structured forms of recreation can stifle both mental and physical
well-being.\textsuperscript{17} Children with disabilities, even when included in educa-
tional systems, often are not appropriately accommodated.\textsuperscript{18} This
marginalization (even when inadvertent) undermines the socializing
effect of being with non-disabled peers in the classroom as well as
non-structured play periods. Indeed, reports of human rights abuses
in institutions such as mental health facilities or orphanages for chil-
dren with disabilities often document the lack of stimulation offered by
engagement in sport, recreational, and cultural activities.\textsuperscript{19} Women’s
rights organizations similarly have emphasized that in many coun-
tries the girl child with a disability is particularly deprived of attention
and nurturing within the family, and isolated from social interaction.\textsuperscript{20}
Disability rights advocacy has thus served to place SRLP rights on

\begin{itemize}
\item \textsuperscript{16} This is well-documented in each of the following reports by the international
non-governmental organization Mental Disability Rights International: Ruined
Lives: Segregation from Society in Argentina’s Psychiatric Asylums (2007);
Hidden Suffering: Romania’s Segregation and Abuse of Infants and Children with
Disabilities (2006); Behind Closed Doors: Human Rights Abuses in the Psychiatric
Facilities, Orphanages and Rehabilitation Centers of Turkey (2005); Human Rights
and Mental Health in Peru (2004); Not on the Agenda: Human Rights of People
with Mental Disabilities in Kosovo (2002); Human Rights & Mental Health: Mexico
(2000); Children in Russia’s Institutions: Human Rights and Opportunities for
Reform (1999); Human Rights & Mental Health: Hungary (1997); Human Rights &
Mental Health: Uruguay (1995) [hereinafter MDRI Reports]. Each of these reports is
\item \textsuperscript{17} There is a well-developed literature on the role of play in ensuring the
well-being of children with disabilities. \textit{See, e.g.,} Ellen M. Hamm, \textit{Playfulness
and Environmental Support of Play in Children with and without Developmental
Disabilities}, 26 Occupation, Participation and Health 88-96 (2006); Leasha M.
Barry & Suzanne B. Burlew, \textit{Using Social Stories to Teach Choice and Play Skills
to Children with Autism}, 19 Focus on Autism and Other Developmental Disabilities
\item \textsuperscript{18} Mark C. Weber, Disability Harassment 6 (2007) (cataloging school-based fail-
ures to accommodate children with disabilities, including harassment in schools,
and noting that the “[l]ack of daily contact at a level of true equality with persons with
disabilities promotes and constantly reinforces stereotypes”).
\item \textsuperscript{19} \textit{See, e.g.,} MDRI Reports, supra note 16.
\item \textsuperscript{20} DAWN Ontario (Disabled Women’s Network of Ontario), \textit{Fact Sheets on
Women with Disabilities}, available at <http://dawn.thot.net/fact.html>. In this context,
organizations such as DAWN emphasize the need to ensure that early stimulation
and intervention programs are made available to female children with disabilities.
\textit{Id.}
\end{itemize}
the human rights agenda, along with the full array of human rights to which all persons with disabilities are entitled.

3. Article 30(5) SRLP Participation Rights

The CRPD's commitment to inclusion and substantive equality in all aspects of life represents a potentially powerful response to social exclusion and its deleterious effects. Notably, Article 30 of the Convention recognizes a number of specific measures designed to enhance participation in various realms of social and cultural life.21 The CRPD comprehends that people with disabilities are full participants in their communities as professional and amateur athletes, engaged spectators, tourists, artists, musicians, scholars, and actors and audience. As such, participation in the sport, recreation and play domain—as part of the “major life activity of belonging”—is essential for fully realizing the promise of human rights enjoyment.22

The Convention’s articulation of the right of persons with disabilities to participate in SRLP activities is the fullest expression of this right in a human rights treaty.23 States must encourage and promote the inclusion of individuals with disabilities in mainstream

21 These include the duty of States to take measures to support access to places where cultural performances or services are held, such as theatres, museums, cinemas, libraries and tourism services. CRPD, supra note 1, at art. 30(1)(c). It also includes, as far as possible, access to monuments and sites of national cultural importance. Id. at 30(2). The CRPD affirms the right of people with disabilities to develop their creative, artistic, and intellectual potential for both individual and societal benefit. Id. at 30(3). Article 30 also expresses the duty of States to ensure that laws protecting intellectual property rights do not present unreasonable or discriminatory barriers in access to cultural materials by persons with disabilities. Id. at 30(3). This includes translating books and other material into Braille, providing audiocassettes or providing sign language or forms of accessible technology for artistic performances. Id. at 30(4). The right of persons with disabilities to equal recognition and support of their cultural and linguistic identity is likewise a fundamental cultural right expressed in Article 30. Id. at 30(4) and serves to further facilitate participation in society on one’s own terms including, for example, the right to use sign language as well as the recognition and support of Deaf culture.
23 See CRPD, supra note 1, at art. 30(5).
sporting activities, an approach that favors inclusive programming. Consequently, persons with disabilities have the right to enjoy equal access to sport at all levels, to recreational facilities (e.g., playgrounds and park areas), and to be reasonably accommodated in so doing. Article 30(5) likewise requires States to provide opportunities for participation in both disability-specific sport and recreation (for instance, wheelchair rugby) and mainstream sport programming (such as ice-swimming). Further, the CRPD affirms the right of persons with disabilities to organize, develop, and participate in sport and recreation with other persons with disabilities and, if they so choose, in mainstream programs. States must also take specific measures to ensure that persons with disabilities receive organizers’ services and programming. Finally, Article 30 recognizes the right of children with disabilities to play and participate in recreation, leisure and sporting activities in the school system. This includes access to playgrounds and other child-specific sport, recreation and

24 “Inclusion” in this context has been defined as “the final stage of integration of people with disabilities in sport competition or organization, in which they are involved, accepted and respected at all levels of the competition or organization.” Howard L. Nixon II, Constructing Diverse Sports Opportunities for People with Disabilities, 31 J. Sport & Social Issues 417, 419 (2007).
25 See CRPD, supra note 1, at art 30(5) (“With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures: … (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues....”).
26 See id. at art. 30(5)(a) (calling on States “[t]o encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels”).
27 See id. at art. 30(5)(b) (requiring States to take measures “[t]o ensure that persons with disabilities have an opportunity to organize, develop, and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources”).
28 See id. at art. 30(5)(e) (requiring States “[t]o ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities”); art. 30(5)(c) (requiring States to take measures “[t]o ensure that persons with disabilities have access to sporting, recreational and tourism venues”).
29 See id. at art. 30(5)(d) (calling on States “[t]o ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system”).
play venues in the community and adaptive physical education in schools.\textsuperscript{30}

Regarding the modalities of participating in SRLP activities, the reporting obligation exhorts States Parties to provide specific information that fully expresses the equality agenda. In this respect, Article 3 (General principles) must animate the reporting process.\textsuperscript{31} States should therefore provide information on a range of issues, which could include, by way of illustration: (1) whether and how persons with disabilities and their representative organizations are engaged in meaningful consultation on law, policy and programming in the areas of sport, recreation and play; (2) what legislative basis exists to guarantee Article 30(5) rights; (3) what specific measures (e.g., accessibility guidelines) have been put in place to ensure access to sporting and recreational facilities; (4) whether and how school physical education curriculum and play periods are adjusted or adapted to accommodate children with disabilities; and (5) whether and how individualized educational plans are crafted as to include sport and play for students with disabilities.\textsuperscript{32}

Last, in addition to ensuring that general principles and other articles expressing the equality framework of the CRPD are applied in relation to Article 30(5) SRLP rights, the general obligations set forth in Article 4 make clear the need to ground Convention obligations in national law, policy and programming, in consultation with

\textsuperscript{30} On adapted physical activity for children with disabilities generally, see Adapted Physical Activity (Robert Daniel Steadward et al. eds., 2003).

\textsuperscript{31} See CRPD, supra note 1, at art 35 (“1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.”). Article 3 articulates the following general principles that must be applied across the text of the CRPD. Id. at art. 3.

persons with disabilities.\textsuperscript{33} Thus, Article 4 obligations emphasize that Article 30(5) obligations must be reinforced in the domestic legislative framework.\textsuperscript{34}

4. Expressive and Socializing Effects of SRLP Rights

Participation in sporting and related activities serves as a vital channel of engagement with society for persons with disabilities when the community embraces that participation.\textsuperscript{35} Much has been written about the role that participation in SRLP activities plays in increasing the self-reliance and empowerment of persons with disabilities,\textsuperscript{36} and in providing tools to facilitate fuller community engagement in all

\begin{itemize}
\item \textsuperscript{33} See CRPD, \textit{supra} note 1, at art 4(1) (“States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake: … (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities; (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes; … (i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.”).
\item \textsuperscript{35} Expressions of the dignitarian value in participating in the life of one’s community are ubiquitous and often tied to inclusion in sport and recreational activities. Senator Robert Dole, a disabled war veteran and supporter of the Americans with Disabilities Act, stated: “Living independently and with dignity means [having the] opportunity to participate fully in every activity of daily life, be it going to the movies, dining in a restaurant, cheering at a baseball game, communicating by phone or going to the doctor.” 136 Cong. Rec. S17,376 (daily ed. July 13, 1990) (statement of Sen. Dole).
\item \textsuperscript{36} See, \textit{e.g.}, Goli Hashemi & Penny Parnes, \textit{Sport as a Means to Foster Inclusion, Health and Well-Being of People with Disabilities} (2008), available at <http://iwg.sportanddev.org>.
\end{itemize}
social realms, including education and employment. Conversely, the consequences of being denied meaningful opportunities in SRLP activities can be devastating for socialization and indeed physical and mental well-being. In this respect, the CRPD’s narrative regarding the unnecessary and amenable nature of the historical exclusion of persons with disabilities across societies can serve a vital function beyond the particular implementation of its substantive obligations in law and policy.

As we have argued elsewhere, the Convention signals the global community’s recognition that persons with disabilities have equal dignity, autonomy, and worth. Such recognition is reflected in expressive law which explores the processes whereby legal instruments affect preferences and behavior by altering social perceptions and conventions. Using expressive law criteria to analyze the CRPD, especially in the context of its SRLP provisions, suggests that the treaty can precipitate belief changes by providing information to societies about the rights of persons with disabilities. As such, its

37 As one commentator noted:

“Sport works to improve the inclusion and well-being of persons with disabilities in two ways—by changing what communities think and feel about persons with disabilities and by changing what persons with disabilities think and feel about themselves. The first is necessary to reduce the stigma and discrimination associated with disability. The second empowers persons with disabilities so that they may recognize their own potential and advocate for changes in society to enable them to fully realize it. The community impact and individual impact of sport help reduce the isolation of persons with disabilities and integrate them more fully into community life.”


38 See supra, sub-chapter ‘2. Disability, SRLP Rights, and Exclusion’.

39 See CRPD, supra note 1, at pmbl. para. k (expressing concern that “persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”).


