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Human rights and disability: the current use and future potential of United Nations human rights instruments in the Context of Disability

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Human Rights and Disability

The current use and future potential of United Nations human rights instruments in the context of disability

Gerard Quinn and Theresia Degener

with

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Dr. Ursula Kilkelly, Shivaun Quinlivan



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Foreword

It has been one of my goals as High Commissioner to have more attention given to the human rights of persons with disabilities, and to have the United Nations system respond more effectively in this area. I am very pleased, therefore, that this study on human rights and disability was based on an initiative of the Commission on Human Rights.

In 2000 the Commission requested me as High Commissioner to examine what might be done to strengthen both the protection and the monitoring of the human rights of persons with disability. As a first step it was decided to commission a study on the human rights dimensions of disability. The study would, it was hoped, clarify the conceptual and policy issues as well as report on both the experience and the potential of the international treaty bodies in monitoring and advancing protection.

This comprehensive and well researched study of human rights and disability is the result. I warmly welcome the study and commend it to all concerned with human rights and disability. On behalf of the Office of the High Commissioner for Human Rights I thank the authors and researchers who have worked together to provide us with an indispensable and practical resource for the use of international and national human rights mechanisms to defend the human rights of those with disabilities. At the same time, the book will be an essential foundation for the further initiatives on protection being considered by the General Assembly of the United Nations. I wish to acknowledge the support of the Government of Ireland, which made the project possible.

Mary Robinson

High Commissioner for Human Rights

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Executive summary

The present study is about the current use and future potential of the United Nations human rights instruments in the specific field of disability.

Over 600 million people, or approximately 10 per cent of the world's population, have a disability of one form or another. Over two thirds of them live in developing countries. Only 2 per cent of disabled children in the developing world receive any education or rehabilitation. The link between disability and poverty and social exclusion is direct and strong throughout the world.

A dramatic shift in perspective has taken place over the past two decades from an approach motivated by charity towards the disabled to one based on rights. In essence, the human rights perspective on disability means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems towards viewing them as holders of rights. Importantly, it means locating problems outside the disabled person and addressing the manner in which various economic and social processes accommodate the difference of disability - or not, as the case may be. The debate about the rights of the disabled is therefore connected to a larger debate about the place of difference in society.

The disability rights debate is not so much about the enjoyment of specific rights as it is about ensuring the equal effective enjoyment of all human rights, without discrimination, by people with disabilities. The non-discrimination principle helps make human rights in general relevant in the specific context of disability, just as it does in the contexts of age, sex and children. Non-discrimination, and the equal effective enjoyment of all human rights by people with disabilities, are therefore the dominant theme of the long-overdue reform in the way disability and the disabled are viewed throughout the world.

The process of ensuring that people with disabilities enjoy their human rights is slow and uneven. But it is taking place, in all economic and social systems. It is inspired by the values that underpin human rights: the inestimable dignity of each and every human being, the concept of autonomy or self-determination that demands that the person be placed at the centre of all decisions affecting him/her, the inherent equality of all regardless of difference, and the ethic of solidarity that requires society to sustain the freedom of the person with appropriate social supports.

The shift to the human rights perspective has been authoritatively endorsed at the level of the United Nations over the past two decades. This is best exemplified by the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities, adopted by the General Assembly in resolution 48/96 of 20 December 1993. The Rules are monitored by a United Nations Special Rapporteur, Bengt Lindqvist, who has received his mandate from the United Nations Commission for Social Development. The Rules, and especially the role played by the Special Rapporteur, continue to make a vital contribution to the process of raising consciousness about the human rights of persons with disabilities and in stimulating positive change throughout the world.

The United Nations human rights treaty bodies have considerable potential in this field but have generally been underused in advancing the rights of persons with disabilities. The study focuses on the bodies monitoring six main United Nations human rights treaties: the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, 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. The main thesis of the study is that the process of disability reform that is taking place across the globe could be immeasurably strengthened and accelerated if greater and more targeted use were made of these instruments.

It has to be emphasized that the primary responsibility for ensuring respect for the human rights of persons with disabilities rests with States. That is, the use and value of the United Nations human rights machinery is vindicated by meaningful domestic reform. The human rights instruments provide not merely guidance, but place obligations on States parties to reform.

States parties are demonstrably moving in the direction of the human rights perspective on disability. Recent research shows that 39 States in all parts of the world have adopted non-discrimination or equal opportunity legislation in the context of disability. States parties' dialogue with the human rights treaty bodies is constructive in the context of their efforts to secure disability reform; a significant amount of good practice now exists on a worldwide basis which can be usefully propagated through the human rights treaty system.

The shift to the human rights perspective is also reflected in the fact that national institutions for the promotion and protection of human rights throughout the world have begun to take an active interest in disability issues. This is important since these institutions help in providing a bridge between international human rights law and domestic debates about disability law and policy reform. National institutions are strategic partners in the process of change, and their increasing engagement on the issue of human rights for persons with disabilities is a highly encouraging sign for the future.

People with disabilities themselves are now framing their long-felt sense of grievance and injustice into the language of rights. Isolated injustices need no longer be experienced in isolation. NGOs working with disability issues such as the collaborative project Disability Awareness in Action are beginning to see themselves also as human rights NGOs. They are beginning to collect and process hard information on alleged violations of the human rights of persons with disabilities. While still relatively limited, their human rights capacities are growing. A similar process of self-transformation is under way within traditional human rights NGOs, which are increasingly approaching disability as a mainstream human rights issue. This is important, since these NGOs have highly developed structures, and the development of a healthy synergy between disability NGOs and traditional human rights NGOs is not only long overdue, but inevitable.

All in all, the time is right for a stock-taking of the current use and future potential of the United Nations human rights instruments in the context of disability.

Aims of the study

The study has three main aims.

The first aim is clarify the relevance of the six United Nations human rights treaties to disability. In order to do this, the study will identify the various obligations of States parties under the treaties and explain how the relevant enforcement mechanisms work in the context of disability. We hope that it will constitute a useful reference work for all stakeholders, including the States parties, the treaty monitoring bodies, the Office of the High Commissioner for Human Rights, national human rights institutions and civil society. It does not purport to be exhaustive. It creates added value for the existing literature by demonstrating the relevance of the human rights protections provided for under the six treaties to disability. More refined analysis will be needed as the debate moves on.

The second aim of the study is to review how the system actually works in practice with respect to disability, by looking at how States parties report to the treaty monitoring bodies on human rights and disability and how the treaty monitoring bodies respond. A total of approximately 147 recent periodic State party reports were examined. They were selected on the basis of the availability of documentation and to ensure a reasonable geographic spread. No criticism of any State party is intended. The object of this analysis was simply to derive some sense of how States parties saw themselves as discharging their obligations in the specific context of disability. Indeed, no criticism is intended of the treaty monitoring bodies. Their attention and scarce resources are drawn in many different directions, and the fact that they have developed a sense of the relevance of the various human rights treaties in the context of disability attests to their understanding that disability is a human rights issue. While our analysis with respect to the evaluative component of the study does not purport to be scientific, it nevertheless provides a sufficient basis for general conclusions to be drawn - conclusions that we hope will help to mainstream disability issues in a more sustained and focused manner.

The third aim of the study - the main one - is to provide options for the future. As such, it provides observations, comments and recommendations as to how the various stakeholders might enhance the use of the six human rights instruments in the context of disability. The study aims at strengthening the system, while arguing for the adoption of a thematic convention on the rights of persons with disabilities. For a variety of reasons, the authors conclude that such a convention is necessary and would underpin - and not undermine - the existing instruments in the field of disability.

Outline of the study

The study is divided into three parts.

Part 1 examines the nature of the shift to the human rights framework of reference in the context of disability. It is composed of three chapters.

Chapter 1 explains the relevance of human rights values and doctrine to disability. It asserts that the core problem in the field of disability is the relative invisibility of persons with disabilities, both in society and under the existing international human rights instruments. It concludes that the main human rights challenge is

accommodating the difference of disability and making people with disabilities visible within the treaty system.

Chapter 2 recounts briefly how the shift of perspective was given authoritative expression in a wide variety of instruments adopted in the context of the United Nations system over the past two decades. It sets the stage for an examination of how the United Nations human rights treaty system is currently accommodating the rights of persons with disabilities.

Chapter 3 presents the United Nations human rights treaty system and provides the bridge between so-called “soft law” and “hard law”. One important operating principle of the study is that it is necessary to cross over this bridge and to make full use of the human rights treaties in the context of disability.

Part 2 of the study is an evaluation of the current use of the United Nations human rights instruments, providing a detailed analysis of the actual and potential relevance of each of the six human rights treaties in the context of disability. This part is composed of six chapters corresponding to the six treaties.

The analysis contained in Part 2 is intended to be part expository and part evaluative. The expository dimension involves making the contents of the treaties transparently relevant in the context of disability. Each of the rights protected is examined and its relevance elucidated. The evaluative part is made up of a series of case studies on how the provisions of the respective treaties are applied in general in the context of disability.

Chapter 4 deals with freedom and disability under the ICCPR. This treaty is looked at first because the key ethic of the worldwide disability rights movement is freedom and participation. In other words, what people with disabilities aspire to most is to have access to the same rights - and civic responsibilities - as all other persons. Consistent respect for the ICCPR rights of the disabled would not merely protect people with disabilities against abuses, but would also be a huge help in breaking down barriers to the mainstream. In the sample of States parties’ reports surveyed, many States continue to report on disability as a welfare issue and not as a rights issue under the ICCPR. The authors found approximately nine individual complaints addressing disability issues submitted to the Human Rights Committee under the first Optional Protocol to the Covenant. Most were found to be inadmissible. At least one complaint has led to very positive case law on the treatment of prisoners with disabilities. In essence, the Committee held that it is the duty of States parties to accommodate prisoners with special needs. This shows an awareness on the part of the Committee that it is not enough to treat all persons the same, but that added allowance (or “reasonable accommodation”) may be necessary to make rights “real” for people with disabilities. This positive normative development offers great promise for persons with disabilities.

Chapter 5 deals with the ethic of social justice and disability in the context of disability. Disability is one of the best areas in which to assert and prove the indivisibility and interdependence of civil, political, economic, social and cultural rights. Using formal law to break down barriers to the mainstream is necessary but not sufficient. People with disabilities must be afforded freedom, but also the means to take advantage of it. This can be done by providing relevant social supports and, in

particular, by respecting economic, social and cultural rights. The authors decided to place this chapter after the one on the ICCPR in view of the standing danger that ICESCR rights will be viewed as being of primary importance in the context of disability since they are so obviously connected with social support. In the admirable General Comment No. 5 on persons with disabilities adopted by the Committee on Economic, Social and Cultural Rights in 1994, the Committee views the rights in the Covenant as providing the indispensable means of empowering people with disabilities in their own lives and providing ongoing support for a life of active participation in society. The right to health (art. 12), for example, is interpreted by the Committee as having a direct link to participation in society. In the sample of States parties' reports surveyed, States parties tend not to draw the link between ICESCR rights and the achievement of the goals of independence, autonomy and participation. Notwithstanding this, General Comment No. 5 remains a landmark and the Covenant in general has a hugely important role to play in sensitizing all stakeholders to how appropriate social supports and rights can best be used to break down barriers and enable people with disabilities to participate in all spheres of life.

Chapter 6 deals with the important question of protecting people with disabilities against torture and cruel, inhuman or degrading treatment under the Convention against Torture. This is especially relevant to the many millions of people with disabilities who live in institutions or in other types of residential care. Disability reinforces the imbalance of power in many such institutions and heightens the vulnerability of people with disabilities to abuse. Disability issues tend not to figure prominently in the sample of periodic reports surveyed. One individual complaint concerning the situation of disabled prisoners that was submitted to the Committee against Torture (CAT) was ruled inadmissible on the grounds that domestic remedies had not been exhausted.

Chapter 7 deals with the Convention on the Elimination of All Forms of Discrimination against Women insofar as it is relevant to women with disabilities. General Comment No. 5 refers to a tendency to think of people with disabilities as genderless. The Committee on the Elimination of Discrimination against Women (CEDAW) has itself adopted General Recommendation No. 18 on women with disabilities which requests States parties to include information on women with disabilities in their periodic reports with respect to their exercise of several rights contained in the Convention. In the sample of periodic reports surveyed there was little consistent reporting on the double discrimination experienced by women with disabilities.

Chapter 8 deals with the Convention on the Rights of the Child insofar as it is relevant to children with disabilities. The Convention is unique among the human rights treaties in that it contains a specific article on disabled children (art. 23). This article is, of course, without prejudice to the general applicability of all of the Convention's provisions to children with disabilities. The Committee on the Rights of the Child (CRC) has an impressively high level of awareness of disability issues. In 1997, it held an important day of general discussion on disabled children which has had a very positive impact on how the Committee addresses the situation pertaining to children with disabilities. The Committee seems to be well on the way to developing a coherent perspective on children with disabilities.