41 See generally Alex Geisinger, A Belief Change Theory of Expressive Law, 88 Iowa L. Rev. 35 (2002).

potential for altering social mores may be fully realized through the Convention’s provisions supporting its use as an educational tool. The global community increasingly understands the potential for sport, recreation and play to serve as relational vehicles supporting a broad array of human rights ideas and rights-based interventions. The systematic removal of discriminatory and isolating barriers in social life and the equalization of opportunities in support of full participation in society is a core goal of the disability rights movement, and indeed of other minority rights agendas. An important dimension of this work has therefore included a push for the realization of participatory justice in social life. The European Union, for example, makes reference to the role of sport “as a factor for improving the quality of life, self-esteem, independence and social integration of persons with disabilities” in its 2006-2007 European Action Plan. Programming at community, national and international levels increasingly reflect an understanding that sport and recreational activities can serve as cohesion tools and conveyors of social issue messaging. The role of sport in fostering peace-building and social mobilization is also increasingly recognized. Disability sport, for example, has been effectively utilized as a tool for continued

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43 See, e.g., CRPD, supra note 1, at art. 8 (requiring States Parties “to adopt immediate, effective and appropriate measures...[t]o raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities...”). In this regard, the tools of human rights education assume an important role in fostering the expressive value of the CRPD. See, e.g., Janet E. Lord, et al., Human Rights. YES! (2007), available at <http://www1.umn.edu/humanrts/edumat/hreduseries/TB6/).

44 See, e.g., UNICEF, IMPLEMENTATION HANDBOOK ON THE RIGHTS OF THE CHILD 468 (2d ed. 2002).

45 See generally Stein, supra note 3, at 114 (“One way to view human rights is to consider them existing along a continuum that progressively extends towards marginalized groups. New instruments are thus vehicles through which to remove mistaken justifications for socially constructed exclusion.”).


48 See Charlotte McClain, Sport for Inclusive Development!, in UN SPORT, supra note 37, at 20, 21.

national reconciliation in Cambodia. Likewise, celebrations in recognition of International Day of Disabled Persons have often been marked by disability rights awareness events in which sporting events are key platforms.

The meaningful application of SRLP rights to the lives of persons with disabilities works to identify how persons with disabilities can be included in ways that promote individual as well as community empowerment and development. Inclusion under the model envisioned by the Convention also requires participation in the selection of appropriate sporting and recreational activities and roles within sport (e.g., as spectator or competitor) in line with particular, individualized motivations, interest and talents and, clearly, in consultation with people with disabilities themselves and their representative organizations. As one commentator has argued persuasively in the context of supporting fairness and participation in sport, developing inclusive models of sport options for disabled athletes opens options for all, including “able-bodied people who find the existing sports opportunity structure inaccessible or unappealing.”

The role that media plays in and around sporting, recreational and play opportunities is also an important factor in combating—or all too

50 See Sport for Development and Peace Working Group, Sport League Drives Reintegration of Disability Community in Cambodia (on file with authors) (detailing the success story of the National Standing Cambodian Volleyball League). For more on the team, see the League website, available at <http://www.standupcambodia.org>.
52 It should be underscored that designating participation as a general principle in Article 3 and consultation with persons with disabilities and their representative organization as a general obligation in Article 4(3), require application to Article 30. CRPD, supra note 1, at arts. 3(c), 4(3).
53 Nixon, supra note 24, at 430.
frequently, reinforcing—disability discrimination and stereotyping.\textsuperscript{54} Public media serves to shape popular conceptions about disability and ideas about the capacity of people with disabilities to be competent in various types of sporting and cultural activities.\textsuperscript{55} Scholars working in the area of disability sport have argued that the visibility of an increasing number of successful athletes with disabilities in the mainstream could help to transform negative stereotypes about disability, persons with disabilities and the sporting body.\textsuperscript{56} This idea is certainly expressed in the disability advocacy strategy of holding community sporting events hosted by DPOs and disabled participants to raise the image and voice of people with disabilities in their societies.\textsuperscript{57}


\textsuperscript{55} Karen Depauw, for example, has argued that the association of disability and sport compels a redefinition of athleticism and notions of the body according to which sport is socially constructed as an exclusive activity of the able-bodied participant. See Karen P. Depauw, \textit{The (In)visibility of Disability: Cultural Context and “Sporting Bodies,”} Quest 416-430 (1997); see also Karen P. Depauw & Susan J. Gavron, \textit{Disability Sport} (2005); Karen P. Depauw, \textit{Girls and Women with Disabilities in Sport}. 70 J. Phys. Ed. Rec. & Dance (1999).

\textsuperscript{56} See, e.g., David Promis, Nirmala Erevelles & Jerry Matthews, \textit{Reconceptualizing Inclusion: The Politics of University Sports and Recreation Programs for Students with Mobility Impairments}, 18 Soc. Sport J. 37 (2001) (arguing that people with disabilities need to be seen as athletes regardless of their impairment, which requires a reconceptualization of the sporting body).

\textsuperscript{57} In 1997, the theme for December 3 was Arts, Sports and Disabilities and the UN focused its celebration efforts that year on the achievements and contributions of artists and athletes with disabilities. Regarding the events, the UN stated: “Arts and sports play a vital role in preparing people with disabilities for learning and career success. Participation nurtures the independence and self-worth of persons with disabilities and contributes to the cultural and economic life of their communities. This, in turn, can help bring about positive changes in public attitudes.” United Nations Disabled Persons Bulletin No. 3 of 1997, Secretary General’s Message, available at <http://www.un.org/esa/socdev/enable/disb973b.htm>.
In sum, Article 30 of the CRPD is a core component of realizing the substantive equality vision of the disability rights project. The explicit coupling of non-discrimination and the reasonable accommodation mandate together with the requirement that they be applied across the CRPD, inclusive of social rights, represents the clearest and strongest legal expression of SRLP rights in international human rights law. Given that the social rights of sport, recreation and play occupy a remote position on the human rights playing field, and considering the marginalization of disability rights within the human rights system generally, the challenge of applying CRPD rights, well-explicated though they are, is considerable.

5. Conclusion

The Convention recognizes that the effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, and SRLP rights, along with access to public places and services and the basic necessities of life to maintain an adequate standard of living. The obligation in the face of persistent discrimination 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. States Parties to the CRPD thus must do more than merely abstain from taking measures which might have a negative impact on their citizens with disabilities. Significantly, the equality framework set forth in the CRPD has the potential to transform social rights claims in the realm of cultural life and sport that the
European Court of Human Rights has viewed with skepticism. As noted by Colm O’Cinneide, the emerging disability jurisprudence of the European Social Charter is suggestive of the direction that the CRPD Committee might take in the application of ESC rights.

The CRPD represents a significant advance in the expression of SRLP rights. The potential for the CRPD to generate a rich substantive equality jurisprudence is evident not only in its fusion of reasonable accommodation and positive measures to all substantive rights including SRLP rights, but also in view of the general principles that further inform the interpretation of the Convention, giving additional meaning and texture to disability rights claims. The principle of participation, for example, requires the participation of people with disabilities (along with other stakeholders) in decision-making processes generally, including all level of political decision-making, as well as processes of societal reconstruction, so that they may claim

58 See, e.g., Botta v. Italy, 26 EHRR 241 (1998). In the Botta case, an applicant with a disability was unable to access the beach and sea at a private beach resort, notwithstanding the requirement to provide facilities for disabled persons under Italian law. The applicant had to rely on Article 8 (privacy, family life) and Article 14 (non-discrimination) under the European Convention on Human Rights in order to press his claim. The Court held that the right to access the beach and sea at a location some distance from the applicant’s normal place of residence did not fall within the scope of Article 8, nor indeed the general parameters of Article 14. The Court reasoned that there was an insufficient “direct and immediate link” between the entitlement claimed and the right asserted. In other words, access to general amenities was not a direct enough link to the enjoyment of the core right. In offering a stand-alone right to participate in cultural life, sport, recreation and leisure, the CRPD offers promise for supporting social rights premised on the failure to make positive provision to render rights meaningful. See also Zehnalova and Zehnal v. Czech Republic, Application No. 38621/97, Decision of 14 February 2002, ECtHR (holding that the entitlement claimed by the applicants premised on Article 8 and Article 14 in relation to lack of access to many public buildings in violation of Czech law did not fall within the general ambit of Article 8 so that neither Article 8 or Article 14 were applicable).


60 See CRPD, supra note 1, at arts. 5, 9. It should be noted that specific provisions of general application across the CRPD are also reflected in art. 6 (Women with disabilities) and art. 7 (Children with disabilities), thereby providing richer context to the principle of equality between men and women and the principle of “respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities” in art. 3 (General principles).
their rights. To comply with this framework, States must collaborate in policy design, implementation, enforcement, and monitoring with people with disabilities, their families, advocates and organizations, as well as other aspects of civil society. This will ensure a sense of ownership among those citizens targeted by the process. Including disabled persons also makes it more likely that the policies enacted will accurately reflect their social conditions, and have greater impact on their daily lives.

Finally, by assuring the inclusion and equality of persons with disabilities within a robust equality framework that animates SRLP rights, the CRPD provides a conceptual model for the empowerment of other socially excluded groups, such as ethnic minorities, women, and people living in poverty, through sport and related activities. It also provides impetus for the more progressive development of disability rights in the jurisprudence of other bodies, such as the European Court of Human Rights, among others, which have tended to marginalize disability rights as well as the social rights claims of disadvantaged groups.

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61 See CRPD, supra note 1, at arts. 4(3), 29.
62 Id.
63 The connection between the disability rights framework under the CRPD and the application of substantive equality in respect of the rights of other marginalized groups is apparent. First, the group classified as ‘disabled’ often overlaps significantly with other socially marginalized groups, such as people living in poverty. Second, because the equality and non-discrimination framework laid out in the CRPD focuses on individual needs, States may apply this model to develop the individual talents of other excluded groups who have failed to realize their ESC rights against a formal and thus limited equality framework. Note, however, that some scholars hold the view that the substantive equality model proffered by the CRPD falls short of a more progressive ‘universal’ model, insofar as it mirrors a minority rights conception which still tries to channel disabled people into the normalcy fold. See generally Rosemary Kayess & Philip French, Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities, 8 Hum. Rts. L. Rev. 1 (2008).
64 See discussion, supra note 58.
Chapter 12:

Mental Health Law and Human Rights: Evolution, Challenges and the Promise of the New Convention

Michael Perlin and Éva Szeli

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1. Introduction

As recently as fifteen years ago, disability was not broadly acknowledged as a human rights issue. Although there were prior cases decided in the United States and in Europe that, retrospectively, had been litigated from a human rights perspective\(^1\) the characterization of “disability rights” (especially the rights of persons with mental disabilities) was not discussed in a global public, political or legal debate until the early 1990s. Instead, disability was seen only as a medical problem of the individual requiring a treatment or cure. By contrast, viewing disability as a human rights issue requires us to recognize the inherent equality of all people, regardless of abili-

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\(^1\) See e.g., O’Connor v. Donaldson, 422 U.S. 563 (1975) (unconstitutional to confine a nondangerous person capable of surviving safely in freedom to a mental hospital); Wyatt v. Stickney, 325 F.Supp. 781 (M.D. Ala. 1971); aff’d sub. nom. Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974) (persons with mental illness have constitutional right to adequate treatment in mental hospital); Lessard v. Schmidt, 349 F.Supp. 1078 (E.D. Wis. 1972) (a statute that fails to provide person alleged to be mentally ill with adequate procedural safeguards is unconstitutional)); Winterwerp v. the Netherlands (1979) 2 EHRR 387.(detention on grounds of unsoundness of mind must be based on objective medical evidence of a true mental disorder, be a proportionate response and be carried out in accordance with a procedure prescribed by law); see generally, 1 & 2 Michael L. Perlin, Mental Disability Law: Civil and Criminal, chapters 2 & 3 (2d ed. 1998), (2d ed. 1999).
ties, disabilities, or differences, and obligates society to remove the attitudinal and physical barriers to equality and inclusion of people with disabilities.  