Chapter 9 deals with another sub-group of the disabled, namely disabled persons who also belong to racial or other minority groups. While such persons may be discriminated against largely on account of their race, the possibility of double discrimination cannot be discounted. Indeed, the phenomenon of double discrimination on the ground of race and disability was expressly acknowledged at the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance. Many States parties already include information on discrimination on the ground of disability on a regular basis in their periodic reports to CERD, generally by providing background information on their general anti-discrimination laws. This provides CERD with a useful opportunity for dialogue with States parties on double discrimination.

Part 3 of the study outlines options for the future. It is composed of four chapters.

Chapter 10 contains the authors' analysis of a detailed questionnaire that was sent out to disability NGOs around the world. There were about 80 responses from international NGOs, regional NGOs and domestic NGOs from every part of the world. The response rate was good given the time constraints. It had been decided to send the questionnaire to disability NGOs and not to traditional human rights NGOs in order to gauge whether and how they address the issues as human rights issues and what their views on the existing treaty system are.

An analysis of the responses reveals the extent to which the disability NGOs have themselves made the transition to the rights-based perspective on disability. Many of the NGOs that responded to the questionnaire stated that they saw themselves primarily as human rights NGOs. Many of them use United Nations human rights doctrine in their work. Some of them already have some experience of engagement with the United Nations human rights treaty system and generally had positive things to say about this experience. Most of them felt inhibited by a general lack of material and human resources and were deterred by the seeming inaccessibility of information about how the human rights treaties work in the context of disability.

These findings are highly positive. They show how the shift to the human rights perspective is being mirrored in the self-understanding of the disability NGOs, who are interested in engaging with the United Nations human rights machinery. They also reveal factors inhibiting such engagement. The analysis of the findings could usefully be complemented in the future by an analysis of how traditional human rights NGOs are themselves beginning to absorb disability as a mainstream human rights issue. Doubtless a convergence of perspective is now under way.

Chapter 11 looks at the experiences and views of national human rights institutions and factors in their views. It contains the authors' analysis of a questionnaire sent to national institutions and, again, the response rate was good given the time constraints. An analysis of the responses reveals that national institutions are in fact acutely aware of the human rights perspective on disability. Many of them have already produced important studies and reports on the question of the human rights of persons with disabilities. Some of these reports have been highly influential in helping to reform domestic disability law and policy. All of the respondent national institutions expressed a keen interest in the field and also a willingness to step up their activities in this regard. This is a highly positive and encouraging finding and augurs well for the future.

Chapter 12 sets out a range of observations, comments and recommendations designed to enhance the future use of the United Nations human rights system in the context of disability. For the sake of completeness, they are addressed to a wide variety of stakeholders in the field.

State practice with respect to periodic reporting on disability is clearly improving. This is, no doubt, due to the increasing attention paid to disability and human rights in the United Nations system over the past two decades and especially under the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities. With respect to the States parties, the authors make three recommendations designed to ensure heightened visibility for disability in the treaty system. Specifically, they recommend: (a) that States parties step up their efforts to report regularly on the situation affecting the rights of persons with disabilities; (b) that they consult with disability NGOs when compiling their respective periodic reports, it being understood that final responsibility for reports rests exclusively with the States parties; and (c) that they consider nominating persons with disabilities for membership in the six treaty monitoring bodies.

The treaty monitoring bodies do an excellent job overall on the issue of disability given their limited resources and the obvious need to deal with a wide variety of issues and groups. Again, the spirit and language of the United Nations Standard Rules has had an impact in this regard. The following recommendations are made in the spirit of assisting the treaty monitoring bodies to enhance further their treatment of disability issues. Specifically, the authors recommend: (a) that they emulate the good practice of the Committee on Economic, Social and Cultural Rights and adopt general comments on the nature of State obligations under the respective treaties in the context of disability; (b) that they emulate the good practice of the Committee on the Rights of the Child by setting aside a thematic day of discussion, or similar occasion, on disability; (c) that the list of issues sent to States parties by those treaty monitoring bodies that issue such documents more regularly request information on the enjoyment of human rights by persons with disabilities, in keeping with the thematic priorities to be set in general comments; (d) that the dialogue with States parties feature disability issues on a more regular basis; (e) that concluding observations contain references to disability, where necessary, in order to identify areas where more sustained attention is required and to request more detailed information from States parties in subsequent reports; (f) that concluding observations be used more regularly to highlight good practice for the benefit of all the stakeholders.

The Commission on Human Rights and the Office of the High Commissioner for Human Rights have demonstrated their engagement with the issue of human rights and disability. This is important at the symbolic level, but it is also significant from a practical point of view given the pivotal role played by the Office in the overall United Nations human rights system. The authors' recommendations in this regard are geared towards enhancing this engagement. Specifically, they recommend that the Commission on Human Rights encourage the Office: (a) to make knowledge concerning the relevance and operation of the United Nations human rights system in the specific context of disability more accessible by adding a disability-specific dimension to its web site (with appropriate and extensive links to the relevant activities of other sectors of the United Nations, the specialized agencies and national institutions); (b) to plan, after consultation with the stakeholders, a series of more

focused thematic studies and practical manuals on subjects such as the human rights of institutionalized persons, the right to education for disabled children, the principle of non-discrimination and the value of human diversity in the context of genetics, bioethics and disability, and the human rights issues connected with intellectual disability; (c) to assign at least one staff member on a full-time basis to the question of disability and human rights issues; (d) to indicate that it welcomes applications for internships from disabled persons; (e) to play a role in stimulating university-based human rights programmes to become more actively involved in human rights and disability; (f) to take a leading role in advancing the cause of the human rights of persons with disabilities within the wider United Nations system, with due regard to the equal ownership of the issue by all relevant institutional stakeholders. It is important that the human rights perspective on disability continue to be increasingly mainstreamed throughout the United Nations system, including in the relevant development activities. It is also important that the issue should be multi-tracked among all the concerned entities. More guidance from OHCHR could aid immeasurably in the process of mainstreaming, as well as enhance the contributions of the various and diverse elements of the system. The authors also recommend that the Office explore options for bringing together the treaty monitoring bodies to discuss the relevance and the potential contribution of their respective treaties in the context of disability.

With respect to the United Nations Commission on Human Rights, the authors recommend that it maintain and enhance the process of mainstreaming disability as a human rights issue in its work and that it give active consideration to the appointment of a special rapporteur on the human rights of persons with disabilities. The authors believe that there is a need for such an entity to raise the visibility of the disability issue as a human rights issue and to provide a focal point for disability in the human rights system.

With respect to the national human rights institutions, the authors recommend that they actively consider forming a forum or working group on disability and human rights. Such a forum would enable the national institutions to develop a deeper understanding of disability as a human rights issue and enable them to exchange valuable experiences.

With respect to civil society, the authors recommend that the disability NGOs combine their resources and form an international Disability Human Rights Watch or similar body that could help raise levels of awareness as well as human rights capacities within the disability sector. Such a grouping should develop close ties with the mainstream human rights NGOs in order to learn from their experiences and also in order to influence them to adopt disability as a human rights issue. The authors highlight good practice in the form of funding from the Swedish International Development Agency for a project on the human rights of children with disabilities. Given that the majority of people with disabilities live in developing countries, the authors believe that other donor countries should fund human rights projects in the area of disability as part of their development, democratization and human rights programmes.

Chapter 13 deals with the possibility of augmenting the existing human rights system in the context of disability with the adoption of a thematic treaty on the rights of persons with disabilities. In November 2001, the General Assembly adopted a historic

resolution to establish an ad hoc committee, open to the participation of all Member States, to consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the field of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development.

The authors find the arguments for such a convention to be highly persuasive. It would enable attention to be focused on disability and would tailor general human rights norms to meet the particular circumstances of persons with disabilities. It would add visibility to the disability issue within the human rights system. It would have practical advantages for all the stakeholders inasmuch as States parties would be clearer on their precise obligations in the disability field, and civil society would also be able to focus on one coherent set of norms rather than six different sets of norms. These advantages were long ago spelled out by Leandro Despouy, the Special Rapporteur of the Sub-Commission, in his study on disability, *Human Rights and Disabled Persons*, published in 1992.

The authors view such a convention as underpinning – and not undermining – the web of existing human rights treaties insofar as they relate to disability. That is, such a convention should enable the relevant treaty monitoring body to develop normative expertise in the field, and this should, in turn, help to stimulate the mainstreaming of disability into the existing human rights system. A convention would address collectively people with physical, sensory, mental or intellectual disabilities. The drafting process should provide an occasion for considering how best to use all human rights – civil, political, economic, social and cultural – to achieve the goal of full participation in society of people with disabilities. The convention should include appropriate protections, especially for those persons with disabilities who are institutionalized.

All in all, the United Nations is entering an exciting phase of its activities in the field of human rights and disabilities. Disability issues are being brought home into the human rights domain. The authors are confident that the range of suggestions and recommendations contained in the study and outlined above will lead to more and better use of the six human rights treaties in the context of disability. They are also confident that a thematic treaty would immeasurably advance the rights of persons with disabilities, while at the same time enhancing the capacity of the existing instruments to respond appropriately.

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Part 1

**Background: The shift to a human rights framework
of reference**

Chapter 1

The moral authority for change: human rights values and the worldwide process of disability reform

Gerard Quinn, Theresia Degener

Disability is a human rights issue! I repeat: disability is a human rights issue.

Those of us who happen to have a disability are fed up being treated by the society and our fellow citizens as if we did not exist or as if we were aliens from outer space. We are human beings with equal value, claiming equal rights...

If asked, most people, including politicians and other decision makers, agree with us. The problem is that they do not realize the consequences of this principle and they are not ready to take action accordingly.

Speech by Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission for Social Development, at the nineteenth Congress of Rehabilitation International, Rio de Janeiro, 25 – 30 August 2000

A clear perception of the values that underlie the human rights mission is needed to understand the nature and significance of the switch to a human rights perspective on disability. These values form the bedrock of an elaborate system of basic freedoms supported and advanced by international human rights law. Disability challenges society to live up to its values and sets international law the task of engineering positive change.

In this chapter we examine these values and explain the system of fundamental freedoms to which they give rise. We also explore the core problem of putting these values into practice in the context of disability, a problem that stems largely from the relative invisibility of people with disabilities in the past. They tended to be viewed as objects rather than subjects in their own right and the legal protections normally associated with the rule of law were either not applied at all or were severely curtailed.

Seeing people with disabilities as subjects rather than objects entails giving them access to the full benefits of basic freedoms that most people take for granted and doing so in a way that is respectful and accommodating of their difference. It means abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights.

1.1 Human values – the human being as subject and not object

The core values of the human rights mission underpin a system of basic freedoms that affords protection against the abuse of power and creates space for the development of the human spirit. Four values – dignity, autonomy, equality and solidarity – are of particular importance, both in general terms and in the context of disability.

(a) Human dignity and the social construct of disability

Human dignity is the anchor norm of human rights. Each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful but because of their inherent self-worth.

Recognition of the value of human dignity serves as a powerful reminder that people with disabilities have a stake in and a claim on society that must be honoured quite apart from any considerations of social or economic utility. They are ends in themselves and not means to the ends of others. This view militates strongly against the contrary social impulse to rank people in terms of their usefulness and to screen out those with significant differences.

Dignity as a value has been a crucial factor in the switch to a human rights perspective on disability. Owing to their relative invisibility, people with disabilities were often treated in the past as objects to be protected or pitied. The crucial change came when they saw themselves (and were seen by others) as subjects and not as objects.

The seventeenth-century English historian William Blackstone described women's loss of full legal personality on marriage as a form of "civil death". The main aim of reform ever since has been to restore to women all the indicia of legal personhood on genuinely equal terms with men – to change their status from object to subject. Much the same can be said of people with disabilities except that civil death in their case has occurred either at birth or at the moment of disablement later in life.

The "medical model" of disability has frequently been contrasted in recent years with the "human rights" model. The medical model focuses on persons' medical traits such as their specific impairments. This has the effect of locating the "problem" of disability within the person. The medical model encapsulates a broader and deeper social attitude – a tendency to problematize the person and view him/her as an object for clinical intervention.

The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centrestage in all decisions affecting him/her and, most importantly, locates the main "problem" outside the person and in society. The "problem" of disability under this model stems from a lack of responsiveness by the State and civil society to the difference that disability represents. It follows that the State has a responsibility to tackle socially created obstacles in order to ensure full respect for the dignity and equal rights of all persons.

Another way of making the same point is to describe disability as a "social construct". This idea is quite simple and straightforward although it is often clouded by

theoretical analysis. The first premise of the “social construct” model is that human difference is not innate but something socially constructed and applied through labels such as “the disabled”. Thus, one is not born “black” or “a woman” or “disabled”. One is labelled as such in relation to some unstated norm such as maleness, being white or being able-bodied (for want of a better expression).

The second premise is that the norm in relation to which one is evaluated and labelled (maleness, whiteness, being able-bodied) is generally not selected through a neutral or disinterested process. Selection usually occurs through an apparatus of power whose minimum goal is to preserve that power. Indeed many disability rights advocates consider that “the disabled” should be used instead of “persons with disabilities” precisely in order to highlight the fact that it is society which disables the person.

The third premise of the social construct model is crucial, namely that the social construct of disability is used not only to *set people apart* but also to *keep people apart*. All points of access to the structures of everyday life – the world of education, of work, of the family or of social interaction – are established largely by reference to the dominant norm, in this instance that of the able-bodied. As deviations or differences from the arbitrarily selected norm are generally not catered for, difference serves as a ground for subtle (and sometimes not so subtle) exclusion. For example, the built environment is constructed for those who can walk and not for those who use wheelchairs. The communications environment generally assumes a capacity to listen and to speak. The education environment makes little allowance for different ways of learning and so on.

A powerful link can be forged between the “social construct” model of disability and the human rights perspective on disability. Society has ignored or discounted the difference of disability in regulating the terms of entry into and participation in the mainstream, thus excluding – or effectively excluding – 10 per cent of any given population. This is not merely irrational from an economic point of view; it also violates the inherent dignity of all human beings.

To state the matter in positive terms, the end goal from the perspective of the human rights model is to build societies that are genuinely inclusive, societies that value difference and respect the dignity and equality of all human beings regardless of difference. In this regard, the disability rights movement is very much in tune with a deeper and broader movement to create genuinely inclusive societies for all. It has been described as the “next generation” civil rights movement.

(b) *Autonomy and creation of space for the
development of the human spirit*

Autonomy as a value associated with dignity derives from the ancient Greek commitment to autonomy or self-governance. It entails opening up a free or uncoerced space for voluntary action based on a person’s conscience and freely made life choices, while preserving comparable liberty for others.

The value of autonomy is based on the presumption of a capacity for self-directed action and behaviour. It thus rests on the implicit image of a “morally free” person – an image that has long been deeply contested. There are two main problems with this ideal image in the context of disability. One is that society seems over-inclined in

many instances to conflate disability – especially intellectual disability – with a lack of capacity for moral freedom. This presumption often rests on sheer prejudice. The human rights perspective on disability involves a much more nuanced approach, one that is not over-inclined to detect incompetence and that places equal emphasis on the need for effective protection of the rights and interests of those proclaimed legally incompetent.

The other problem is that society often fails to take seriously the autonomy of persons with disabilities who enjoy full legal competence. Their life choices are not perceived to be as worthy of social support as those of the non-disabled. Low expectations have led to neglect of the material conditions that people with disabilities need to take control of their lives and live as they wish. For the most part, societies have not done enough to *enable* those with disabilities who have a clear capacity for moral freedom to exercise their right of self-determination. It is one thing to have the ability to study astrophysics despite disability – it is another to be able to do so in the absence of accessible transportation.

(c) *Equality – valuing difference*

Human equality, a related value, is also central to the system of basic freedoms postulated by human rights law. Its core premise is that all persons not only possess inestimable inherent self-worth but are also inherently equal in terms of self-worth, regardless of their difference. Thus, distinctions between persons stemming from factors that are arbitrary from a moral point of view (race, gender, age, disability) should be treated as having no rational foundation and therefore invalid.

This is not to say that there are no differences between people. In positive terms, it means that a genuinely equal society is one that has a positive approach to and positively accommodates human difference. Valuing human difference is the aim of the “social construct” approach and is also validated by the human rights perspective.

It is crucially important to an understanding of international developments to realize that there are at least three ways of understanding the concept of equality. The interpretation chosen affects what one identifies as “wrong” in contemporary social arrangements and what remedies are deemed appropriate.

1. The first interpretation of equality focuses on the need for even-handedness by parliaments when they create inevitable distinctions in law and policy. This interpretation of formal or juridical equality is, of course, vital and will continue to form the bedrock of any understanding of equality. However, it is not sufficiently attuned to the concrete needs of those who are in fact “different” or who are not similarly situated.

On the other hand, to insist on strict equality between persons with disabilities and other persons would be to ignore real differences. A formal anti-discrimination law, for instance, may proscribe disability discrimination but fail to move beyond the “equality as neutrality” philosophy and take the further vital step of requiring “reasonable accommodation” of the difference of disability. This kind of “equality” is plainly hollow. It confers illusory benefits and invites cynicism vis-à-vis the law. Although the endeavour to accommodate real differences within a theory of equality

may result in paradox and pose its own set of problems, it seems necessary to make equality meaningful and to produce real change.

2. A second interpretation of equality is “equality of opportunity”. Most modern thinking accepts the “equal opportunity model” as the most appropriate one in the context of disability. According to this philosophy, factors over which a person has no control and which are thus “arbitrary from a moral point of view” should not be allowed to dictate that person’s life chances. Familiar examples are social status, colour, gender and disability.

Taking the ethic of “equality of opportunity” seriously in the context of disability implies calling for several forms of governmental action or intervention.

(i) Equality of opportunity entails tackling structural exclusion in such areas as transport, social amenities, public services and communications. No meaningful change is conceivable unless the social and economic processes of civil society are structured more inclusively and opened up to persons with disabilities on a genuinely equal basis. Such changes necessarily take time but the main thing is to inaugurate an irreversible process of structural change with clear goals and timetables.

(ii) Equality of opportunity entails ensuring that persons with disabilities are trained to the very best of their abilities to take up socially responsible and productive roles in civil society. This entails putting the education system on a genuinely equal basis and supplementing it where necessary. An important point is that the process of inclusion is both an end and a means. It is a means in that children with disabilities are socialized just like other children. It is an end in that able-bodied children have a right to the presence of “others” to prepare them for a life of coping with difference and plurality.

(iii) Equality of opportunity entails tackling instances of discrimination that exclude persons with disabilities from various spheres of everyday life. This calls for clear and easily enforceable anti-discrimination laws – covering the economy, the social sphere, public services and civic obligations – that frankly acknowledge the need for positive accommodation of the difference of disability. Many recent anti-discrimination laws focus on discrimination in employment, since economic independence is crucial for the full and effective enjoyment of countless other rights. No amount of structural improvement and high-quality education can produce real change and economic independence until space is found in the economy for persons with disabilities. Such space already exists theoretically in any market that rationally values talent, but markets are seldom rational when it comes to using the abilities of persons with disabilities. They must be prised open and prospective employers must become more focused on the abilities and merits of employees with disabilities.

(iv) A coherent “equality of opportunity” programme entails tackling deep-seated social attitudes to disability. While “good” laws can, through their educational effect, bring about a different and conducive milieu, innovative laws are liable to founder unless a sustained attempt is made to prepare the ground and to educate the public at large.

One of the main unarticulated premises of the philosophy of “equality of opportunity”, in general and in the context of disability, is that every human being has something to contribute to humanity and that social structures should be built inclusively with human empowerment as a key goal.

3. A third understanding of equality focuses on “equality of results”, which is usually taken to mean that each person – by virtue of his/her inherent equal worth and dignity – is entitled to certain minimum rights (particularly economic and social rights) regardless of his/her contribution or capacity to contribute. This approach has not, however, dominated thinking about disability. People with disabilities want to be accepted on their merits and given the material support they need to exercise their rights.

The current international trend is towards full “equality of opportunity” for persons with disabilities, entailing structural change, preparing people for greater participation, tackling discrimination in a number of areas and changing social attitudes.

Equalization of opportunities was defined in the 1982 World Programme of Action concerning Disabled Persons:

Equalization of opportunities means the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.¹

International literature emphasizes the need for a different role for social welfare in the achievement of “equality of opportunity”. For most people, welfare stops at the point where they enter the labour force and their earnings exceed a certain threshold. Traditional models of welfare need to be modified in the case of disability. People with disabilities are different in that they have *continuing* medical and other social support needs. It is now almost universally acknowledged that some measure of active welfare support to meet these extra needs should continue *even when a person is in employment*.

If there is a neglected issue in the philosophy of “equality of opportunity”, it is the assumption of an *ability* to function in civil society and the assumption of arbitrary exclusion *despite* that ability. There are some, however, who lack this ability totally or to a large extent - although one must guard against the danger of exaggerating incapacity. The needs and rights of this group are somewhat neglected in the equal opportunity model, which is to some extent understandable since, historically, the exclusion of people with ability constituted the main problem.

¹ World Programme of Action concerning Disabled Persons endorsed by United Nations General Assembly resolution 37/52 of 18 February 1982, para. 12.

(d) *Solidarity – social support for a free and equal people*

The value of solidarity is based on an acknowledgement that mutual ties and obligations exist between people by virtue of their shared membership of a political community. Freedom does not exist in a vacuum – it must be made tangible and this often means buttressing the system of basic freedoms by substantive social and economic supports.

There is much rhetoric about the indivisibility, interdependence and interrelatedness of civil and political rights, on the one hand, and economic, social and cultural rights on the other. The connections between the two sets of rights are very real and run deep. But they become tangible in the context of disability since the removal of barriers through civil rights and non-discrimination law is clearly not enough. People with disabilities sometimes (but not always) require additional support.

A point to be emphasized over and over again is that the main purpose of solidarity should be to prime people for participation in all mainstream processes of society. It is to be judged valuable to the extent that it liberates people in their own lives. All too often social protection systems have entrapped people with disabilities. While they stand to gain from the modern trend towards ensuring that social welfare systems contribute to an active society, people with disabilities are entitled to social support regardless of the utility of their potential contribution to society. The dignity of all persons merits such support irrespective of their "use value" to others.

1.2 From values to rights: a system of freedom built on human values

Although the full continuum of human rights conveys an impression of complexity and even chaos, all rights in the continuum hang together. The common denominators are the above-mentioned values of dignity, autonomy, equality and solidarity. From these basic values it is possible to conceptualize the system of basic freedoms that human rights advance and support – a system that is flexible enough to accommodate most socio-economic systems and solid enough to support them.

What follows is a brief account of the different sets of rights in terms of the values they advance, the functions they serve and their overall utility in the context of disability.

(a) *Civil rights - protecting people against the abuse of power*

Civil rights serve to protect and promote the values of human dignity and autonomy. They imply (and help to preserve) a clear-cut division between public power and civil society or the private sphere. They also imply the existence of a more or less voluntaristic civil society in which people are free to make their own life choices and carry them into effect. So while protecting people against the abuse of power, civil rights also open up space in civil society for personal fulfilment.

In doctrinal terms, several familiar rights play a pivotal role in ensuring respect for the person and affording protection against the abuse of power. The right to life protects

existence itself. Freedom from torture and from inhuman or degrading treatment provides a shield of immunity. These rights protect the individual's physical and mental integrity and nurture his/her capacity for self-reflection and goal-directed behaviour. Integrity of body and mind are, of course, vital factors in helping to prepare a person for an active life and self-realization.

The right to liberty is crucial since it builds a bridge between the person's *forum internum* (protection of the internal capacity for self-direction) and the *forum externum* (preservation of external space for action or behaviour predicated on freely chosen goals). It is no accident that the very highest level of due process protection is reserved in most legal systems for loss of the right to liberty. More generally, access to a court in order to vindicate rights is an important safeguard in any society. It enables disputes between persons to be resolved peacefully and it enables a disinterested party (the courts) to establish the boundaries between competing rights.

The right to association enables the individual to construct his/her own legal universe freely with others. Although it is applicable mostly in the economic sphere (e.g., the right to join trade unions or employers' associations), it also has critically important applications in the political sphere (right to form or join a political party) and in the social sphere (right to associate with others on intimate terms). The family might to some extent be perceived as an example of the exercise of freedom of association although it also naturally serves other autonomous and important social and moral ends.

The right to equality serves to control the quality of State action or legislation inasmuch as it presupposes that burdens or benefits should not be invidiously distributed in society. This formal or juridical interpretation of equality is familiar throughout the world but there are other possible interpretations, most importantly the concept of equality of opportunity which requires the State to play an active role in ensuring genuinely equal opportunities for all regardless of difference. It should thus allocate and apply its resources, for example in the educational sphere, in such a way as to ensure equal opportunities for all.

But it also means that the State has a role to play in regulating the behaviour of private actors when it has or tends to have a negative impact on equality of opportunity. It generally does so through non-discrimination legislation, which is also applicable to the private sector. In the case of disability, such legislation normally requires the would-be discriminator to take positive account of the disability and to "reasonably accommodate" the person concerned.

All in all, civil rights create space for personal development by negating State power and opening up a realm in which individuals can assume power over their lives, freely choosing their own goals and interacting with others on a voluntary basis to achieve them.

In the United Nations system, civil rights are advanced primarily by the International Covenant on Civil and Political Rights (ICCPR) and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

(b) *Political rights – influencing public power*

While civil rights serve mainly (though not exclusively) to negate State power, political rights enable individuals to exercise democratic control over State power and public policy. Human rights are not merely about protecting people against the abuse of power – they are also about giving people access to power. Human rights doctrine envisages an active citizenry that participates in the political life of the polity.