In this chapter, we seek to provide a selective overview of some key developments and issues in the mental disability rights area. First, we discuss the path via which disability rights have finally, and tardily, become seen as human rights issues. Next, we look at the newly-ratified UN Convention on the Rights of Persons with Disabilities and consider the expansion of human rights in disability law in an international context. We then turn to the role of sanism, and explain why that must be “center stage” in any consideration of these issues. Following that, we discuss how sanism, pretextuality and international human rights must all be studied together to make sense of this entire subject matter area. We end with some brief conclusions.

2. Disability Rights Have At Last Been Recognized as Human Rights

Remarkably, the issue of the human rights of people with disabilities, particularly people with mental disabilities, had been ignored for decades by the international agencies vested with the protection of human rights on a global scale. Early developments in global international human rights law following World War II -- and the various forms of human rights advocacy that emerged in the decades that followed -- failed to focus on mental disability rights. In 1991, the General Assembly adopted the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental

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2 The first section of this article is adapted from Michael L. Perlin et al, International Human Rights and Comparative Mental Disability Law 3-7 (2006).

3 There is no single, universally-accepted definition of “mental disabilities.” The terminology varies from country to country, jurisdiction to jurisdiction, and even document to document. In this chapter, we use “mental disabilities” to encompass both psychiatric disorders and intellectual disabilities.
Health Care (widely referred to as the “MI Principles”). The MI Principles established the most comprehensive international human rights standards for persons with mental disabilities, and their adoption was a critical global step in recognizing mental disability rights issues within the human rights arena.

Historically, mainstream human rights protection systems and advocacy organizations had difficulty acknowledging mental disability rights as part of their mandates. The human rights issues encountered by persons with mental disabilities may have been perceived as too complex or esoteric. This challenge was sometimes articulated in rather unfortunate ways, such as “We work in human rights, not mental disability rights.” While the oblique suggestion that people with mental disabilities were not “human” was generally unintended, it may well have reflected deep-seated beliefs that they were somehow less human than the broader population whose human rights merited unquestioned protection. But while human rights are - by definition - universally possessed by all humans, the formal recognition of the applicability of these rights in contexts specific to vulnerable populations is critical for their enforcement.

To some extent, this new interest in human rights protections for people with disabilities echoes a larger international movement to

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5 Variations on such a statement have been encountered by the authors and their colleagues in discussions with human rights organizations across the globe, on practically every continent.


> When I have shared with others our vision of [doing mental disability law advocacy work and teaching on-line mental disability law courses] in sub-Saharan East Africa, those others have often scoffed, suggesting that the problems faced in that part of the world are so profound that it is almost frivolous to create the programs we are seeking to launch. As you might expect, I disagree, profoundly.
protect human rights, and appears to more precisely follow track C. Raj Kumar’s observation that “the judicial protection of human rights and constitutionalization of human rights may be two important objectives by which the rule of law can be preserved and which may govern future human rights work”.

To be sure, some of the results to date have been modest. Few will quarrel with Douglass Cassel’s observation that “[t]he direct impact of international human rights law on practice in most of the world remains weak and inconsistent.” But, as Cassel perceptively noted further:

“Both this incipient body of law, and to a lesser degree its direct and even more its Indirect influence on conduct, have grown rapidly in historical terms, and appear to be spreading in ways that cannot be explained by a worldview based solely on state power and rational calculations of self-interest. To appreciate its effectiveness and potential, international human rights law must be understood as part of a broader set of interrelated, mutually reinforcing processes and institutions—interwoven strands in a rope—that together pull human rights forward, and to which international law makes distinctive contributions.”

Thus understood, international law, Cassell concluded, “can be seen as a useful tool for the protection of human rights, and one which promises to be more useful in the future.”

Within the legal literature, the first time disability rights was directly conceptualized as a human rights issue may have been as recently as 1993. In their groundbreaking article, Eric Rosenthal and Leonard

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Rubenstein applied international human rights principles to the institutionalization of people with mental disabilities.\(^\text{10}\)

Meanwhile, regional human rights courts across the globe had begun to exhibit an increasing willingness to address mental disability rights issues. In 1979, over a decade earlier, the European Court of Human Rights had already heard its first mental disability rights case, Winterwerp v. Netherlands\(^\text{11}\), under the European Convention of Human Rights.\(^\text{12}\) Over the following decades, the European Court heard dozens of mental disability rights cases, defining and refining the contours of human rights as applied in mental health contexts under the European Convention.\(^\text{13}\) In the Americas, the Inter-American Commission on Human Rights heard its first mental disability rights case, Victor Rosario Congo v. Ecuador\(^\text{14}\), under the American Convention on Human Rights\(^\text{15}\) in 1999, breaking new ground in formalizing the use of the MI Principles as a guide for interpreting and applying binding human rights standards. And subsequently, in 2003, the African Commission decided its first mental disability rights case, Purohit and Moore v. The Gambia\(^\text{16}\), under the African Charter.\(^\text{17}\) All of this case law has served to validate the connection between mental health and human rights, providing

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regional fora for recognizing and enforcing the human rights of individuals labeled with mental disabilities.\textsuperscript{18}

However, during the late 20th century, much of the mental disability rights advocacy occurred outside of formal legal settings. Local, regional, and international non-governmental organizations conducted investigations, wrote reports, and brought media attention to egregious human rights abuses suffered by people labeled with mental disabilities.\textsuperscript{19} Most significantly, the emergence of a “consumer movement” supported the natural advocacy capacities of stakeholders. By definition, the focal point of the mental disability rights movement is, or certainly should be, individuals who are identified as having mental disabilities. Yet, historically, their voices were often ignored, while others deemed to speak for those who purportedly could not speak for themselves. Referring to themselves as consumers, users, ex-users, ex-patients, or survivors of mental health services, individuals who had been labeled with mental disabilities began to organize not only locally, but also regionally and globally.\textsuperscript{20} Such self-advocacy groups have since become instrumental in iden-

\textsuperscript{18} We cannot fall into the trap of assuming that, simply because a court issued a decision, that conditions in institutions immediately changed or that procedural safeguards were immediately instituted in response to such decisions. The history of mental disability law is all too often the history of “paper victories,” and even the most rights-protective court decisions may be slow to produce significant real-life changes. See \textit{infra} note 53.


MDRI’s work has continued to gain momentum into the new century, with additional investigations and reports, including Mental Disability Rights International, Torment Not Treatment: Serbia’s Segregation and Abuse of Children and Adults with Disabilities (2007); Mental Disability Rights International, Ruined Lives: Segregation from Society in Argentina’s Psychiatric Asylums (2007).

\textsuperscript{20} Examples include, but are not limited to, the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP), and the World Network of Users and Survivors of Psychiatry (WNUSP). For discussions of US-based groups, see \textit{infra} notes 46-47.
tifying violations of their human rights, and in advocating reform in the policies and systems that directly affect their lives.21

3. A Challenge Remains: Fighting “Sanism”

There has always been great ambivalence on the part of the human rights community in its perception of the rights of persons with mental disabilities, and the value of those rights. We believe that the explanation for the roots of this ambivalence can be found in what we call “sanism” and what we call “pretextuality.” It is critical, we believe, for those seriously interested in this topic to understand these concepts and how their malignancy has distorted all aspects of mental disability law, domestic and international.

“Sanism” is an irrational prejudice of the same quality and character of other irrational prejudices that cause (and are reflected in) prevailing social attitudes of racism, sexism, homophobia, and ethnic bigotry. It permeates all aspects of mental disability law and affects all participants in the mental disability law system: litigants, fact finders, counsel, expert and lay witnesses. Its corrosive effects have warped mental disability law jurisprudence in involuntary civil commitment law, institutional law, tort law, and all aspects of the criminal process.22

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rights lawyer Florynce Kennedy has characterized as the “pathology of oppression.”

“Pretextuality” defines the ways in which courts accept (either implicitly or explicitly) testimonial dishonesty and engage similarly in dishonest (and frequently meretricious) decisionmaking. It is especially poisonous where witnesses, especially expert witnesses, show a “high propensity to purposely distort their testimony in order to achieve desired ends”. This pretextuality infects all participants in the judicial system, breeds cynicism and disrespect for the law, demeans participants, and reinforces shoddy lawyering, blasé judging, and, at times, perjurious and/or corrupt testifying.

In previous works, one of us (MLP) has explored the relationships between sanism and pretextuality in matters involving, inter alia, competency to stand trial, sexual autonomy, the right to refuse treatment, “autonomous decisionmaking,” the Americans

29 E.g., Michael L. Perlin, “Make Promises by the Hour” : Sex, Drugs, the ADA, and Psychiatric Hospitalization, 46 DePaul L. Rev. 947 (1997).
with Disabilities Act,\textsuperscript{30} competency to plead guilty or waive counsel,\textsuperscript{31} jury decisionmaking in death penalty cases,\textsuperscript{32} and the bar’s attitude towards mentally disabled counsel.\textsuperscript{33} But, these factors can be even more pernicious as they relate to the job that lawyers do when they represent persons with mental disabilities in court proceedings. Writing about this latter topic six years ago, one of us (MLP) alleged:

“Sanism permeates the legal representation process both in cases in which mental capacity is a central issue, and those in which such capacity is a collateral question. Sanist lawyers (1) distrust their mentally disabled clients, (2) trivialize their complaints, (3) fail to forge authentic attorney-client relationships with such clients and reject their clients’ potential contributions to case-strategizing, and (4) take less seriously case outcomes that are adverse to their clients.\textsuperscript{34}"

\textsuperscript{34} Perlin, Lepers, supra note 22, at 695.
4. Sanism, Pretextuality, and International Human Rights

There is now some nascent literature on the relationship between sanism, pretextuality and international human rights law,\textsuperscript{35} especially focusing on circumstances in nations with developing economies.\textsuperscript{36} For example, an analysis of the European Commission on Human Rights\textsuperscript{37} concluded that it has interpreted the European Convention on Human Rights “very restrictively in psychiatric cases.”\textsuperscript{38} The cases included in this analysis, which characterize the handcuffing


of patients as “therapeutically necessary,” or sanction the use of seclusion for “disciplinary” purposes, certainly bespeak pretextuality. It is essential that such pretextuality be identified and answered. This is especially timely in light of the ratification of the new UN Convention. The Convention’s focus on questions of empowerment forces us to consider whether the legal system will continue to perpetuate the sort of sanism and pretextuality that has had such a negative impact on the lives of persons with mental disabilities, and will continue to condone teleological judicial behavior through overreliance on cognitive-simplifying heuristics.

As discussed above, although there is a robust “psychiatric survivor” movement both in the United States and elsewhere, this

41 It should be underscored that there have been many decisions about many aspects of substantive and procedural civil commitment law in the ECHR and other bodies. These decisions, however, by themselves, have not created a robust corpus of international human rights law.
44 See e.g., Michael L. Perlin, “His Brain Has Been Mismanaged with Great Skill”: How Will Jurors Respond to Neuroimaging Testimony in Insanity Defense Cases? 42 Akron L. Rev. 885, 891-92 (2009), discussing the dominance and the power of the vividness heuristic, a cognitive-simplifying device through which a “single vivid, memorable case overwhelms mountains of abstract, colorless data upon which rational choices should be made,” see Michael L. Perlin, “The Borderline Which Separated You From Me “: The Insanity Defense, the Authoritarian Spirit, the Fear of Faking, and the Culture of Punishment, 82 Iowa L. Rev. 1375, 1417 (1997).