Hence the intimacy of the link between human rights and democracy, a link which can be understood in two ways. First, human rights may be viewed as the prime achievement of democratic polities. The greater the say people have in shaping their common destiny through access to political power, the more they tend to respect rights. Second, human rights may be perceived as the bedrock on which democratic societies are built and function, helping to forestall any slide towards despotism.

A web of rights exists to promote the goal of public participation. Freedom of expression plays a vital role in oiling the wheels of change in the political marketplace. It enables new ideas to replace old ones and advances the ideal of democratic accountability. Although freedom of association can be defended from the perspective of individual self-fulfilment, it also plays a vital role in keeping the door open for democratic change. The right to stand for office and the right to vote are also of obvious importance in shaping the common destiny of the polity and ensuring that one's perspective is not ignored.

These rights are important in themselves as an expression of the principle that political power is legitimate if it rests on the individual's democratic consent. But they are also important in that they enable change to occur peacefully and legitimately through the democratic process. If people with disabilities are not given a say in this process – or if their voice is systematically ignored – little change can be expected.

Political rights are promoted in the United Nations system by the International Covenant on Civil and Political Rights (ICCPR).

(c) *Economic, social and cultural rights – empowering people in their own lives*

Economic, social and cultural rights are much misunderstood. In practice, they underpin the system of basic freedoms promoted by civil and political rights. They give tangible expression to the ethic of solidarity and they are compatible with all socio-economic systems, including market-based systems.

Many such rights involve preparations for an active and productive life (right to education, right to vocational training). They reflect society's confidence that the next generation will contribute positively and productively to the life of the polity. If the value of equality is to be applied consistently, it is important to ensure that all persons – including those with disabilities – are included in such preparatory processes.

Most economic, social and cultural rights are related to active participation in the labour market (right to work, right to just and favourable conditions of work, right to association, right to collective bargaining). While such rights can certainly be

defended as "productive factors" in market economies, their value does not rest solely on their economic utility but derives also from the inherent dignity of the worker. A real commitment to equality means taking these rights seriously in the context of disability and taking positive action to accommodate the difference of disability in the workplace.

Another substantive set of economic, social and cultural rights includes the right to health and the right to housing. These rights should be protected not just because they enable people to lead active and productive lives (value of autonomy) but also because of the obligations of solidarity that exist within society. They should also be protected without discrimination, inter alia on grounds of disability. The right to health is of great importance to people with disabilities, who often receive fewer or poorer-quality health services. Practices such as selective non-treatment of persons with disabilities seem common enough to cause concern.

The right to housing is also of vital importance to people with disabilities for two reasons. First, it is essential to have an affordable and accessible housing stock. But it is also important to ensure that the housing environment is "visitable" so that people with disabilities can participate in the life of the community. Housing is not just important in itself – it gives people a foothold in the life of their community.

The right to cultural expression is important to people with disabilities for a variety of reasons. It enables them to transcend the commonplace, to share in a collective vision of the world and to tackle the ways in which they are portrayed and perceived by others. Moreover, it allows for the development of a sense of separate identity and community. The importance of all of these functions cannot be overstressed.

Economic, social and cultural rights are promoted in the United Nations system by the International Covenant on Economic, Social and Cultural Rights (ICESCR). A variety of other instruments covering these rights have also been adopted by United Nations specialized agencies, for example the Convention against Discrimination in Education adopted by the United Nations Educational, Scientific and Cultural Organization (UNESCO), the Discrimination (Employment and Occupation) Convention, 1958 (No. 111) and the Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159) adopted by the International Labour Organization (ILO) and the Declaration of Alma-Ata adopted by the World Health Organization (WHO).

(d) Human rights and the symbiosis of private and public freedom

To sum up, one might say that the above values - and the human rights they underpin – presuppose adequate protection against power, access for people to power, especially over their own lives and the life of the political community, and an elaborate social support structure designed to liberate people in their own lives and not to imprison them in gilded cages.

A powerful symbiosis thus exists in human rights doctrine between private freedom (protection against the abuse of power) and public freedom (admission of people to public space and social support for their presence). Historically, people with disabilities have not fared well at any level.

1.3 The core problem: the "invisibility" of people with disabilities in the system of freedom

(a) *The phenomenon of invisibility*

The above-mentioned values and the system of basic freedoms that they underpin are worthy of universal approval. The problem is not the values themselves or the system of basic freedoms that they postulate but the fact that they are either not applied or are applied differently to people with disabilities. This is a legacy of the past, when people with disabilities were often virtually invisible citizens of many societies. They have been marginalized in nearly all cultures throughout history. A common reaction (on the part of both the general public and policy-makers) was either pity or revulsion. There was a tendency to take the relative (or sometimes absolute) invisibility of persons with disabilities for granted or to accept it as "natural". The difference of disability was perceived as a ground for exclusion rather than a cause for celebration of the diversity of the human family. The greater the tendency to construct everyday life with only the able-bodied in mind and the greater the lack of a physical presence of disabled persons in the mainstream, the more "natural" this assumption appeared to be. Much of the exclusion was funded by welfare programmes that were more conducive to entrapment than to liberation.

The most extreme form of marginalization is elimination. It should never be forgotten that people with disabilities were one of the main – and earliest – victims of the Nazi concentration camps. The United Nations human rights machinery is largely a response to the atrocities of that period.

Invisibility has also led to a tendency to disregard the normal legal protections for the advancement of human freedom that we take for granted. It is as though existing legal protections are either not applied or are applied with much less rigour in the case of persons with disabilities. One of the main tasks of the international human rights system in this field is to make societies aware of the contradiction between their self-professed values and their application (or rather their non-application or misapplication) in the context of disability.

(b) *Double invisibility - some are more invisible than others*

Some groups of people with disabilities are more invisible than others. Children with disabilities have traditionally been seen as less worthy of social investment (for example through education) than other children. Women with disabilities often suffer double discrimination. Other minority groups, including racial and ethnic minorities, fare little better. People with intellectual disabilities find it difficult in many societies to make progress – or at least as much progress as other groups with disabilities.

Three human rights conventions have a major role to play in countering double invisibility: the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Rights of the Child (CRC) and the International Convention on the Elimination of all Forms of Racial Discrimination (ICERD).

The practical value of these conventions in combating the invisibility of women, children and racial minorities with disabilities is discussed in part 2 of this book.

(c) *Effects of invisibility on civil rights*

The relative invisibility of people with disabilities can have a dramatic impact on their enjoyment of civil rights. The right to life has been violated through abortion on the basis of disability. Euthanasia legislation and the phenomenon of selective medical non-treatment are challenges that still exist.

The right to freedom from torture and from inhuman and degrading treatment may also be violated where people with disabilities are institutionalized. Persons with mental disabilities or multiple or profound physical disabilities are particularly at risk. However well regulated institutions may look on paper, the regulations may simply not be applied in practice. Standards of care and treatment in institutions may fall short of what is required to respect the value of human dignity and autonomy. In the past, the rights of these marginalized and forgotten groups have not been championed either from outside the system (by NGOs) or from within, although there has been a palpable change in recent times. If society lived up to its aim of achieving an independent life for all, many such institutions would not exist.

The right to liberty is affected by institutionalization, also in the case of civil commitment of the mentally ill. There have been many changes for the better in "due process" requirements in cases of mental disability and in the development of a substantive right to treatment. But much still needs to be done. The fact that the norms applied to civil commitment in the past contrasted sharply with the strictures of "due process" used in "normal" criminal trials shows the extent to which people with mental disabilities were viewed as "different" and how this difference was used to justify radically different levels of legal protection for their rights and interests.

If one adopts a more imaginative approach to the concept of liberty, a host of challenges emerge. Most people take for granted the ability to move about in the built environment and to use normal channels of communication. They factor this into their background understanding of "liberty". But although this ability is not universal, mainstream facilities are not designed on an inclusive basis. It is important to characterize inaccessible transport, an inaccessible built environment and an inaccessible communications environment as factors that detract to such an extent from the value of liberty that they call into question its existence for people with disabilities. This is an admittedly broad definition of liberty. Yet if liberty is not defined broadly for people with disabilities, it is of little worth to them.

Many restrictions are still placed on family and privacy rights for people with disabilities, especially those in institutions, throughout the world. Their right to adopt children on an equal footing with others is a virtually unrecognized issue on which little has been written.

Some categories of persons with disabilities seem not to enjoy full freedom of association. Legal incapacity still exists with respect to participation in legal proceedings and the giving of evidence. These rules seem to be premised on outdated notions of incapacity that fail to do full justice to the actual capacities of persons with disabilities.

Equality norms in constitutions and other legislation often fail to cater adequately for the difference of disability. This situation is changing but a great deal remains to be done.

(d) *Effects of invisibility on political rights*

Persons with disabilities often have no voice or a very feeble voice in the democratic process. Even where they have a strong voice, they are not necessarily listened to. A lack of participation in the political debate can result in policy being formed without the active involvement of groups likely to be affected by its outcome. It can lead to alienation from democratic processes and cynicism about the possibility of achieving justice through law. It can also lead to passivity and dependence – factors that serve to reinforce stereotypes, compounding and perpetuating the invisibility of persons with disabilities.

The right to stand for election and the right to vote are sometimes explicitly withheld from persons with disabilities. Even if the right to vote is protected by law, in practice a myriad of factors can render it hollow. These include the lack of accessible polling stations, material (for example in Braille), campaign literature, transportation to and from polling stations and postal voting.

Over the past decade or so the disability NGO movement has grown considerably. Grievances are no longer experienced in isolation. Disability NGOs are beginning to speak a common language – the language of rights – and to engage the political system directly. This phenomenon is worldwide and a hopeful sign for the future. But if people with disabilities are to make the most of it, existing impediments to political participation need to be removed.

(e) *Effects of invisibility on social policy*

The assumption that people with disabilities were objects and not subjects and the tendency to react with pity rather than respect has had implications for the operation of welfare systems. Welfare was generally used to support people with disabilities or to compensate them for their absence from the mainstream of society. Disability was treated by Governments solely as a welfare issue.

The invisibility factor was discernible in the way many systems excluded children with disabilities from the ordinary education system and the benefits of vocational education and guidance. Where they were admitted to the mainstream, the resources appropriated to these children were often insufficient to ensure meaningful enjoyment of the right to education. When children with disabilities graduated and gained entry into third-level education, they still faced seemingly insurmountable obstacles.

Invisibility was also discernible in the assumption that people with disabilities had virtually no role to play in the open labour market. They were therefore channelled into segregated (and expensive) work environments. Employment prospects for persons with disabilities throughout the world are still dismal, to some extent reflecting low (unnecessarily low) levels of educational attainment and to some extent unwillingness to ensure that labour markets respond appropriately and positively to the difference of disability. Either way, we would argue, everybody loses, including the taxpayer.

Working conditions in sheltered and other alternative forms of employment leave much to be desired in terms of the human rights of disabled workers. Social protection systems tend to compensate for the loss of a right that most take for granted – the right to participate and to play a responsible and productive role in society – and they are usually not designed to help people with disabilities to lead active lives. The extra cost associated with disability under social protection systems generally disappears once the person enters the labour market.

(f) Effects of invisibility on freedom

To sum up, the relative or absolute invisibility of persons with disabilities has meant that the legal structures created to advance private freedom (protection against the abuse of power) and public freedom (participation in the mainstream) have either not been applied or have been applied with less rigour in the case of people with disabilities.

This has produced a category of person who, while being dependent on the public sphere for survival, lacks access to or influence over public policy. Such persons are denied full admission to public power and full control over their individual destiny. They remain outside the mainstream of civil society. This lack of presence – or invisibility – serves to reinforce stereotypical assumptions about the incapacity of persons with disabilities. It encourages a lack of respect for people with disabilities as rights holders on an equal footing with others.

1.4 Human rights as a “visibility” project in the context of disability

Times are changing. The disability rights movement has sunk deep roots in many countries around the world, especially over the past decade. It is in many ways a “visibility project”. Its prime message is to remind us of something that we should not need reminding about, namely that persons with disabilities are human beings and therefore share the same human rights as everybody else and the right to enjoy them to the same degree.

(a) Visibility and revaluing the difference of disability

The human rights perspective seeks to cast a positive spotlight on difference. In the past the relative or absolute invisibility of persons with disabilities led to a depreciation of the system of basic freedoms when applied to the difference of disability.

A human rights approach should now be used to restore full civil rights, including adequate due process safeguards, to persons with disabilities, in other words all the protections of private freedom (protection against the abuse of power) that most others in society already enjoy.

It should seek to break down barriers impeding access for persons with disabilities to the system of public freedom that human rights help to preserve and advance. Its goal is thus to secure acknowledgement that persons with disabilities have a rightful place in life's mainstream and that the achievement of independence and participation on

genuinely equal terms is not only a socially desirable goal but also a right. Herein lies the connection between the disability rights movement and the visibility project, the transcendent aim being to achieve genuinely inclusive societies for all.

(b) *Visibility and human rights violations*

The next question is how best to characterize human rights violations in the context of disability. It is possible and credible to focus on specific violations, for instance violations of the right to vote, the right to a fair trial, the right to education or the right to work, or physical and sexual abuse in institutions. Focusing on violations makes sense, especially where a clear culprit can be identified and an effective remedy found.

It can also make sense to examine patterns of violations or abuses. It is possible – and often very useful – to characterize specific violations in terms of the overarching problem of the invisibility of people with disabilities and the need to use rights to counter that legacy.

(c) *Visibility and the equal enjoyment of all human rights*

More often than not, invisibility has meant that a universal right is simply not applied equally (if applied at all) to persons with disabilities. For example, in the case of education, violations can have as much to do with the right to an *equal and effective* education as with the right to education as such. Likewise, in the case of civil commitment, the issue can be that relevant due process principles are not applied equally (*mutatis mutandis*) to persons with mental illness. Reform of the law on mental disability can be campaigned for as requiring restoration of equal rights and equal protection of the rule of law.

The answer to invisibility is an insistence on the *equal* application of all human rights to persons with disabilities. This addresses the need to restore parity for persons with disabilities in terms of private freedom (protecting people against the abuse of power) and public freedom (giving people power over their own lives). It also goes a long way towards explaining why the “equal opportunity model” has been the dominant rights model in the context of disability for the last twenty years or so, especially since the adoption of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. The Standard Rules define the notion of equal rights as follows:

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.²

The “equal opportunity” model rests on the assumption that people with disabilities share all human rights – civil, political, economic, social and cultural – with others.

² Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by General Assembly resolution 48/96 of 20 December 1993, paras. 25 and 26.

While it focuses on the need to increase levels of public freedom, it also has a great deal to say about private freedom and appropriate social support. It places the accent where it should be – on the capacity and willingness of people with disabilities to lead independent lives and play active and productive roles in the body politic.

Our conclusion is that the answer to invisibility is an insistence on the *equal* application of *all* human rights to persons with disabilities. The chapters that follow are intended to explain how the United Nations human rights system can help to attain that goal. The book as a whole is a visibility project in itself inasmuch as it seeks to make the rights that are available to all persons directly relevant to people with disabilities.

Chapter 2

The application of moral authority: the shift to the human rights perspective on disability through United Nations “soft” law

Gerard Quinn, Theresia Degener

The previous chapter set out the basic values that drive the human rights mission and underpin universal human rights. The purpose of this chapter is to give a brief account of some of the main developments relating to the question of disability in the United Nations system over the past twenty years or so. Given the scope of this study, it cannot be exhaustive. It does not deal with the wide variety of related activities and normative developments in the family of United Nations specialized agencies or indeed with the many positive developments in regional bodies such as the Organization of American States or the European Union. These are well documented elsewhere.

The background developments presented in this chapter lend considerable moral authority to the human rights perspective on disability. These developments have gradually and inexorably moved disability issues away from areas of welfare and medicine and towards that of human rights. They have reflected and helped to engineer the shift towards the human rights perspective on disability. Logically enough, this shift prompts an examination of whether the United Nations human rights instruments have taken due account of disability, a subject addressed in Part 2 of this study.

A special unit of the Division for Social Policy and Development in the United Nations Department of Economic and Social Affairs (DESA) serves as the focal point for disability issues in the United Nations system. It maintains a highly informative and useful web site for basic documentation (www.un.org/esa/socdev/enable). One of the items it contains is a “Compilation of International Norms and Standards relating to Disability” (1999) with a general introduction to United Nations human rights treaties. The web site also contains a useful review of the history of United Nations involvement in the disability field, “The United Nations and Disabled Persons: The First Fifty Years”, and most of the documentation relating to the World Programme of Action concerning Disabled Persons (see 2.2 below) and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (see 2.4 below).

2.1 Early United Nations General Assembly resolutions on disability

The General Assembly and the Economic and Social Council adopted a number of resolutions from the 1950s onwards dealing in the main with prevention and rehabilitation. A useful collection of the texts – which are now primarily of historic

interest – is contained in Maria Rita Saulle’s pioneering book *Disabled Persons and International Organizations* (Rome, 1982).

The Economic and Social Council seems to have been particularly active. It adopted a major resolution in 1950 dealing with “Social rehabilitation of the physically handicapped”.

Two resolutions adopted in the 1970s deserve special mention because they are the first signs of a shift from a “caring” to a “rights-based” approach. In 1971 the General Assembly adopted a resolution entitled “Declaration on the Rights of Mentally Retarded Persons”.¹ Significantly, this resolution begins by stating that such persons enjoy the same human rights as all other human beings (article 1). It then itemizes rights that are of special importance to them (including education, training and rehabilitation). The resolution is conscious of the need to protect the interests of such persons and to appoint a qualified guardian where necessary. Significantly, it cautions against taking the mere inability to exercise rights fully as a *carte blanche* for their complete withdrawal.

The General Assembly adopted another milestone resolution in 1975 entitled “Declaration on the Rights of Disabled Persons”.² The Declaration asserts that persons with disabilities have the same civil and political rights as other human beings (paragraph 4). Furthermore, such persons are “entitled to the measures designed to enable them to become as self-reliant as possible” (paragraph 5). The Declaration identifies a number of economic and social rights that are of obvious importance for the development of capacities and social integration (paragraph 6). Other noteworthy passages refer to the right of disabled persons to have their special needs taken into consideration at all stages of economic and social planning (paragraph 8), the right to protection against exploitation and treatment of an abusive or degrading nature (paragraph 10) and the right of organizations of persons with disabilities to be “usefully consulted in all matters regarding the rights of disabled persons” (paragraph 12).

2.2 The emergence of the rights model in the 1980s: the World Programme of Action (1982)

The 1980s marked an irreversible shift from the “caring” to the “rights” model. The year 1981 was proclaimed the International Year of the Disabled (IYDP) by the United Nations General Assembly with the slogan “Full participation and equality”.

The decade from 1983 to 1992 was proclaimed the International Decade of Disabled Persons. The General Assembly adopted a landmark resolution in 1982 entitled the “World Programme of Action concerning Disabled Persons” (WPA).³

The WPA consists of three parts: objectives, background and concepts (paragraphs 1 to 36), the current situation (paragraphs 37 to 81) and implementation (paragraphs 82

¹ General Assembly resolution 2856 (XXVI) of 20 December 1971.

² General Assembly resolution 3447 (XXX) of 9 December 1975.

³ General Assembly resolution 37/52 of 3 December 1982.

to 200). The overall aims of the WPA are threefold: (i) prevention, (ii) rehabilitation and (iii) equalization of opportunities.

The first two aims are the traditional ones found in the “caring” model. The presence of the third in the WPA is evidence of the slow but sure shift towards a rights-based model.

In paragraph 12, the WPA defines “equalization of opportunities” as:

the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.

In paragraph 21, the WPA states that the achievement of “equality of opportunity” necessitates measures that go beyond the traditionally rehabilitative ones:

Experience shows that it is largely the environment which determines the effect of an impairment or a disability on a person’s daily life.

Thus, achieving “equality of opportunity” means tackling structural exclusion in the sense mentioned earlier. The WPA also emphasizes the equality of the able-bodied and persons with disabilities in terms of obligations as well as rights (paragraph 26).

Part 3 of the WPA deals with implementation of the Programme. A Special Representative of the Secretary General was appointed to oversee progress in implementing the aims of the Decade.

Among other things, the WPA calls for the development of long-term national programmes to achieve the objectives of the Programme domestically (paragraph 88). Each government ministry was expected to assume responsibility for the achievement of the national plan within its area of competence (paragraph 89). In other words, there was not to be a separate ministry with sole responsibility for implementation. According to paragraph 90, to implement the WPA it was (and is) deemed necessary for States, *inter alia*:

...

To create, through legislation, the necessary legal bases and authority for measures to achieve the objectives;

To ensure opportunities by eliminating barriers to full participation;

...

To support the establishment and growth of organizations of disabled persons;

...

The goal of equalizing opportunities is greatly amplified in paragraphs 108 to 138 under the headings legislation, physical environment, income maintenance and social security, education and training, employment, recreation, culture, religion and sports.

The WPA “required” periodic monitoring at the domestic, regional and international levels. The first major international review took place in 1987 and the second in 1992.⁴ Not a great deal of progress could be reported even by 1992.

The 1987 review in Stockholm at the Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons actually recommended the drafting of a convention on the human rights of persons with disabilities. Italy raised the question of a convention at the forty-second session of the General Assembly in 1987.⁵ And in 1989 Sweden proposed the drafting of a convention at the forty-fourth session of the General Assembly to no avail.⁶

The 1992 report, for example, noted that the implementation of the WPA continued to be bedevilled by poverty, disease, war and other factors. It reported that persons with disabilities were still not playing an integral part in decision-making processes. Many countries had not yet adopted comprehensive national programmes. Such programmes - where they existed - tended to remain separate from overall socio-economic development. Both *de jure* and *de facto* discrimination persisted. While many efforts were being made in several countries to “equalize opportunities”, it was still too early to say (in 1992) whether these efforts would succeed.

The WPA is reviewed every five years (1987, 1992, 1997). The next quinquennial review is due in 2002. The 1987 Global Meeting of Experts actually recommended the convening of a special conference to draft a full convention on the rights of persons with disabilities. Although drafts were prepared by Italy and Sweden, no consensus existed at the time as to the appropriateness of a convention. The Economic and Social Council therefore recommended the drafting of a different kind of international instrument (see next sub-section).⁷

A Long-Term Strategy to Implement the World Programme of Action concerning Disabled Persons to the Year 2000 and Beyond was adopted in 1994. The 1997 review contains a useful summary of relevant developments throughout the 1990s.

An important United Nations Voluntary Fund on Disability was established by General Assembly resolution 32/133 in connection with the International Year of Disabled Persons (1981). States Members of the United Nations make donations to the Fund on a voluntary basis. The Fund was subsequently renamed the Voluntary Fund for the United Nations Decade of Disabled Persons (1983-1992) to support catalytic action to implement the core themes of the Decade. The General Assembly extended the life of the Voluntary Fund beyond the Decade in order to achieve the goal of a “Society for all”. The Fund awards monies to proposed projects: (a) to promote greater awareness of disability issues and exchanges of knowledge and experience; (b) to build national capacities and institutional capabilities for integrated policies and programmes in the disability field and for national disability legislation;

⁴ See, for example, the Report of the Secretary-General: Implementation of the World Programme of Action and the United Nations Decade of Disabled Persons, United Nations Document A/47/415, 11 December 1992.

⁵ United Nations document A/C.3/42/SR.16.

⁶ United Nations document A/C.3/44/SR.16.

⁷ All reviews of the WPA may be consulted on the DESA web site.

(c) to improve data collection, applied research and evaluation; (d) to facilitate pilot efforts; and (e) to promote wide dissemination of appropriate disability technologies. Details of how to apply for funding are given on the DESA web site mentioned at the beginning of this chapter.

An often unnoticed section of the WPA established a direct link between the United Nations human rights instruments and the disability agenda (paragraph 164). It stated that:

organizations and bodies involved in the United Nations system responsible for the preparation and administration of international agreements, covenants and other instruments that might have a direct or indirect impact on disabled people should ensure that such instruments fully take into account the situation of persons who are disabled.

Broadly the same point was reiterated in 2000, but with the authority of the United Nations Commission on Human Rights itself (see 2.6 below).

2.3 United Nations studies and guidelines

Mention should be made of two influential United Nations studies carried out in the 1980s.

The first was a report prepared by Erica-Irene A. Daes who was appointed Special Rapporteur by the Sub-Commission on Prevention of Discrimination and Protection of Minorities. It was entitled *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder* (1986).⁸

In 1991 the General Assembly adopted a key resolution entitled “Principles for the protection of persons with mental illness and the improvement of mental health care”.⁹ These principles have been hailed as a new departure in the perception of the role of law in this area. Almost as much emphasis is placed on positive treatment and the quality of treatment as on more traditional concerns such as the right to liberty.¹⁰

The second report was prepared by Leandro Despouy, who was also appointed a Special Rapporteur by the Sub-Commission. His thoughtful and comprehensive report was entitled *Human Rights and Disabled Persons* (1993).¹¹ The Despouy report chronicles widespread human rights abuses in the area of disability and cites a number of such abuses as causes of disability. His report is highly authoritative and was endorsed by the United Nations Commission on Human Rights and the General Assembly.

⁸ United Nations publication, Sales No. E.85.XIV.9.

⁹ General Assembly resolution 46/119 of 17 December 1991.

¹⁰ See generally Eric Rosenthal and Leonard S. Rubenstein, “International human rights advocacy under the ‘Principles for the Protection of Persons with Mental Illness’”, *International Journal of Law and Psychiatry*, vol. 16 (1993), p. 257.