By teleological, we refer to outcome-determinative reasoning; social science that enables judges to satisfy predetermined positions are privileged, while data that would require judges to question such ends are rejected or subordinated. See e.g., Perlin, The Case of Competency, supra note 26.
voice is typically ignored. For at least 25 years, formerly-hospitalized individuals and their supporters have formed an important role in the reform of the mental health system and in test case litigation. “Yet, there is little evidence that these groups are taken seriously either by lawyers or academics.”

46 But see, Perlin, Lepers, supra note 22, at 700 n. 90:


Survivors, on the other hand, were an important voice in the drafting of the UN Convention. See e.g., News about the MFI Global Campaign Committee, available at http://www.mindfreedom.org/campaign/global/news-about-the-mfi-international-campaign-committee (Accessed January 26, 2008) (discussing role of MindFreedom in enabling “psychiatric survivors enter the UN to participate in international negotiating sessions about the human rights of people labeled with disabilities”). For an early discussion of the role of such groups in the UN drafting process, see Theresia Degener, International Disability Law - A New Legal Subject on the Rise: The Interregional Experts’ Meeting in Hong Kong, December 13-17, 1999, 18 Berkeley J. Intl. L. 180, 189 (2000).

47 Perlin, Lepers, supra note 22, at 699-700 (footnotes omitted). See also, Perlin, Social Change, supra note 36, at 444 n. 39:

[S]urvivor groups generally have opposed the constitutionality or application of involuntary civil commitment statutes, see, e.g., Project Release v. Prevost, 722 F.2d 960 (2d Cir. 1983), or supported the right of patients to refuse the involuntary administration of psychotropic drugs, see Rennie v. Klein, 653 F.2d 836, 838 (3d Cir. 1981) (Alliance for the Liberation of Mental Patients, amicus curiae), but also have involved themselves in a far broader range of litigation. See, e.g., Colorado v. Connelly, 479 U.S. 157 (1986) (impact of severe mental disability on Miranda waiver; Coalition for the Fundamental Rights and Equality of Ex-patients, amicus). The involvement of such groups in test case litigation—exercising the right of self-determination in an effort to control, to the greatest extent possible, their own destinies, see, e.g., Judi Chamberlin, On Our Own: Patient-Controlled Alternatives to the Mental Health System (1978)—is a major development that cannot be overlooked by participants in subsequent mental disability litigation.
In the civil commitment context, any sanism-inspired blunders by lawyers can easily be fatal to the client’s chance of success.48 If a lawyer rejects the notion that his client may be competent (indeed, if s/he engages in the not-atypical “presumption of incompetency” that is all too often de rigeur in these cases),49 the chances are far slimmer that s/he will advocate for such a client in the way that lawyers have been taught - or, at the least, should be taught - to advocate for their clients. In nations with no traditions of an “expanded due process model”50 in cases involving persons subject to commitment to psychiatric institutions or those already institutionalized, sanism in lawyers can be fatal to an individual’s chance for release or for a judicial order mandating amelioration of conditions of confinement and/or access to treatment and/or to be free from unwanted treatment interventions.51

48 One of the core factors of comparative mental disability law is the abject lack of counsel made available to persons facing involuntary civil commitment:

Neither counsel nor judicial review is present in most of the world’s mental disability law systems. It is rare for even minimal access to counsel to be statutorily (or judicially) mandated, and, even where counsel is legislatively ordered, it is rarely provided. Moreover, the lack of meaningful judicial review makes the commitment hearing system little more than a meretricious pretext.

Perlin, Universal Factors, supra note 35, at 342. See also generally, Perlin, Global Clinical Education, supra note 36.

49 Michael L. Perlin, Therapeutic Jurisprudence and Outpatient Commitment: Kendra’s Law as Case Study, 9 Psychol. Pub. Pol’y & L. 183, 193 (2003) (“In short, the presumption in which courts have regularly engaged—that there is both a de facto and de jure presumption of incompetency to be applied to medication decision making -appears to be based on an empirical fallacy: psychiatric patients are not necessarily more incompetent than nonmentally ill persons to engage in independent medication decision making”) (footnote omitted).

50 See Michael L. Perlin, “Make Promises by the Hour”: Sex, Drugs, the ADA, and Psychiatric Hospitalization, 46 DePaul L. Rev. 947, 971 (1997).

51 This analysis and critique are not leveled solely at the practice in the United States. See e.g., Perlin, Global Clinical Education, supra note 36 (discussing lack of adequate counsel in civil commitment cases in almost all nations), and Perlin, Universal Factors, supra note 35 (discussing the significant number of nations in which there is no provision of counsel to individuals facing civil commitment).
5. Conclusion

The legislative and judicial creation of rights, both positive and negative, is illusory unless there is a parallel mandate of counsel that is (1) free and (2) regularized and organized.\(^{52}\) Without the presence of such counsel, any rights articulated by a court or human rights commission or legislature become merely “paper victories.”\(^{53}\) Further, to be authentically effective, counsel needs to be available both for individual cases (in which commitment, initial or extended, of the patient is being sought) and in “affirmative” cases (that is, cases consciously thought of as “public interest” or “law reform” cases in which persons with disabilities file suit as plaintiffs seeking variably to have courts articulate procedural and/or substantive due process rights in the commitment process,\(^{54}\) or to have courts articulate such rights with regard to conditions of confinement, the latter cohort encompassing both positive rights, e.g., a right to treatment services,\(^{55}\) and negative rights, e.g., the right to refuse treatment).\(^{56}\)

\(^{52}\) See generally, Perlin, supra note 1, chapter 2B; Perlin, Global Clinical Education, supra note 36.


\(^{54}\) E.g., Lessard v. Schmidt, 349 F.Supp. 1078 (E.D. Wis. 1972) (a statute that fails to provide person alleged to be mentally ill with adequate procedural safeguards is unconstitutional).

\(^{55}\) E.g., Wyatt v. Stickney, 325 F.Supp. 781 (M.D. Ala. 1971); aff’d sub. nom. Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974) (mentally ill have constitutional right to adequate treatment in mental hospital).

\(^{56}\) E.g., Rennie v. Klein, 653 F.2d 836 (3d Cir. 1981) (patients with mental illness committed involuntarily retain their constitutional right to refuse antipsychotic drugs).

On the role of counsel in mental disability/law reform cases in general, see 1 Perlin supra note 1, chapter 2B. Without the presence of effective counsel, substantive mental disability law reform recommendations may turn into ‘an empty shell.’ Perlin, Best Friend, supra note 28, at 748.

Lawyers have significant advocacy roles beyond their work in the courtroom, and the importance of these roles is magnified in areas of law such as this that are so under-litigated (as the body of caselaw is so thin as to be evanescent in many nations). A fuller discussion of this important issue is beyond the scope of this chapter.
An argument can certainly be made that the presence of sanism (a factor that affects lawyers, even those active in the clinical movement\(^\text{57}\) in the same ways that it affects others) and the additional technical complexity of involuntary civil commitment cases (involving, necessarily, expert testimony by mental health professionals and subtle predictions about “future dangerousness”)\(^\text{58}\) that the gap would be even wider in such cases. In arguing why the United States should ratify the new UN Convention, Tara Melish focused on the “deeply entrenched attitudes and stereotypes about disability that have rendered many of the most flagrant abuses of the rights of persons with disabilities ‘invisible’ from the mainstream human rights lens”.\(^\text{59}\) These stereotypes are the essence of sanism; vigorous, advocacy-focused counsel is needed to answer and rebut them.


\(^{58}\) See generally, 1 Perlin, supra note 1, Chapter 2A.

Chapter 13:

Persons with Deafblindness in Light of International Agreements

Riku Virtanen

1. Introduction

Most people use vision and hearing to know about the world, to gather information and communicate, and to travel from place to place. Persons with deafblindness do not have the same sensory means to achieve these goals, and they encounter barriers to a high quality of life, including lack of access to communication\(^1\), stereotyping\(^2\) of persons with deafblindness and the effects of years of neglect and isolation.

In many developing countries, fewer than 10 percent of children with disabilities have access to education. For those who are deafblind, the number of unserved is considerably higher. Because of the lack of basic education, most persons with deafblindness are unemployed and isolated from their community. There are organizations for the deaf\(^3\) and visually impaired\(^4\) in many countries. However, persons with deafblindness are a group with multiple disabilities, and they have their own needs. Because of the small number of persons with deafblindness, there are only a very few national deafblind associations in the world. The World Federation of the Deafblind (WFDB) is a worldwide organization of persons with disabilities, and as such according to the CRPD, this civil society should be involved in decision-making processes.

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2 T. Sutherland, *Disabled We Stand* (Souvenir Press, 1981), Chapter 6.

The first significant agreement pertaining to human rights was the Universal Declaration of Human Rights sixty years ago. The Declaration has since then been followed by other United Nations agreements. After the creation of conventions for women, children and migrant workers, it was observed that persons with disabilities had been totally forgotten. In 2001, the General Assembly of the United Nations decided to take action in order to create an agreement for persons with disabilities. Negotiations were begun, and the organizations of persons with disabilities were invited to co-operate in doing the preparation work. Finally, representatives of these organizations worked as specialists in the negotiations concerning disability issues.

This is how the deafblind received an agreement called Convention on the Rights of Persons with Disabilities (CRPD). There is a fairly common agreement amongst deafblind persons. When 192 governments, cultures and systems have to agree, the result will always be a compromise. In this article, I will deal with the United Nations CRPD and give some examples. I will also describe the impact it has had or should have on the work of persons with deafblindness as well as on the work of related professionals. While there have been discussions about deafblind persons, there have been no discus-

sions about the people with deafblindness themselves. As you can see from the title of the article, the theme is people, not deafblindness. The term “deafblind person” refers to the disability and, from this point of view, deafblind people are seen as patients of doctors. On the other hand, the term “person with deafblindness” refers to an individual who has rights and obligations of his or her own.\textsuperscript{10}

The Convention is an official and legal document. Therefore deafblind persons now have a document which has been signed by the General Assembly of the United Nations and over a hundred countries. A signature means that the State in question accepts the contents of the agreement. At the moment, the matters dealt with by the Convention are being incorporated into national legislation. As soon as this process is over, the Convention will be ratified. So far it has been ratified by over 50 States. Since being ratified by the 20th State, the Convention has been legally binding for each State.

The ratification of the agreement can be accomplished in two ways.\textsuperscript{11} The ratification process may occur first and be followed by the adaptation of the agreement to domestic legislation. However, most Nordic countries seem to have acted in the opposite manner. They first adapt the agreement to their domestic legislation, and then ratify the Convention. It is irrelevant which of these two processes is chosen; the important thing is that deafblind persons are there, taking part in the process. If deafblind persons are not, deafblind persons as a small group with special needs will be forgotten. The Convention includes provisions concerning monitoring and implementation.\textsuperscript{12} Traditionally, all too often professionals have decided

what the best choice is for persons with disabilities. Nowadays the trend is that persons with deafblindness will be heard, but only if they, in the role of decision-makers, are involved in the appropriate decision making processes.\textsuperscript{13}


First, I will discuss Article 12, entitled “Equal recognition before the law”. In this Article, the question concerns legality, not only morality. This is the basis of the Convention, a turning point in attitudes towards persons with deafblindness. In short, deafblind persons are no longer objects, recipients of care and charity\textsuperscript{14} who need help from society. No longer must persons with deafblindness talk about “strong shoulders” needed to support the disadvantaged. What are such “strong shoulders”? Persons with deafblindness are as strong and capable as others.\textsuperscript{15}

Accessibility\textsuperscript{16} is not the only theme of the Convention, although many articles do deal with it. Furthermore, in the Nordic countries, there is a common misunderstanding that the Convention only deals with non-discrimination. Although non-discrimination is part of legislation in many countries\textsuperscript{17}, the question is more often about morality


\textsuperscript{15} J. Swain \textit{et al} (eds.), Disabling Barriers – Enabling Environments (Sage Publications 2004).