¹¹ United Nations publication, Sales No. E.92.XIV.4.

The Despouy report commented (in paragraphs 280 and 281) on the fact that other groups had the benefit of thematic conventions whilst the disabled did not:

It must be said that at the end of the period (since the adoption of the World Programme of Action), persons with disabilities are going to find themselves in a legal disadvantage in relation to other vulnerable groups such as refugees, women, migrant workers, etc. The latter have the protection of a single body of binding norms [the text then lists the thematic conventions].

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

Despouy recommended that all treaty monitoring bodies should supervise the application of their respective human rights treaties to people with disabilities. However, his main specific recommendation was that the Committee on Economic, Social and Cultural Rights (the body that monitors implementation of the International Covenant on Economic, Social and Cultural Rights) should be assigned the lead role in implementing the human rights of persons with disabilities. The recommendation was well argued. Unlike other bodies, that Committee (which was not created by the treaty) can be assigned tasks by the Economic and Social Council. The Committee adopted its famous General Comment No. 5 on persons with disabilities in 1994. Most people would now agree that all treaty monitoring bodies should play a more active role in the field of disability.

The General Assembly adopted a resolution in 1990 endorsing the “Tallinn Guidelines for Action on Human Resources Development in the Field of Disability”.¹² The basic idea underlying this document is that the development of the human resources of persons with disabilities has too long been neglected and should be viewed as a key means of enabling such persons to exercise their human rights and responsibilities like other members of society. Several strategies for human resource development are singled out. They include the participation of persons with disabilities in society (breaking down physical and communication barriers), strengthening of grassroots and self-help efforts, and promotion of education and training, employment, community awareness, and regional and international cooperation.

2.4 The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)

The United Nations General Assembly adopted a landmark resolution in 1993 entitled “Standard Rules on the Equalization of Opportunities for Persons with Disabilities”.¹³ These Rules do not form part of a treaty and therefore lack legal effect.

¹² General Assembly resolution 44/70 of 15 March 1990, annex.

¹³ General Assembly resolution 48/96 of 20 December 1993. See generally Bengt Lindqvist, “Standard rules in the disability field - a United Nations instrument”, *Human Rights and Disabled Persons*, Degener and Koster-Dreese, eds., (Dordrecht, Kluwer Academic Publishers Group, 1995), p. 63.

The Standard Rules are the main United Nations rules guiding action in this area. It should be noted that the traditional preoccupations of prevention and rehabilitation have been relegated to the background in favour of the rights perspective, even in their title.

The Rules consist of four parts:

1. Preconditions for equal participation;
2. Target areas for equal participation;
3. Implementation measures; and
4. Monitoring mechanism.

They were drafted against the backdrop of the 1982 WPA and explicitly take as their political and moral foundation the International Bill of Human Rights mentioned earlier.¹⁴ Although the Standard Rules lack the legal character of a convention,

[t]hey imply a strong moral and political commitment on behalf of States to take action for the equalization of opportunities for persons with disabilities.¹⁵

Although the rules are not compulsory, they can become international customary rules when they are applied by a great number of States with the intention of respecting a rule in international law.¹⁶

As befits a document that is inspired by the “rights-based” philosophy, the purpose of the Standard Rules is to:

ensure that girls, boys, men and women with disabilities, as members of their societies, may exercise the same rights and obligations as others.¹⁷

In general terms, States are required to remove obstacles to equal participation and actively to involve disability NGOs as partners in this process. Particular emphasis is placed on groups of people with disabilities who may otherwise be vulnerable on account of, for example, gender, youth, poverty, ethnic minority status, etc. Parenthetically, even though persons with disabilities constitute a significant statistical minority in the world, they are not considered to be a minority for the purposes of United Nations law and policy.¹⁸

The definition of disability used in the Standard Rules emphasizes environmental factors. The term “equalization of opportunities” is defined in much the same way as under the WPA. Again, the Rules emphasize equal rights and equal obligations, the purpose being to stress that the core claim is not (as is too often assumed) for special rights on behalf of special groups but for the achievement of equality on the same terms as all persons.

¹⁴ Standard Rules on the Equalization of Opportunities for Persons with Disabilities, paras. 6-13.

¹⁵ Ibid., para. 14.

¹⁶ Ibid., para. 14.

¹⁷ Ibid., para. 15.

¹⁸ For a discussion of this point see Degener and Koster-Dreese, *Human Rights and Disabled Persons*, p. 12.

Section I of the Standard Rules deals with the preconditions for equal participation. These include: (Rule 1) the need to educate society at large about the situation of persons with disabilities and the need for change; (Rule 2) multidisciplinary medical care; (Rule 3) adequate rehabilitation; and (Rule 4) adequate social support services.

Section II of the Rules identifies the following target areas for priority reform:

- Accessibility (physical and communicational)(Rule 5)
- Education (Rule 6)
- Employment (Rule 7)
- Income maintenance and social security (Rule 8)
- Family life and personal integrity (Rule 9)
- Culture (Rule 10)
- Recreation and sports (Rule 11)
- Religion (Rule 12)

Section III of the Rules deals with implementation. The central “obligation” - such as it is - devolves on States themselves. It may be of interest to highlight some of the more relevant rules.

Rule 13 concerns one of the core preconditions for rational planning, namely the collection and analysis of accurate data. Paragraph 2 reads:

States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities.

States are expected to develop terminology and criteria for the conduct of national surveys “in cooperation with organizations of persons with disabilities”. Rule 14 deals with the need for States to develop (in association with NGOs) adequate policies at the national, regional and local levels and to integrate the needs and concerns of persons with disabilities into general development plans rather than treating them separately.

Rule 15 deals with the ideal contents of legislation to achieve equality of opportunity. Unfortunately, the wording of this Rule is quite weak. It states that general human rights legislation (where it exists) should include the rights and obligations of persons with disabilities. It requires the removal of existing de jure discrimination and states that legislative action “may be needed” to break down barriers and punish violations. Interestingly the Rules do not take a definitive stand on whether this legislation should form a separate corpus (in accordance with the worldwide trend) or should be integrated into broad or general anti-discrimination law. A combination of approaches may well be desirable, as may affirmative action (Rule 15, paragraph 3). Rule 15 also requires that “consideration” should be given to the establishment of a formal complaints mechanism.

Rule 16 stipulates that persons with disabilities should be kept in mind when formulating economic policies in concert with NGOs. All kinds of economic tools, including tax exemptions, loans, earmarked grants etc., should be considered. Rule 17 deals with the need to establish a national coordinating committee (or other similar body) to act as a focal point. It should be permanent, given a legal basis and comprise representatives of public and private organizations, organizations of persons with disabilities and other NGOs.

Rule 18 concerns the need to encourage and support economically organizations of persons with disabilities, families and/or advocates. Such organizations play a vital role as a conduit for information and feedback and a source of input for policy development. Rule 19 stresses the need for adequate personnel training - especially where service providers are actively engaged in delivering services to persons with disabilities. Training modules ought to be planned in conjunction with disability organizations. Rule 20 deals with national monitoring of the progress of national plans. States are expected to cooperate internationally in developing "common standards" for national evaluation.

Rules 21 and 22 deal with cooperation between States and in the international community. It is interesting to note that the Standard Rules accept the notion of conditioning development aid programmes to the achievement of equality goals (Rules 21, paragraph 2, and 22, paragraph 2).

Section 4 of the Standard Rules deals with the monitoring mechanism. This sets the Rules apart from other "ordinary" General Assembly resolutions. The purpose of the mechanism is "to further the effective implementation of the Rules". It should "identify obstacles and suggest suitable measures that would contribute to the successful implementation of the Rules". A Special Rapporteur is assigned the task of monitoring implementation. The first such rapporteur, Bengt Lindqvist of Sweden, held office for two full terms from 1994 to 1997 and from 1997 to 2000. In 2000 the Economic and Social Council decided to renew his mandate "for a further period through the year 2002".¹⁹ He reports to the Commission for Social Development. In 2000 he was invited to make a presentation to the United Nations Commission on Human Rights. Disability organizations were invited to select from among themselves a panel of experts to be consulted by the Special Rapporteur, an excellent innovation. He is due to report on ways of reforming the Standard Rules in 2002.

The United Nations Special Rapporteur maintains his own web site (www.disability-rapporteur.org). He carried out surveys on disability and produced two final reports at the end of his two terms of office. Details of the first survey are contained in the first final report.²⁰ States were asked four simple questions concerning their use of the Standard Rules. The results were deeply disappointing: only 38 submissions were received.

A second more comprehensive survey was conducted by the Special Rapporteur with the assistance of his panel of experts. This survey was designed (a) to assess the level

¹⁹ Economic and Social Council resolution 2000/10 of 27 July 2000.

²⁰ "Monitoring the Implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities", United Nations document A/52/56, annex.

of implementation of the Standard Rules; (b) to identify the main changes and accomplishments in the field of disability; and (c) to identify major problems and obstacles encountered during the implementation process. The results were published in 1997.²¹ It focuses on issues of general policy and legislation (Rule 15), accessibility (Rule 5), organizations of persons with disabilities (Rule 18) and coordination of work (Rule 17). A startling finding of the survey was that countries rank prevention and rehabilitation more highly in terms of their policy emphasis than effective anti-discrimination legislation. According to the survey, which was a highly significant stock-taking exercise, “it is clear that the traditional approach to disability is still very widespread.”²² The Special Rapporteur also collaborated in related surveys dealing with education (UNESCO), the right to work (ILO) and the right to health (WHO).

The Special Rapporteur’s second final report (E/CN.5/2000/3, annex) covers the period from 1997 to 2000. It makes for very interesting reading. In paragraph 119, he draws attention to aspects of the Rules that need to be updated and to gaps that need to be filled:

Some dimensions of disability policy have not been treated sufficiently. This is true concerning children with disabilities, in the gender dimension and for certain groups, mainly persons with developmental and psychiatric disabilities. It has been pointed out that the Rules do not include a strategy for improving living conditions of disabled people in regions with extreme poverty. Disabled persons in refugee or emergency situations are other areas that have not been dealt with ... [T]he whole area of housing has not been included. Among other things this means that there is no guidance concerning the handling of the institutions where a great number of persons with disabilities still spend their whole lives under miserable circumstances. The important events in the human rights area during the 1990s should perhaps also be more clearly reflected.

2.5. World conferences and disability

The above-mentioned resolutions, declarations and other documents pertain directly to disability. Many other important resolutions and declarations have indirect relevance. A few may be mentioned in passing.

Of general interest is the Vienna Declaration and Programme of Action adopted by the World Conference on Human Rights on 25 June 1993. One of the main reasons for the Declaration was to allay lingering doubts about the “universality” of human rights and the strength of the international community’s commitment to them. Interestingly, persons with disabilities are mentioned in paragraphs 63 and 64 of section II.B under the heading “Equality, dignity and tolerance”. Paragraph 63 reaffirms that persons with disabilities are entitled to all the human rights enjoyed by others. Paragraph 64 goes on to state that:

The place of disabled persons is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society.

²¹ Dimitris Michailakis, *Government Action on Disability Policy: A Global Survey*, Office of the United Nations Special Rapporteur on Disability (Stockholm, Gotab, 1997).

²² *Ibid.* p. 15.

The Copenhagen Declaration on Social Development and the Programme of Action of the World Summit for Social Development held in Copenhagen from 6 to 12 March 1995²³ are extremely wide-ranging and profoundly interesting documents that should be consulted in their own right. Many of the general provisions are directly applicable to the field of disability. Briefly, persons with disabilities figure explicitly in several places. There is a recognition that persons with disabilities are one of the world's largest minorities.²⁴ Mention is made of the need to ensure access to rehabilitation, independent living services and assistive technology²⁵ and of the need to promote community-based, long-term care services for those facing loss of independence.²⁶ The needs and rights of children with disabilities are singled out.²⁷ Specific mention is made of the need to broaden the range of employment opportunities for persons with disabilities.²⁸ This entails ending existing discrimination, taking proactive measures and

Making appropriate adjustments in the workplace to accommodate persons with disabilities, including in that respect the promotion of innovative technologies.²⁹

Most significantly, the Programme of Action states that one way of responding to special social needs (e.g. in the case of persons with disabilities) would be for Governments to promote and implement the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.³⁰ They should:

work towards the equalization of opportunities so that people with disabilities can contribute to and benefit from full participation in society. Policies concerning people with disabilities should focus on their abilities rather than their disabilities and should ensure their dignity as citizens.³¹

A report on WPA implementation was addressed to the Commission for Social Development as a follow-up to the World Summit for Social Development by the United Nations Secretary-General in 1999.³²

A special session of the General Assembly on follow-up to the World Summit on Social Development was held in 2000. It produced an outcome document entitled "Further Initiatives for Social Development", which refers to disability and the need to:

66. Expand the range of policies and measures, inter alia by promoting the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, to empower persons with disabilities to play their full role in society. Special

²³ United Nations document A/CONF.166/9, annexes I (Declaration) and II (Programme of Action).