\textsuperscript{17} A-M, M. Cotter, This Ability. An International Legal Analysis of Disability Discrimination (Ashgate Publishing, 2007).
and attitudes. The Convention deals with people before the law, their rights and obligations.

Many persons with deafblindness do not understand anything about legislation. Since birth, persons with deafblindness often have many other functional limitations as well. It is difficult for them to understand that they are now legally capable and equal to other people in all sectors of life. For instance, they have the right to sign official documents, to have a private household, to inherit, to become elected, to marry and to have children. In short, they possess the same rights as anyone else.

This was one of the most difficult issues during the negotiations of the Convention. What should professionals do if they think that persons with deafblindness are not able to make decisions for themselves or do not understand what a given issue is about? Should they make the decision on behalf of a person with deafblindness, assuming that professionals know better? In these sorts of matters, indeed, proficiency is needed. Therefore Section three of the Article guarantees one the provision of appropriate support, which might be necessary when exercising one’s legal capacity. Unfortunately Section three is not generally enacted exactly how the support should be.

This next segment discusses the general principles of the Convention. These are respect for inherent dignity; individual autonomy including the freedom to make one’s own choices and the independence of persons.

As to persons with deafblindness, these principles are hard to comply with, because both persons with deafblindness since birth and persons with deafblindness for some other reason are dependent upon others. So, instead of a person with deafblindness having to plead for him- or herself, it is now required that a person with deafblindness be supplied with support.

The right to take risks is the only thing that persons with deafblindness did not manage to include in the Convention. As persons with deafblindness are entitled to make their own decisions, persons

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with deafblindness should also have the right to make mistakes. Unfortunately, this idea did not go through. A person with deafblindness makes lots of mistakes, and when s/he works, s/he also makes mistakes. However, the biggest mistake would be to not do anything at all.

Another basic principle is non-discrimination, and, of course, full and effective participation and inclusion in social life. There is also another psycho-cultural problem: attitudes should be changed. All of us have an ideal in our minds about what we would like to be: rich, young, healthy, seeing, hearing, running and always in the right place. In thinking like this, we are only torturing ourselves. According to the Convention, this way of thinking is wrong. Instead, differences should be respected, and functional limitations should be accepted as part of the diversity among people. Everyone has the right to be different – in everything. Still, everyone should have the same rights and similar legal competence.

In addition, the possibilities for the development of children with disabilities and their right to keep their own identity shall be respected. Identity? Indeed, do persons with deafblindness have an identity? Have persons with deafblindness had identities since birth? Do they recognize it? How can anyone decide about the identity of a person with deafblindness since birth, decide about what it is like? It is an identity which comes from others, but still a person with deafblindness has the right to identity.

Every person with deafblindness has a right to the respect of their mental and physical integrity. In other words, a person with deafblindness should integrate into society but, on the other hand, s/he is allowed to be herself and her characteristics must be respected. How is this possible to implement e.g. in institutions? Is there a possibility for respect, or do the problems affected by deafblindness draw all of the attention? There are fields of tension here.

A person with deafblindness also has a right to freedom and security. What does this mean in practice? Are persons with deafblindness not bound to the place where they live? Although the

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Convention mentions the right to freedom of movement and transport, how free can persons with deafblindness actually be as persons with deafblindness? However, this, as a target, is guaranteed by the Convention.

Next I have chosen to discuss Article 19, entitled “Living independently and being included in the community”. This Article is important in negotiations e.g. with politicians. It deals with independent living and participation in the community. In this connection, it must be stated that inclusion is not the same as integration, which means that a person with deafblindness can integrate into society. Integration is a term that used to be used, but presently inclusion and/or participation are preferred. Of course, a deafblind person herself must learn to live with deafblindness, but on the other hand, society, too, has to adapt to accept her\textsuperscript{20}. Persons with deafblindness have been accepted as a part of society, a part different from most others. So it is again a matter of diversity. Society has to be flexible, and I mean society not only as the whole world but also as the community where I live.

Persons with disabilities have to have an equal right to decide about their domicile and who they want to live with.\textsuperscript{21} They are not obliged to use certain housing arrangements. Here the tension increases because in the Convention the term “institution” is not actually used in the phrase “a form of accommodation”.\textsuperscript{22} In the author’s view, there are many possibilities to change the situations of persons with deafblindness. Persons with deafblindness have small units, homes for small groups. At which point do they become institutions? In the whole system, it is not often the persons who live in these institutions and their possibilities that are the focal point, but rather labour legislation and the working conditions and qualifications of the people who work there. Yet, the focus should be on the resident, the person whose home is in question. Just imagine that a person with deafblindness lives in an institution and wants to visit her friend. The whole system of support personnel and guides will have to be

\begin{thebibliography}{9}
\bibitem{20} J. Swain, \textit{supra} note 15.
\bibitem{22} A. Lawson, \textit{Disability and Equality Law in Britain. The Role of Reasonable Adjustment} (Hart Publishing, 2008).
\end{thebibliography}
reorganized so that s/he can reach her friend. Examples like this arise constantly. Fortunately, the process of deinstitutionalisation has already begun in some countries. In particular, persons with multiple disabilities require different services, and traditionally such services have been available only in institutions. Recently, living independently with personal assistance services has become an increasing trend.

For instance, let us take a deafblind student as an example. When s/he moved to live independently for the sake of her university studies, one of the biggest obstacles relating to food was that s/he had never learned to make choices. Both in the comprehensive school for pupils with hearing disabilities and at home, everything had been arranged on her behalf. Then suddenly s/he was confronted with the right to choose. Someone was there to tell her about the various options from which s/he could select. That was a situation totally new to her.

When negotiating with politicians, an even more important issue for persons with disabilities is the right to select housing and institution services. What is this service? Is it some kind of local service, which either is or is not available? Indeed, instead of thinking about existing services, we should use our imaginations and think about services which should be there. Many persons with deafblindness are still living in social exclusion, without having any possibilities to participate in community and family life. This is mainly a matter of necessary personal assistance and interpretation services as well as assistive technology. Here one must be accurate because all of this concerns participation in community, inclusion and an equal right with others to live as a member of society. Persons with deafblindness have to take advantage of all available possibilities. The most important of them are in danger of being forgotten because people do not know what it is like to live as a person with deafblindness. In this matter, undeniably, the Convention is needed.

Next, let’s look at Article 23, which deals with respect for the home and family. According to this Article, children shall not be separated from their parents. Consequently, it cannot be decided that deafblindness is such a severe impairment that a child cannot live at home. Here, indeed, a change in attitude has been needed. The family is important. Parents and siblings are important. Instead of
institutions, the family or the circumstances resembling it are now considered primary issues.

Now, what things are of special importance for persons with deafblindness? They are, of course, the different communication methods and devices which persons with deafblindness use. In the Convention, tactile communication\(^{23}\) is recognized as a method of communication among the others, Braille has been accepted as a literary language and sign language as a language.

For example, when a teacher asked a person with deafblindness if s/he would like to learn Braille, her first thought was that s/he could use it for reading stories to her little sister. Well, s/he learnt Braille, and currently s/he uses a computer only via Braille display.

There is a qualification which is unique to persons with deafblindness: persons with deafblindness have tactile memory. This means that they explore their way in life via their hands. Persons with deafblindness use the senses of taste and smell, and they learn things differently from persons who see and hear. For this reason, Article 24, which concerns education, is of great importance. Education does not end when one turns 18. Education is lifelong learning. In the Convention, there is an extensive article about education. Education has to be inclusive; in other words, the system itself has to adapt to the needs of an individual. It is easy to think that all students should be made to sit together as one class. Just think of a person with deafblindness sitting in a class in which the teacher writes the things to be learned on the blackboard. When s/he was ten, s/he used a pair of small binoculars in order to be able to read what was written on the blackboard. Nowadays this does not work any more. In a situation such as this, a personal assistant is can be helpful. But this is actually not enough, because education also means that s/he should be able to communicate with others in the classroom. Besides, a deafblind person learns things in a different way, via a sense of touch. Although persons with disabilities have special\(^{23}\) J. Mesch, *Tactile Sign Language: Turn Taking and Question in Signed Conversations of Deaf-Blind People* (International Studies on Sign Language and Communication of the Deaf, Vol. 38, Signum, 2001); R. Lahtinen, *Haptic and Haptomes: A Case Study of Developmental Process in Social-Haptic Communication of Acquired Deafblind People* (A1 Management UK, 2008); W. Schiff and E. Foulke (eds.), *Tactual Perception: A Sourcebook* (Cambridge University 1982).
characteristics, it is important that their chances for academic and social development are maximised. The Convention guarantees the right to special education for children with deafblindness. However, sometimes a mainstream school provides a better quality of education and development of social skills than a small special school. In situations like this, my own choice would be a mainstream school.

Another example is of a deafblind law student. When s/he studied in high school, s/he needed an interpreter in order to follow the instruction. S/he saw how her parents, without any legal or administrative education, tried to get the services which s/he needed. It was stressful for them. This pressure on her parents was one of the major motivations behind her decision to become legally trained. After this decision, s/he started to specialise in the rights of persons with disabilities.

Some persons with deafblindness have some remnant of hearing, but many of them do not. Some of them know sign language. Cochlear implantation has been an issue of much dispute. Unfortunately, many parents and authorities assume that if a child gets an implant, there will be no need for sign language teaching. Although some children have received relatively good results with implants, my opinion is that all pre-lingually deaf and hard-of-hearing children have a right to language. According to many studies, the language skills of bilingual children are often at least as good as those of monolingual children. The right to language is more important than the traditional way of thinking which, by artificial means, aims to change a deaf child to a hearing one. Getting all this included in the Convention has demanded hard work.

So, instead of problems, we will concentrate on the strengths and needs of individuals in order to develop these strengths in us. One of the most important impacts of the Convention is a new, powerful tool concerning awareness-raising of persons with disabilities. The Convention deals with all main sectors of life and explains how these issues relate to persons with disabilities.

In the Convention, there are also articles which deal with assistive technologies. In addition, there is an article pertaining to statistics and the collection of information. Although this is also an important part of the Convention, it will not be covered here.

4. The Convention as a trigger

The CRPD has expressive value insofar as it constitutes an acknowledgement by the global community of the human rights of persons with disabilities. The Convention can be seen as an educational tool which is a signal for States from the international community, and it represents a paradigm shift from the medical model to the human rights-based model concerning persons with disabilities. Persons with deafblindness have become a visible and recognized group on the international level because the CRPD explicitly mentions persons with deafblindness with respect to education. The CRPD is designed to trigger a national level engagement with disability law and policy among States. Only about forty States have disability rights laws\textsuperscript{25}, of which many are outdated or of questionable value. The CRPD requires that States take steps in order to fulfil the obligations of the treaty. According to the ideology of the CRPD, domestic change must occur in a transparent and participatory process. Many disability organizations have worked to further the legal rights of persons with disabilities. Although there are only a few national deafblind associations in the world, the legal status and possibilities for persons with deafblindness have developed during last decades and we can expect that this development will continue in the future.

Finally, the CRPD does offer an opportunity to trigger the social integration of persons with deafblindness into society through its mandate of inclusive development. According to the purpose of the CRPD, aid-sponsored programs should incorporate disability issues, and people with deafblindness, into development programs.

\textsuperscript{25} T. Degener and G. Quinn, \textit{supra} note 5, provides a catalogue.
Chapter 14:

From Devil’s Seed to Disabled God
– Disability and the Human Rights Approach on
the Bible Studies and Practices of Christian
Communities

Amu Urhonen

1. Introduction

Some time ago the Finnish Evangelical Lutheran Church decided to find out once and for all what causes homosexuality. The results were to define the church’s attitude towards sexual minorities. If the research showed that some people are born with an innate attraction to the same sex, they would receive equal rights in the church. In other words, a priest could then be openly gay or lesbian, same sex couples’ marriages would be blessed in the church and so on. If the opposite conclusion were demonstrated, then the discrimination would continue per tradition.

Questions of reason are essential for spiritual movements. Many say they believe in God because that kind of faith answers their difficult questions better than anything secular. By asking why, religious groups actually ask how they should behave when it comes to a certain kind of situation. Additionally Christian churches have interpreted various phenomena to be messages from God.

Disability, just like many other human issues, has made many Christian thinkers confused. It has been claimed to be a punishment or a special positive sign from God. The theme of healing has been strong in Christian writings. It is extremely difficult to say anything simplistic about disability in Christian theology, but some general concepts can be distinguished.

Disability has typically been considered to be an individual problem. Even when it has been thought to be the consequence of a
crime committed by the whole community, no effort has been made to adjust the common environment to meet disabled people’s needs. Furthermore, Christianity has considered disability to be a tragedy, never neutral or positive. Sometimes, though, disabled people are represented as heroes with extraordinary talents, but even then the status is a compensation for the tragedy of suffering due to the disability.¹

Nevertheless, Christian theologies have emphasised that every human being is created by God and therefore valuable. Many representatives of Christianity have worked for every individual’s right to exist. They have given statements against abortions on grounds of disability. Christian communities have taken care of essential services for disabled people in countries where the state has not. This is still a common function of Christian communities all over the world.

Critics of Christian ways of understanding disability and treating disabled people have risen from the modern human rights movement. Christianity has been accused of discrimination and of objectifying disabled people instead of encouraging personal dignity and self-expression.

The relationship between human rights and theology is not a simple one. Christian speakers have emphasised that the Bible is the basis of Western culture, and therefore also of human rights. Critics have on their side claimed that Christianity is preventing human rights by supporting belief in a single divine power instead of democracy.

The search for new ways of interpreting the Bible began at the grassroots level. Liberation theologies are invented by the penniless citizens of slums. They refused to accept the authority of spiritual leaders and read the Bible from their own circumstances. In addition, feminist science has had much to contribute to Bible studies and other areas of theology. These developments have given many traditionally subordinated groups in society the courage and inspiration to find their own truth in the Holy Book. One of these groups is disabled people.

This article is a humble effort to have a look at the questions surrounding disability and Christianity from a human rights point of view. In the conclusion, some areas in need of further research will be presented.

2. Disability in the Bible – Tragic Heroes Waiting to get Healed

Disability was not absent from the society from which the Bible was conceived. Accidents happened where people became physically impaired. Treatments were less developed. Harms that would be easily possible to cure today caused permanent damage to people in ancient times. Some were also born with impairments.²

The word disabled is not used in the Bible. However, it tells us about people who would be called disabled today: crippled, blind, deaf and so on. Mental disorders are mentioned. If disability is seen as a reason for social exclusion and lower status in that society, gender seems to have been a disability. Infertile women in particular were considered disabled before the spread of Christianity. Poverty could give rise to a sort of social disability as well. Physically disabled and poor people are often mentioned in the same context in the Bible. God had left both without a supposed necessity according to common opinion.³

The Bible is a rich collection of text with great diversity. As is acknowledged today, it includes several attitudes about almost everything. Living exactly according to the Bible is practically impossible because different parts give different advice. When it comes to disability, the picture is not any clearer. If different ways to interpret the book are added to all this complexity, it is even harder to draw any common lines. However, a couple of very general conclusions can be made about the Bible’s view on disability.

Disabled people are represented in the Bible in three roles. First, there are tragic characters whose disability is a punishment for their

³ Ibid., p. 61.
or their parents’ actions. The punishment is often compensated for with some special gift or skill.\textsuperscript{4} If no obvious reason for punishment is seen, disability can be seen as a sign of God’s power.\textsuperscript{5} Even then, disability is a tragedy for the disabled person.

The idea of disability as divine punishment was not developed by the ancient Jews alone. Physical or mental imperfection was explained with the supernatural in many other cultures, as well. It was common for groups of people to look for messages from gods in their everyday experiences. A tragedy like disability, infertility or fire meant that humankind had made the spiritual powers angry. Some even thought that disabled people were disabled because their very origins were evil. This logic can be seen in some Christian and Jewish writings, too.

Extra close relations to the divine brings us the next way the Bible deals with disability. Some disabled people enjoyed great social appreciation in their societies because they were said to have some divine gift. God had taken something from them but replaced it with something extraordinary. The price for the gift was high but by paying it one was extremely generously rewarded. Disabled persons were extra protected by God, closer to Him than most.\textsuperscript{6}

This kind of idea can be seen in theologies that viewed disabled person’s visible vulnerability as a sign of all people’s weakness. Making someone disabled was God’s manner of showing people their imperfection compared to Him. According to this way of thinking, disability is to make people humble in front of God. In other words, the disabled people had an extraordinarily important social reason for existence.\textsuperscript{7}

Sometimes, this mind-set was connected to human sin. People with disabilities were given the gift of carrying other’s sins in their disabilities. Like with having a special talent, carrying other’s sins brought the person closer to God.

\textsuperscript{4} Ibid., pp. 41-44.  
\textsuperscript{5} Creamer, supra note 1, p. 35.  
\textsuperscript{6} Ibid., p. 36.  
\textsuperscript{7} Avalos et al, supra note 2, p. 92.
Even closer to the divine are the ones who are healed. The most well known Christian miracle works were performed by Jesus himself. Healing the blind, crippled and mentally ill was not simply repairing people like putting pieces of a broken vase back together with glue. For the early Christians, the healings were understood as a symbol of spiritual healing that Jesus was to bring to everyone on the Last Day. Later, when latter Christian generations saw that Jesus was not coming as soon as the founders of their communities had expected, Jesus healing people began to be seen as a sign of God’s mercy in a more general sense. Adopting the Christian faith would be a way to be relieved of the burdens of humanity.

Disability has much to do with the physical body. Therefore, it is essential to understand theologies about the body. In the Christian tradition there is a strong dualism between the body and the spirit. In the strictest theologies the body is a symbol for the secular and the spirit for the divine. In this division, the human body often represents sin, weakness, temptation and pain. The human body with all its needs is a heavy burden seducing people away from God’s path. By torturing the body, one can make the spirit grow. In other words, by living ascetically, the divine inside the person can win its battle with the secular side. Physical joy leads away from God and therefore has to be renounced.

A disabled body has been considered to be an even heavier burden than a so called normal, non-disabled body. People with disabilities don’t have to create pain and other physical difficulties for themselves, because they are thought to suffer anyways. This is one explanation for the idea that disabled people are more spiritual than people in general. The physical difficulties have made disabled people seek answers for essential questions. Difficulties are to make people more humble and therefore open to God’s will.

The human body plays a significant role in the very beginning of Genesis. God is said to have created man in his own image to represent him on Earth. When Adam and Eve, the progenitors of humanity were tricked by the evil serpent, they began to feel ashamed of their nudity, their bodies. Theologians have debated for centuries what

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9 Creamer, supra note 1, pp. 35-36.
this means for humankind. Some think Adam and Eve lost the divine characteristics of their bodies together with their innocence. On the other hand, some believe that even though man didn't follow the Lord's orders his body still is in the image of God. The theological interpretations have been much harder on Eve, the woman, than on Adam, the man. The female body has been claimed to consist of more evil than the male body. Femininity in itself could have been characterised as a disability during many eras – and could still be in some contemporary communities.¹⁰

Interpretations of disabled bodies as made in the image of God vary widely. Some have understood the disabled body as having come not from God but from the Devil. Disability has been connected to impurity, for example in the Purity Laws of Leviticus. In the Law of the early Yahweh believers, physical perfection had a high value. Imperfect animals or humans were not good enough for the perfect God (Leviticus 21:17-23). The New Testament seems to imply the opposite. Jesus criticises the Pharisees because they exclude so many from serving God.¹¹ However, instead of claiming that disabled people are good just as they are he heals them. Many Christians emphasise the idea that everyone is God’s child and therefore valuable.¹² It is even said that Christianity is all about the right to life. Therefore, abortions or euthanasia because of disability cannot be accepted by Christian communities. Whether a disabled person is healed or not is then up to God.

In Christianity, the human body is seen as an important part of being human. Therefore, healing has a great symbolic value. Being healed from a disability stands for the spirit’s victory over the body, the good over the bad. Healing works can only be done by or with the support of God. The same kind of healing, the release from the burden of humanity, happens at death in the eternal with God. In heaven, people only have their spiritual self, not the difficult physical one. They will be released from their disabilities, too.

¹⁰ Avalos et al, supra note 2, pp. 61-67.
¹¹ Creamer, supra note 1, p. 45
¹² Ibid., p.81.

Disability theologies manifest as certain practices in Christian communities. On the other hand, practices have effects on theology. Since Christianity has been dominant in Western countries for several hundred years, ideas of theological thinkers have also had a great effect on the profane functions of societies. As history has shown, disabled people’s role has not been the easiest.

Attitudes towards disabled people have varied a great deal from era to era and from region to region. Political and other trends have had their effect on the Christian communities, sometimes less and sometimes more. I will not go through all of world history but stop at some interesting phenomena.

Demonstrating good will has always been important for Christians who want to follow Jesus’ example. Disabled people have been and still are one of the most popular objects of charity. Charity can be material or practical. Indulgences in the Middle Ages and the weekly whip-round in the service have been used to support “the most vulnerable”, for example the blind, deaf and crippled. The collected money went to provide services of care, social activities or technical aid. Food and even money have also been forms of help. In many countries Christian communities are significant actors in social politics, either with a special contract with the secular government or by providing independent services that the public sector has not arranged for one reason or another.\(^{13}\)

Unfortunately, providing services has not been the only role that the Christian communities have assumed when it comes to disability. In the 1930’s when race hygiene was popular, some theological speakers also spoke for it. Arguments were found from theologies emphasising perfection of the human body. Disability was connected to the Devil. God would not want to see imperfect creatures in his perfect new kingdom. Luther was often quoted in these texts because

\(^{13}\) More about the role in social welfare systems can be found in many general publications about social politics, for example A. Karisto et al, Matkalla nykyaikaan: elintason, elämäntavan ja sosiaalipoliitikan muutos Suomessa (WSOY, Porvoo, 1998).
he seemed to support the idea about the perfection of humanity. Apparently, these writers had jumped to their conclusions too quickly without looking at the big picture.

An important question about Christian practices and disability is whether there have been disabled people in important positions in Christian communities. At least we know that some of the nuns and monks who later became saints were disabled. Not much written material has been saved from discussions about choosing the leaders and staff in spiritual communities throughout history. As late as in the 1970’s these issues received more attention in Christian institutions. For example the Finnish Lutheran Church had to establish their stance on disabled priests. It was difficult for many to see the former recipients of charity as active members of the community.