²⁴ *Ibid.*, annex I, para. 16(h).

²⁵ *Ibid.*, annex I, commitment 6(n).

²⁶ *Ibid.*, chap. II, Eradication of poverty, para. 35(j).

²⁷ *Ibid.*, para. 39(e).

²⁸ *Ibid.*, chap. III, Expansion of productive employment and reduction of unemployment, para. 62(a) to (c).

²⁹ *Ibid.*, para. 62(c).

³⁰ *Ibid.*, para. 75(k).

³¹ *Ibid.*

³² Commission for Social Development, "Interim Report of the Secretary-General on Implementation of the World Programme of Action concerning Disabled Persons", A/RES/S-24/2, annex.

attention should be given to women and children with disabilities and to persons with developmental, mental and psychiatric disabilities.

67. Ensure access to employment for persons with disabilities through the organization and design of the workplace environment, and improve their employability through measures which enhance education and acquisition of skills, through rehabilitation within the community wherever possible and other direct measures, which may include incentives to enterprises to employ people with disabilities.

Another interesting document is the Declaration on the Elimination of Violence against Women adopted by the General Assembly in 1993.³³ The Declaration specifically mentions women with disabilities as a group that is especially vulnerable to violence.

The United Nations has long been concerned about torture and has issued many declarations of general application in the field. The General Assembly adopted the “Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment” in 1982.³⁴ They have obvious applications and implications in the context of mental institutions, hospitals and other places of treatment. The General Assembly adopted the “Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment” in 1988.³⁵ These principles of general application are, of course, relevant in the context of compulsory incarceration of persons suffering from mental illness.

2.6 United Nations Commission on Human Rights resolutions and disability

A resolution on disability is adopted by the United Nations Commission on Human Rights every two years. Ireland has sponsored it in recent years. As such resolutions are generally not put to the vote, the text is usually agreed beforehand. They have traditionally focused on the United Nations system and the United Nations Standard Rules. Recently, however, they have established ever closer links between the disability issue and the operation of the United Nations human rights machinery.

Resolution 1994/27 on human rights and disability was adopted at the Commission’s fiftieth session in 1994. It was drafted against the backdrop of the Despouy report and therefore focused on the ICESCR and the need for States and NGOs to provide all pertinent information to the relevant treaty monitoring body. Significantly, even as early as 1994, the resolution also encouraged (in paragraph 6):

all the human rights treaty monitoring bodies to respond positively to its invitation to monitor the compliance of States with their commitments under the relevant human rights instruments in order to ensure the full enjoyment of those rights by disabled persons.

Resolution 1996/27 on the human rights of persons with disabilities was adopted by the Commission on Human Rights at its fifty-second session in 1996. It welcomed the

³³ General Assembly resolution 48/104 of 20 December 1993.

³⁴ General Assembly resolution 37/194 of 18 December 1982.

³⁵ General Assembly resolution 43/173 of 9 December 1988.

work being done by the Committee on Economic, Social and Cultural Rights which had just adopted General Comment No. 5. While encouraging NGOs to provide relevant information to that Committee, it also reiterated the invitation made in the 1994 resolution to all human rights treaty monitoring bodies to monitor compliance by States with their treaty commitments as they related to disability.

The 1998 resolution was more detailed and forthright (resolution 1998/31 on the human rights of persons with disabilities adopted at the fifty-fourth session). It recognized in the very first operative paragraph

that any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules ... is an infringement of the human rights of persons with disabilities.

This wording correctly assumes that the philosophy of the Standard Rules hinges on equality and non-discrimination. This philosophy – which is grounded in human rights – is set forth in considerable detail in the Rules. The resolution then assumes that any breach of the spirit of equality in the Rules is a violation of human rights. The approach that may be criticized as over-identification of the Rules with human rights. On the other hand, the application of the concept of equality in the field of disability requires much more than mere abstention from discrimination. In any event, it is plain that the Standard Rules will have to figure prominently in any potential negotiations on a treaty for the rights of persons with disabilities.

In addition to reiterating the invitation to the treaty monitoring bodies to monitor compliance with human rights commitments as they relate to persons with disabilities, resolution 1998/31 also specifically urged Governments (in paragraph 11):

to cover fully the question of the human rights of persons with disabilities in complying with reporting obligations under the relevant United Nations human rights instruments.

The most recent resolution (Commission resolution 2000/51 on the human rights of persons with disabilities adopted at the fifty-sixth session) begins by taking note of the adoption by the Organization of American States of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (1999) as a good example of regional concern and action. The resolution reiterates in its very first paragraph the passage quoted above from resolution 1998/31 to the effect that any breach of the Standard Rules is an infringement of human rights. This is important since it cements the nexus between the Standard Rules and human rights.

Resolution 2000/51 also invites all special rapporteurs to take into account the situation and human rights of persons with disabilities when carrying out their mandates. Significantly, in paragraph 30 it draws the Office of the High Commissioner for Human Rights deeper into the field of human rights and disabilities, inviting:

the United Nations High Commissioner for Human Rights, in cooperation with the Special Rapporteur on disability of the Commission for Social Development, to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities and to solicit input and proposals from interested parties, including particularly the panel of experts.

Interestingly, the draft version of the resolution contained wording that would have called for the initiation of a procedure for the possible drafting of a United Nations convention on the rights of persons with disabilities. If adopted it would have read:

Considers that the next logical step forward in advancing the effective enjoyment of the rights of persons with disabilities requires that the (United Nations) Commission for Social Development should examine the desirability of an international convention on the rights of people with disabilities, and the form and content of such an instrument, and solicit input and proposals from interested parties, including particularly the panel of experts [i.e. the panel advising the Special Rapporteur under the Standard Rules].

The draft paragraph was withdrawn when the sponsoring delegation sensed that it would not succeed without a vote, which would have been counterproductive.

2.7 United Nations expert seminars on disability

The United Nations Secretariat arranged a series of important expert meetings on disability throughout the world.

Berkeley

One such meeting, a United Nations Consultative Expert Group Meeting on International Norms and Standards relating to Disability was hosted by the Boalt Hall School of Law, University of California at Berkeley, in cooperation with the World Institute on Disability (WID) from 8-12 December 1998. The Meeting was convened to offer findings and recommendations with respect to: (a) ways of increasing understanding of international norms and standards relating to disability in relation to domestic law and politics; (b) promoting their application in the domestic context; and (c) appropriate legislative frameworks to promote relevant application of international norms and standards, including the formulation of model national legislation. The report of the Meeting may be consulted on the Department of Economic and Social Affairs web site.

The Berkeley meeting acknowledged the many positive developments in respect of the issue of disability in the various treaty monitoring bodies. It nevertheless considered that

there was still much that needed to be done to ensure that violations of the human rights of persons with disabilities were both recognized and responded to by human rights organs.

The Meeting considered various wide-ranging strategies for implementation of international standards at the national level and also looked at the question of strategies for implementation at the international level. Interestingly, the Berkeley Meeting recommended (in part 5 of its report) that:

A working group of the Commission on Human Rights should be established to address specific violations in the area of the rights of persons with disabilities. The working group should include persons with disabilities as its members. The Office of the High Commissioner for Human Rights should include persons with disabilities as its members. The Office of the High Commissioner for Human Rights should consider the possibility of holding the meetings of the working group in places around the world in order to ensure accessibility to persons with disabilities from the most number of countries.

The Berkeley Meeting also suggested that the rights of persons with disabilities should be considered under all the human rights procedures, including the thematic procedures, resolution 1235 and resolution 1503.

The Meeting furthermore reviewed the arguments for drawing up a convention on the rights of persons with disabilities. One concern expressed (in part 6 of the report) was that any new disability-specific instrument:

might have the unintended consequence of marginalizing persons with disabilities, and that discrimination could be perpetuated by attention to the rights of persons with disabilities special instrument.

On the other hand, the Berkeley Meeting acknowledged that:

many of the existing norms, principles, declarations, standards, and guidelines dealing with disability issues are dispersed through various instruments; some are not sufficiently specific, legally binding; others are not overall, they do not ensure widespread and effective legally operative freedom from discrimination on the basis of disability. A new convention would afford the opportunity to revise or discard existing standards or statements of rights which were inconsistent with current thinking about the human rights of persons with disabilities or which were unsatisfactory in other respects. It was observed that group-specific instruments, for example those guaranteeing the rights of children, women, minorities, and indigenous peoples, have focused attention on issues that would have remained much less visible under the general human rights instruments.

One of the conclusions of the Berkeley Meeting was to recommend that the United Nations Division for Social Policy and Development should “examine the desirability of a new international instrument and the form and content of such an instrument; and solicit input and proposals ... from interested parties” (part 7 of the Meeting report).

Hong Kong

A follow-up to the Berkeley Meeting, the Interregional Seminar and Symposium on International Norms and Standards Relating to Disability, was held in Hong Kong, China, from 13 to 17 December 1999. Its recommendations were clustered under three headings: (a) international norms and standards relating to disability; (b) capacity-building to promote and monitor implementation of norms and standards; and (c) approaches to the definition of disability.³⁶ The proceedings were wide-ranging.

Among the many interesting recommendations made by the Hong Kong meeting under cluster 1 (international norms and standards, p. 4 of the draft report) was that:

The United Nations Commission on Human Rights should consider appointing a thematic special rapporteur on human rights violations against persons with disabilities to investigate systematic and individual violations of the human rights of persons with disabilities (the mandate, which should be drawn up in consultation with disability groups, should include a comprehensive range of issues, such as gender-based and cross-disability matters).

This is an idea whose time has come.

³⁶ See also T. Degener, “International disability law – a new legal subject on the rise: the Interregional Experts Meeting in Hong Kong”, *Berkeley Journal of International Law*, vol. 14 (1999), pp. 180-195.

The meeting recommended that:

The United Nations, Member States and disability rights organizations should initiate the process for the adoption of a international treaty dealing specifically with the human rights of persons with disabilities. In the process of formulating such an instrument, the following principles need to be observed:

- (a) The process of drafting any new treaty needs to be open, inclusive and representative of the interests of persons with disabilities.
- (b) Persons with disabilities must be principal participants in the drafting of any new treaty at all stages in the negotiation process.
- (c) The formulation of any new treaty must not dilute any existing international provisions on the rights of persons with disabilities and not undermine any national disability standards which provide a higher level of protection of rights.

A Seminar on Human Rights and Disability was convened by the United Nations Special Rapporteur on Disability in Stockholm, Sweden, from 5 to 9 November 2000. The report, entitled *Let the World Know*, was compiled by the Rapporteur, Marcia Rioux. The purpose of the seminar was to “develop guidelines to support disability NGOs in their work to identify and report human rights infringements and abuses”. It was a follow-up to paragraph 30 of Commission on Human Rights resolution 2000/51, which called for cooperation between the Special Rapporteur and the Office of the United Nations High Commissioner for Human Rights in strengthening the protection of the human rights of persons with disabilities.

More specifically, the seminar objectives were:

- To provide a forum to exchange knowledge and expertise and to dialogue on the integration of disability-related issues into the human rights processes;
- To develop a substantive methodology for relating obstacles to participation, neglect, abuse and other forms of discrimination to legal provisions of existing human rights instruments; and
- To design a process for follow-up and for collection and analysis of information and within this to develop and support a reporting capacity in disability NGOs.

These objectives are significant since they address ways of making the human rights machinery work better in the context of disability. A crucial issue is how NGOs can best engage with that machinery, for instance by gathering, processing and using information to which NGOs have access.

The Stockholm seminar agreed on the importance of mainstreaming disability into the United Nations human rights treaty monitoring system. An innovative element related to the development of tools whereby NGOs can report violations in a way that the system can understand and process. The seminar agreed that clear mechanisms and tools are needed to facilitate information gathering and processing.

The Stockholm seminar proposed a mechanism for the documentation of individual violations. It recommended that NGOs should hire, retain or use the skills of a human rights specialist for this kind of work. The seminar made very detailed and useful recommendations on how this work could be done to maximum effect. It proposed the

creation of a legal cases and jurisprudence database covering national laws and policies which would be maintained by the Office of the High Commissioner for Human Rights. The seminar also recommended a disability rights media watch to document human rights abuses in and by the media.

The Stockholm seminar is notable for raising the debate to a new level. The participants looked at how best to use the treaty machinery. And they made a strong and well argued case for some sort of international disability human rights watch.

An Informal Consultative Meeting on International Norms and Standards for Persons with Disabilities was convened in New York on 9 February 2001 by the Division for Social Policy and Development of the United Nations Secretariat. Several papers were prepared for the meeting, whose aim was not to produce recommendations as such but to stimulate discussion about the future. The summary of the discussion contained in the Meeting report is extremely revealing. According to paragraph 22, for example:

Several Governments expressed interest in addressing the rights of persons with disabilities by means of a “twin-track” approach, which would involve elaboration of a convention, and studies on options to mainstream promotion and protection of the rights of persons with disabilities in current international instruments. A convention was viewed [by these States] as a complement and not as a mutually exclusive alternative to current international instruments and the rights of persons with disabilities.