4. Human Rights Based Theology – Disabled God

In the 1970’s the Independent Living movement gave rise to a brand new way of looking at disability. The social model challenged the old medical manner of looking at disability. Disabled activists claimed that the problem was not in or with them but in society. They joined other minority rights activists demanding a better world for everybody. The social model has been developed in recent years into a human rights-oriented model. The United Nations Convention on the Rights of Persons with Disabilities (the UN CRDP) is one of the strongest proofs of the strength of the disability rights movement. This is not to say that this was achieved only by the disabled people, but I know it would not have happened without disabled people.

Awareness of the suppressed groups’ rights put pressures on many social and humanistic sciences. Feminists were the first to look at society, culture and science from an untraditional point of view. This was followed by the emancipation of many others: the poor, ethnic minorities – and the disabled.

In Biblical Studies, adopting the new view meant taking a critical look at traditional ways of explaining things. Feministic theology had a closer look at biblical women and the position of women in the Ancient culture from which the Bible was conceived. In South America
very poor people who lived in slums developed a new way to read the Bible, Liberation Theology. Their idea was to read the texts from their own experience, assuming that God is actually on their side. Because their God was on the most suppressed people’s side, they couldn’t accept that they were suppressed based on His commands. This new approach was a great liberation and empowerment for many. People understood that they had the right to stand up for their rights because God was on their side, not with the suppresser. After the first Liberation Theology movements in South America, the idea spread to many countries all over the world. For example in India it has helped thousands of people break free from the caste system that had left them without human value.

A disability perspective on Biblical Studies also developed. It has used critical methods like the feministic research and looked at the Bible texts from the disabled person’s perspective much like Liberation Theology.

Many disabled people of the new generation have found it difficult to accept the role that the traditional Bible interpretations had given. They refused to dream only about healing and questioned Jesus’ miracles. They didn’t want to be treated like heroes because of the way they happened to be. They demanded an active role for themselves in serving God.

One of the most exciting new ways to read the Bible has been presented by Nancy L. Eiesland. She claims in her study that Jesus in his last few days, full of pain and suffering was actually disabled. The incarnate God was, in his most remembered moments, disabled. He, if anyone, is God of the disabled. Therefore, the disabled need not be ashamed of what they are.14

The UN CRDP applies great pressures on all kinds of social actors, and also on Christian communities. Traditional passive role for disabled people is not sufficient. Equality has not been easy to swallow for the leaders of churches. Some have asked whether a disabled person can handle priest’s work since it involves a great deal of moving from place to place. Or perhaps a disabled priest would scare or shock people by their appearance so they would not

feel comfortable relying on him or her?\textsuperscript{15} Is communion sacred if it is administered with a personal assistant’s help?

The UN CRDP calls for empowerment instead of charity. It will be interesting to see how long it will take before Christianity adopts an empowering mind-set. Active disabled people who make interpretations of the Bible from their own experience can well be the impetus that turns theology about disability into theology of the disabled.

5. Conclusion

In my article, I have looked at some questions concerning Biblical Studies and Christian practices pertaining to disabled people and their human rights. Not much in general can be said before more research is done.

Disabled people have traditionally played a passive role in society. The Independent Living movement and other more inclusive policies have changed the picture. Disabled people have started to see themselves as good just as they are. For them, the traditional idea that disability is a tragedy is absurd for them. These trends have also challenged Christianity on both theological and practical levels.

The saying goes that a change that takes ten years in secular society takes a hundred years in the Christian world. It will no doubt take time before Christianity adopts the ideas of the UN CRDP. On the other hand, new approaches, like feministic theologies and Liberation Theology, have already made Christian churches think and change their practices. The general trends of societies have also had effects on religious communities.

More studies about disabled people in Christian texts and practices are needed. The UN CRDP brings to the fore important questions for the disability theologies of the future.

\textsuperscript{15} N. L. Eiesland \textit{et al}, \textit{supra} note 8, p. 188.
Chapter 15:
Restrictions of Sexual and Reproductive Rights – The Case of Uzbeki Women with Disabilities

Feruza Zagirtdinova

1. Introduction

This article focuses on the phenomenon of self-restriction of Uzbeki women with disabilities in their private lives. First, the article makes a few observations about Uzbekistan and situation of women with disabilities there on the general level, and looks at the relevance of the UN CRPD in the context of this article. Next, the article moves to an overview of the survey-based data collection executed in the Sergeli District in Tashkent. Following that, the article deepens the view and looks at some relations between societal and religious spheres of thinking. Finally, the article concludes by observing some developments in Uzbeki society in the field of human rights of women with disabilities.

2. Background

Uzbekistan, a newly independent state in Central Asia, is one of the former Soviet Union Republics. Uzbekistan is a secular state and is involved in the processes of modernization. There are even some Westernisation tendencies in Uzbek society. Western lifestyle and philosophy has proliferated. However, traditional lifestyle philosophy still influences the behaviour of citizens, especially those who live in the countryside.

Uzbekistan is a secular state, but Islamic standards dictate a certain lifestyle. In modern Western ideology it is possible to notice distinct differences between moral norms based on religious studies (doctrinal statements) and secular norms based on ethical discussions that allow criticism of some religious beliefs. There is no sharp
demarcation between religious and ethical argumentation when forming concepts of modern lifestyle philosophy in the newly independent and transition states of Central Asia. Those in mass media and academia often confuse the arguments and refer to sacred texts, heathen beliefs, national traditions, scientific data and examples of Western behaviour.

Traditionally through the present, a woman does the vast majority of the housekeeping work in Uzbekistan. Housekeeping is considered to be one of the main attributes qualifying a woman for marriage. Naturally, women with limited abilities are unclaimed at this bride’s market. The cult of fertility is quite strong in Uzbek society. Reproductive activity in a healthy woman is encouraged, but at the same time self-restriction of reproductive desire in an unmarried woman – especially a disabled one – is also encouraged by the traditionalist sector of public opinion.

Conservative philosophy dictates that disabled women must restrict their sexual and reproductive desires. Islamic doctrine states that every man has to be married but there is no similar statement pertaining to women. Each family tries to look for a partner for their son even if he is disabled. Not all parents can carry out this task, but wealthy families are usually successful, at least to a certain extent. Traditional morality educates girls in a strict framework: a girl must understand who she is. If a girl is disabled, she must behave accordingly, and disabled girls understand this very well from childhood. Thus, the gender aspect of disability is quite an old issue, but it is a real problem for Uzbek society.

As we look at the topic of self-restriction in women with disabilities, we encounter many connections to the sphere of human rights. In the context of the UN CRPD, we initially need to take note of Article 6, which predominantly regulates on the rights of women with disabilities. Clearly, this Article pushes forward a clear model that women with disabilities have the right to decide over their own life, own body and own thoughts. Also, UN CRPD Article 26 is highly relevant to this topic, as it regulates with respect to the home and family. Women with disabilities have the right to reproduce just as everyone else, and they have the right to decide over their own life cycle. Further, Article 17 protecting the integrity of a person and Article 22 protecting the privacy of a person give very strong support
for women with disabilities in their struggle for independent life and freedom from exploitation. Thus, the UN CRPD gives us a strong and solid background for the analysis of self-restriction of women with disabilities in Uzbekistan.

There are several versions of statistics that describe the situation of disability in the country. The State Statistics Committee provided some partial and general information. Presently, Uzbekistan’s population is nearly 26 million people. One out of two women is of a fertile age. We relied on foreign sources for statistics, for example the World Bank. According to the World Bank report almost 12 per cent of all individuals age 7 and older have at least one serious difficulty or a full limitation.\(^1\) Of all individuals over 7 years of age, just under a quarter of those with official disability status indicate impairment in one or more areas of physical functioning. Authors of this report state that official disability status is held by 3.8 per cent of the population aged 7 and older in the Uzbekistan. The World Bank report primarily paid attention to poverty and protection problems. Gender aspects can be found in the sociological study of the Japan International Cooperation Agency (JICA). According to the JICA sociological study on the Republic of Uzbekistan, only 53 per cent of disabled women are married, whereas 73 per cent of disabled men are married. Many disabled women grow old and remain single. The divorce rate for disabled women is 7.3 % while for disabled men it is 3.3 %.\(^2\)

The situation for disabled women in the city is much easier than for those in the countryside. City women have more opportunities for communication. In Tashkent there are several Non-Governmental Organizations (NGOs) for disabled women. They do not change the situation of disabled women radically, but, to some definite extent, solve the problem of informational isolation, providing interpersonal communication and consolation for women. Some NGOs provide training on independent living.

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3. Survey

Our NGO APLA (the community foundation Assistance to People with Limited Abilities, established 2002) decided to collect our own statistics to gather information on the topic of women’s self-restriction in their private lives. We conducted an investigation of the APLA members, more specifically 184 disabled adults and children living in the Sergeli district of the capital of Uzbekistan, Tashkent. Among APLA members there are 19 families who have 2 or more disabled relatives and 4 families including more than 4 disabled people. We also discovered a second fact: the majority of adult disabled individuals live in their parents’ home without a spouse or partner. Marriages in which a healthy man or woman married a disabled partner are very rare. From the list of disabled APLA members living in Sergeli, only a couple of disabled men and women have established their own family. They have had cerebral palsy since childhood. Now they have their own families with two children who have married each other to avoid stigma.

Why are disabled people often alone, and how can we help disabled children to avoid this in their future? These questions encouraged us to do some research. To confirm its conception, APLA surveyed approximately 300 respondents; however, only 250 out of these 300 were selected for the analysis questionnaire as the others appeared defective due to their being incomplete or incorrectly filled out. Disabled individuals helped by providing the addresses and telephone numbers of their friends from other districts of Tashkent. The questionnaire was prepared, including the following topics: education, work, insertion into the social system, their family situation and problems. The participants’ average age was 42; 47 per cent were female, 46 per cent were married. The survey showed that 28 per cent lived in parents’ or close relatives’ families; 21 per cent of respondents called themselves “single”, 64 per cent confessed that they would like to have a family but could not due to financial status, problems in finding a partner and/or, as a final reason, because of health problems.

The next step was the organization of the set of more detailed ‘deep’ interviews of unmarried members of APLA. Women with congenital disabilities and without mental defects were selected for this case
study. This group of women was chosen because they realized and were confronted with their life problems since early childhood, and because they are actively trying to solve them. This contrasts significantly with our observations that persons who became disabled during life are more passive. Some significant pieces from the interviews follow below.

According to the APLA information source, only two women with severe disabilities since birth are married to men without disability (Gulya, 36, cerebral palsy and Oidin, 46, poliomyelitis). They are from wealthy families, they have good jobs, and their parents provided them with a separate flat. “My father ‘bought’ me a husband from the countryside”, Oidin said. But it is not completely true. These women have leadership skills. They have received good educations; they can work hard if needed.

“To marry a healthy man is Utopia; to marry a sick man will be madness,” was a line often repeated by another disabled woman at the interview (Tanya, 36, genetic disease, impaired mobility). At the onset of the illness, she had the experience of living with a healthy man; he had lived for several months in her flat until she temporarily stopped her official work and housekeeping because of the illness. Her first husband then left. Later she twice tried to join disabled men. The first of them was a man with impaired mobility and the second was diabetic. She said of her last experience that, “I thought he could help me with housekeeping because he looked like a normal man but diabetics are disabled, too”. These attempts also lasted several months.

Relationships with men without a disability never developed into marriage for our respondents, except in the two aforementioned cases. From the interview with Guzal (26, cerebral palsy):

“After the death of my parents, I lived alone in our flat. I met a guy from a province who was looking for a job in Tashkent. He needed a residence permit to work; I registered him on my address. We started living together. When I was pregnant, my boyfriend refused to support me and left. He used me.”
In this connection there is also an interesting story of Misha, a disabled man:

“I was looking for a friend to live together. I put my information in dating service of newspaper and soon I had a date with a pretty young lady. She was so stupid that she sincerely explained her reason ‘I want to live at your place while my husband is in prison; you are always at home and might be able to look after my child.’ That is, she needed accommodation. I used that experience; I invited another woman to live in my flat for her service of me, including night service. No strings attached.”

Next three interviews: Firuza (44, cerebral palsy):

“I grew up as an obedient girl, and I waited for anybody to ask me to marry him until I was 36. Then I decided to have a deep relationship with a good man. But I discovered that the position of being his lover depressed me. I wondered why he did not introduce me to his family. He answered that he was embarrassed of my disability. I broke off that relationship and since then have not desired a ‘deep’ relationship with anyone else”.

A similar story from Tatyana (30, cerebral palsy):

“I have a boyfriend. We always meet in my grandmother’s flat that I inherited after her death. We never go outside together. He is ashamed of my appearance.”

The next was Guli (46, poliomyelitis):

“I respected our tradition and kept my ‘girl’s honey’. At the age of 26, I fell in love with a co-worker but kept my secret for 3 years. Step by step he (in his words) fell in love with me. One day he said ‘Imagine you serve the table with delicious food but your guest has not yet come, and you do not know when he will come. Is it not better to sit down and eat the food with the one who is next to you?’ Since that day we became lovers, our meetings took place at my residence and lasted for 4 years. One day I gave him freedom. I realized that I could never marry anyone because I would not be a good wife; I had a slight impairment to my mobility.”

Usually, according to the authors’ studies, disabled women started their sexual lives between the ages of 25-30. They had waited for marriage according to local traditions, but then became braver and
made the decision to try 'it'. The reasons for this were a dream of a baby, a hope to find a life companion because of the realization of parental mortality and/or they at least wanted to know what a sexual life was. All except one respondent ended up dissatisfied with their ambitious projects.

Younger and older respondents had some opinions in common, but others were different. Nadiya (26, cerebral palsy) says:

“I consider that being a lover or girlfriend is a sin. Two years ago one nice man suggested that we live together without official marriage. I refused. Sometimes I regret it, but I am against sexual relationships out of wedlock. To be honest I did not tell him who I was. It was easy because we communicated via the internet. Later, he insisted on meeting and it happened. He was shocked. Later he suggested the relationship as I described earlier. Again, I considered it at great length before I came to my conclusion. Marriage to a disabled man would mean having a child that would be another me. A healthy man, whom I would want, will not marry me as our rules dictate. So I cannot see any optimistic perspectives, and I will let my life go on as it is going”.

Sofia (22, cerebral palsy) also has strong principles:

“I have not looked for a friend among men and will not. A bridegroom will appear on my life’s journey. And then I shall put on a white wedding dress. If such a chance does not present itself, I shall live with my nephew. One of my disabled girlfriends has married a disabled man, but I do not see any good changes in their lives. I do not envy her life. They have not had a baby yet. Maybe it is better than bringing one more disabled child into this world. When you make peace with fate you can see nice little things in your daily routine, life is not too bad.”

Dilya (18, muscular dystrophy) can console herself:

“I dream about a romantic meeting with a nice guy, but it is just my dream. Where can I meet him? Healthy peers do not pay attention to me. I definitely know my future. I just imagine romantic stories where I am the main character. Certainly, there is a big love in it. My fantasy is like TV soap operas. I am not able to change anything in my life.”
Gulsina (25, cerebral palsy) looks like a top-model, stylish, tall, skinny, big eyes and long hair. Her story is as follows:

"I have pen-pals via the internet. When I informed them of my problem, they asked me about my disease. Then they started communicating with me more cautiously and I lost interest in them. I am afraid of serious things. Perhaps I would agree to be someone’s girlfriend someday, but first I will ask for my mother’s advice."

4. Observations on the Survey Data

All of the women interviewed demonstrated a respect of local marriage traditions. Islamic doctrine states that when a girl comes into the world, her father first takes responsibility and patronage of her, then her brothers, then her husband and finally her son. It is commonly believed that a woman is a weak creature and that men must accompany her during her lifetime. That is why our respondents exclusively plan on or dream of official marriage. If a man gets married he takes responsibility for his wife and future children. Of course, all individuals realize that marriage does not guarantee a happy family life. Marriage is the first test of a man’s readiness to take responsibility for a disabled woman. In Islam, the individual having a deviation in health should, until death, be the responsibility of the healthy and solvent members of family. \(^3\) Why is it so important for disabled people to have family, and not just to be a lover or a partner? Because parents will not be there forever.

Society, state, community and family must take care of individuals vulnerable to discrimination and support them. Consequently the family fundamentally – albeit indirectly – restricts the independence of the personality by dictating a certain lifestyle. Family approval or disapproval of the sexual and reproductive behaviour of an unmarried disabled woman thus influences the choice of a woman.

Additionally, since disabled women are often unemployed, reproductive realization requires a greater effort from the family and extra responsibility for the other members of the family. To avoid this,

unmarried disabled women simply repress their reproductive desire. This applies mainly to women who were disabled prior to marriage. Married disabled women are in a more favourable position, for Islam does not encourage a man to divorce because of the sickness of his wife. Furthermore, in the majority of such cases, they have already had children.

Restriction of sexual and reproductive rights can be observed in some behaviour models: complete refusal of rights; incomplete family (‘a child for herself’); ‘guest marriage’, when the partner sometimes visits a disabled woman; and unmarried (bastard) relationships. Some of the interviewed women might find the behaviour model ‘guest marriage’ somewhat familiar, but as a rule their ‘guest marriages’ did not develop into official marriages.

The condition of illness or suffering is often such an extreme situation that a person cannot keep him- or herself from dwelling upon his or her own nature. Standing by religious stricture does not imply that a person considers him- or herself to be a religious person. Many follow the natural-scientific view of the creation of the world, but that same person can at the same time satisfy themselves with a religious interpretation of matters of suffering in general, and of illness in particular. Such an explanation can be convincingly elaborated: the reason for human suffering is in him- or herself or his or her behaviour, but not his or her enemies’ or said enemies’ designs and intrigues; one cannot escape from suffering and the world is full of it; suffering is a form of evil’s manifestation or its attribute; suffering is not just for nothing, but for something or in the name of something. Due to the above customary beliefs, the idea that ‘it is my fate’ is popular among single disabled women and is very convenient for self-consolation.

Nowadays not many people in Uzbekistan would be content with a reference to an evil spirit. The main ‘evil spirit’ in a human being is him- or herself. The Koran says that when you run into misfortune (after you have made two others unfortunate) why ask from whence it comes? Tell them it is from them. There one can find an answer to the question, ‘Why?’ Whatever good happens to you, it comes from God; and whatever bad happens to you, it comes from yourself. A belief in God’s existence does not remove the problem of personal responsibility. True believers, irrespective of their confessional
belonging or to what God they worship, believe that they will have to stand before the Almighty and answer for their mistakes and sins.

Even when it seems that sickness cannot be attributed to human sin, such as when a harmless child becomes sick or when a sickness is congenital – that is it persists from his or her birth – then the referenced Hadiths can interpret it that any suffering, even a thorn in his or her body, is given to a Muslim as the remission of sins and as liberation from future punishments.⁴

Suffering in this life atones for punishments in life after death, and consequently it is not meaningless but conversely, the Almighty God’s grace to his chosen ones. One should not hurt the sick, the crippled or those suffering from an injury (by God’s will), since they are his chosen ones, they are needy and one cannot take their lives just for the cause of the purity of the nation. One should look after them and support their existence. Moreover, the ill person’s prayer for someone is the best blessing, greater than the prayer of a healthy one, since in Persian the sick person is called ‘bi-mor’ which literally means ‘without a snake’. This is because a healthy person quite easily forgets God, and in so doing his or her breath becomes as poisonous as a snake’s bite; a sick person on the other hand naturally thinks of God continuously, thus escaping any malignancy in his or her breath.⁵

The honour of family demands that an orphan or person with a disability should remain in the family. However, during the recession of the economy in Uzbekistan following independence, a number of special houses for disabled people began to crop up, and people began to depart from the sacred ideals. When economic development brought about greater stability, the moral consciousness of society was also stabilised. The declaration of the new purposes of the state is accompanied by a selection of moral values, including sections on attitudes towards members of society with limited abilities.

⁴ Hadith, Al-jomi’ as-sahih, 4. (Ishonarli to’plam) (Tashkent, 1992), p. 3.
5. Concluding Words

All countries are in the grasp of globalization. The term itself has become very popular. It would actually be more precise to talk about Westernisation or unification rather than globalization. It seems that the Western lifestyle is more regulated by laws, contracts, and so forth, while the Uzbek lifestyle is rather managed by moral values than state laws. Some of them are stronger than state laws. Uzbekistan has begun to bring about societal modernization. Perhaps Westernisation is the price of developing countries for modernization. However there are zones untouched by Westernisation where conservative ideals are dominant, such as in the early private life of disabled women.

In my opinion there are two trends/groups among those people who, in mass media and/or academia, express their views on the matter of norm changes in society instigated by globalization. These trends do not depend on the social, religious, and/or eclectic positions of people. These two trends among people can be characterised as (1) defending a right of choice, and (2) justifying the right choice. As a result, the opinions among local researchers and not indifferent citizens can be reduced to this simple dichotomy. Some mass media involved in the discussion defend the personal right to choose the one ethical decision that is more appropriate from several options, while others claim the existence of absolute truth. Uzbekistani people combine the two approaches. But disabled women have to choose the ‘proper’ life style.

In Uzbekistan today paternalism remains the dominant model of attitude toward disabled individuals who therefore have limited opportunities. The state, community and families are obligated to take care of persons with disabilities, but this concurrently limits the independence of the disabled person. It is my conclusion that the same attitude is traditional for the other Eastern and Muslim societies, where there is not enough of an economic base for the realization of a program of independent life for persons with disabilities. During the interviews, many disabled women said that it is fortunate for a disabled person to be born either in a wealthy family or a wealthy country.
On the other hand, paternalism is not necessarily considered to be a negative phenomenon. It teaches us to look after weak members of families. Also, it is necessary to remember that opportunities for the disabled are limited, and not all is accessible to them. Not casually there are many supporters who think that Western rationality requires Eastern spirituality. The cold bureaucratic solution will never replace direct participation of family members and friends and enable the people to demonstrate noble feelings.

In other words the dichotomy ‘a right to choose or a right choice’ can be described as being guided by will and by duty. The first alternative is to satisfy one’s own desires, while the second is to prioritise the interests of others, mainly of relatives. Disabled women understand their status and so consider the interests of those nearest them. They want the people around them to consider their rights too. Rights do not exist without duties. To protect the rights of each person is an elementary duty. But some prefer taking the rights while passing on the duties to others, don’t they?

The situation with the rights of disabled women is changing slightly. The good news for the disabled women movement in Uzbekistan was that the Uzbek Government signed the UN CRPD on the rights of disabled persons in February, 2009. This means that the activities of the local government will be influenced by controls from outside, the control of the global society. This document delivers results. For example, following the document signing, some working places for disabled persons were checked by state bodies, and a new form of contract between the administration and disabled workers was presented. The Program ‘Access’ will be starting in the capital of the republic. Though we cannot see real achievements yet, at least government workers are discussing the rights of disabled citizens. Disabled women are waiting for the government to take the next step and go beyond promises to real results.