The Meeting report (paragraph 25) also refers to the fact that:

(NGOs)...expressed the view that elaboration of a convention on the rights of persons with disabilities is of great importance particularly since disability now is looked upon primarily as an issue of human rights rather than a matter of concern to medical and social welfare services. It also was noted [by the NGOs] that a convention is considered to be a complement to the “Standard Rules” and not an alternative instrument. While the “Standard Rules” are non-binding, they are an essential instrument and provide useful guidance for policy and practice.

2.8 General Assembly resolution on a convention to promote and protect the rights and dignity of persons with disabilities

In December 2001 the United Nations General Assembly adopted a resolution on a “Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities”.³⁷

It noted with satisfaction that “the Standard Rules ... play an important role in influencing” positive developments at the national and international levels. However, it also recognized that:

despite different efforts made to increase cooperation and integration, and increasing disability awareness and sensitivity to disability issues [by national and international bodies], ... these efforts have not been sufficient to promote full and effective participation and opportunities for persons with disabilities in economic, social, cultural and political life.

In its first operative paragraph the resolution:

³⁷ General Assembly resolution 56/168 of 19 December 2001.

Decides to establish an Ad Hoc Committee, open to the participation of all Member States and observers to the United Nations, to consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development.

Such a move was bound to manifest itself somewhere in the United Nations machinery sooner or later. It should be noted that the decision defers at least to some extent to the recommendations of the Commission on Human Rights and the Commission for Social Development. If these bodies agree to the elaboration of a convention, they will also presumably agree to a process that allows maximum time for consideration of the relevant issues and maximum space for consultation with civil society.

The resolution decides that the Ad Hoc Committee should hold at least one meeting for ten working days prior to the fifty-seventh session of the General Assembly. It invites all relevant bodies – including NGOs and treaty monitoring bodies – to make contributions to the work of the Ad Hoc Committee. It also calls for regional meetings to be arranged so that diverse views may be contributed to the process.

2.9 Conclusions

There has been an inexorable drift in recent years away from “soft law” instruments as the main motor force for change in the disability field. This is plainly visible in the resolutions of the United Nations Commission on Human Rights, which now stress the importance of the six core human rights instruments in the context of disability. The shift is also discernible in the conclusions of the various expert meetings – especially the seminar held in Hong Kong. The Stockholm seminar took the next logical step of addressing how the requisite change can be achieved through the provision of useful information. The shift can be seen most plainly in the resolution of the Third Committee of the General Assembly on the need for a convention.

The unreserved endorsement of a human rights perspective on disability has naturally put pressure on the human rights system to respond positively and appropriately. The next part of this study will examine the record of the human rights treaty monitoring bodies to date.

Chapter 3

Building bridges from “soft law” to “hard law”: the relevance of the United Nations human rights instruments to disability

Gerard Quinn, Theresia Degener

The Commission recognizes that any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities.

United Nations Commission on Human Rights resolution 1998/31 on the human rights of persons with disabilities

3.1 The United Nations human rights treaty system

As noted in the previous chapter, the United Nations Commission on Human Rights has urged the treaty monitoring bodies to take due account of the rights of persons with disabilities in their activities under each of the six core human rights treaties. This is of tremendous importance since it acknowledges the need to harness the potential of the various “hard law” international legal instruments for the benefit of people with disabilities. The purpose of Part 2 of this study is to evaluate how or whether this is being done. Here we briefly outline what the six core human rights treaties are and indicate how relevant developments under them may be tracked.

Each treaty or convention has a treaty monitoring body whose task is to enforce or monitor implementation of the treaty in question. As primary legal responsibility rests with the States parties, the main job of the treaty bodies is to monitor domestic implementation of the treaties. This is done through the examination of periodic State party reports on which the treaty monitoring bodies eventually issue concluding observations, concluding comments or conclusions and recommendations. The United Nations has produced a useful guide to State party reporting entitled *Manual on Human Rights Reporting* (HRI/PUB/91/1 (Rev.1), Geneva, 1997).

Some of the treaties allow for a right of individual complaint to the treaty monitoring bodies, which has led to a considerable volume of jurisprudence or case law. It has become an increasingly common practice for the treaty monitoring bodies to issue “general comments” which purport to be authoritative – though not legally binding – interpretations of the treaties. Such general comments may provide valuable guidance on the application of the treaties in the context of disability.

The two core human rights treaties are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). The ICCPR provides protection for a range of civil and political rights. It seeks to underpin the freedom of the individual and to ensure that he/she is enabled to exert influence over the political life of the polity. The ICESCR seeks to ensure that freedom is buttressed by appropriate social rights and social provision. These two themes of freedom and appropriate social support for freedom are crucial for people with disabilities.

The ICCPR and ICESCR were negotiated during the 1950s and the two Covenants were formally adopted and opened for signature and ratification in 1966. As of 8 February 2002, a total of 148 States had ratified the ICCPR and a total of 145 had ratified the ICESCR. The relevant monitoring body under the ICCPR, the Human Rights Committee, monitors the implementation of the treaty by States parties through the examination of periodic State party reports. The corresponding monitoring body for the ICESCR is the Committee on Economic, Social and Cultural Rights, which also monitors domestic implementation in the light of State party reports. An Optional Protocol to the ICCPR allows individuals to lodge complaints with the Human Rights Committee provided that the relevant State party has ratified the Protocol. A draft protocol to the ICESCR has been proposed by the Committee on Economic, Social and Cultural Rights which, if adopted, would enable individuals to lodge similar complaints under the ICESCR. The Committee on Economic, Social and Cultural Rights adopted an important and farsighted general comment on disability in 1995 (General Comment No. 5).

Four other core United Nations human rights treaties have been adopted. One of them deals with the very specific human right to freedom from torture: the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. This Convention is of obvious importance to, among others, the millions of persons with disabilities who are institutionalized. It was adopted and opened for signature and ratification in 1984. As of 8 February 2002, it had been ratified by 128 States. The Committee against Torture monitors domestic implementation by examining periodic State party reports. Individual complaints may also be considered by the Committee against Torture provided that the State party in question has recognized the Committee's competence in that regard. Inter-State complaints and "inquiries" may also be considered by the Committee under certain circumstances.

The three remaining treaties deal with particular groups or categories of persons who are at risk of discrimination: the 1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the 1989 Convention on the Rights of the Child (CRC) and the 1966 International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). These treaties generally serve two purposes. First, they establish the principle of non-discrimination with respect to the enjoyment of all human rights for the categories of persons covered. Secondly, and to the extent required, they add specificity to the general ICCPR and ICESCR rights, tailoring them more directly to the circumstances of the groups covered.

These group-specific conventions are of obvious importance in the context of double discrimination. Thus, people with disabilities may suffer discrimination not only because they are disabled but also because they belong to other groupings or

minorities such as children, racial groups or women. It is of the utmost importance to extract the maximum protection from these treaties for the groups concerned.

An Optional Protocol to CEDAW allows individual complaints to be lodged with the Committee. As of 8 February 2002, there were 168 States parties to the Convention. The CEDAW Committee has issued a General Recommendation to the effect that States parties should include references to women with disabilities in their reports.

The Convention on the Rights of the Child (CRC) was adopted and opened for signature in 1989. Unlike the other human rights treaties, it contains a very specific article on the rights of disabled children (article 23). The inclusion of this disability-specific article does not, of course, imply that other CRC rights are not applicable in the case of disabled children. The Committee on the Rights of the Child held a very useful general discussion day on children with disabilities in 1997 and this seems to have had a positive impact on its approach to the Convention in the disability context. As of 8 February 2002, there were 191 States parties to the CRC, which makes it the most ratified United Nations human rights treaty. There is no complaints procedure under the Convention.

The International Convention on the Elimination of all Forms of Racial Discrimination (ICERD) was adopted and opened for signature in 1965. ICERD is highly relevant to those who suffer double discrimination on grounds of race and disability. The Convention provides for inter-State and individual complaints procedures. As of 8 February 2002, there were 161 States parties to ICERD.

3.2 Navigating the United Nations human rights treaty system

The treaty bodies database on the web site (www.unhchr.ch) of the Office of the High Commissioner for Human Rights (OHCHR) contains detailed information on the operation of the United Nations human rights treaty bodies.

The “Highlights” section of the OHCHR home page provides up-to-date information on important world conferences with a bearing on human rights. The “Site Map” on the home page provides a fast entry point to the texts of the treaties. It also contains information about all United Nations human rights bodies, including the Commission on Human Rights and the Third Committee of the General Assembly, a thematic listing of contemporary human rights issues and details of the workings of the OHCHR.

The “Site Map” also provides links to the treaty monitoring bodies and, crucially, to databases covering their activities. There are also links to other databases, including the “Charter-based bodies database”, i.e. bodies based on the Charter of the United Nations such as the Economic and Social Council.

The “Treaty bodies database” is of vital importance in helping people to keep track of relevant developments in each of the six core treaties. It can also be accessed by clicking on “Documents” on the OHCHR home page. The left-hand column of the treaty bodies database page provides links to the names of current committee members, relevant documents, the reporting status of individual States parties under

each treaty and the current status of ratification (including information on declarations and reservations).

The “Documents” section of the treaty bodies database is of critical importance. It can be used to access State party reports, general comments, lists of issues sent to States parties by the relevant treaty monitoring body, replies to the lists by the relevant Government, summary records of meetings between Governments and treaty bodies, and the treaty bodies’ concluding observations or comments and recommendations. The “Documents” section also contains information on the case law or jurisprudence of treaty bodies that can consider individual or other types of complaints.

The section is searchable by country, language, symbol, treaty or type. To track a particular State’s record, for example, one searches the database by country. To obtain an overview of how a treaty works, one searches it by treaty.

There are few general publications on the operation of the treaties in the context of disability. One such work is: T. Degener and Y. Koster-Dreese (eds.), *Human Rights and Disabled Persons* (Dordrecht, Martinus Nijhoff, 1995).

Part 2

Evaluation of the current use of the United Nations human rights instruments in the context of disability

Chapter 4

Disability and freedom: the International Covenant on Civil and Political Rights (ICCPR)

Theresia Degener

This chapter assesses the current use and future potential of the International Covenant on Civil and Political Rights (ICCPR) in securing and advancing the rights of persons with disabilities. It is divided into four sections. The first contains an overview of the ICCPR, indicating the relevance of the rights protected for persons with disabilities. The second section analyses the functioning of the ICCPR in the context of disability, clarifying methods of enforcement and considering the relevance of general comments as tools for interpretation. The third section deals with coverage of disability in periodic reports and the response of the Human Rights Committee (HRC). The fourth section considers the complaints procedure under the first Optional Protocol to the ICCPR from the standpoint of disability. The fifth section contains our conclusions regarding the current use of the ICCPR and possible steps to enhance its value in the context of disability.

4.1 The relevance of civil and political rights to disability

4.1.1 The general relevance of ICCPR rights to disability

The 1966 International Covenant on Civil and Political Rights is one of the most important international instruments on human rights. Together with the 1948 Universal Declaration of Human Rights and the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR), it constitutes the International Bill of Human Rights.

The Covenant was adopted in 1966 by the United Nations General Assembly and entered into force in 1976 following ratification by a sufficient number of States. As of 8 February 2002, 148 of the 189 States Members of the United Nations had ratified the Covenant. The ICCPR has two additional Protocols. The first Optional Protocol, which allows for individual complaints by citizens of States parties, was adopted and entered into force at the same time as the Covenant. By 8 February 2002, it had been ratified by 101 State parties. The Second Optional Protocol, which deals with the abolition of the death penalty, was adopted by the United Nations General Assembly in 1989 and entered into force in 2000. It has been ratified by 46 States parties.

Although the drafters of the Covenant did not have people with disabilities in mind, they are clearly covered by its provisions. For one thing, the Covenant is universal in the sense that it covers all human beings. Unlike other treaties such as CEDAW or the CRC, it does not focus on a specific population group. Second, the statement in the Preamble to the Covenant that “recognition of the inherent dignity and of the equal

and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world” can certainly be interpreted to include persons with disabilities. Lastly, while it is true that disabled persons are not explicitly mentioned by the ICCPR, it is by now clear that disability is covered by the term “other status” in articles 2 and 26, which together constitute the non-discrimination clauses of the treaty. The ICESCR Committee has taken this view in interpreting the comparable non-discrimination provisions of that treaty. The United Nations General Assembly has proceeded on the assumption that people with disabilities are covered by the ICCPR in most declarations on disabled persons adopted in the last twenty-five years.¹

During the same twenty five years, disability has emerged as a civil and political rights issue rather than a medical problem to be resolved by a policy of medical intervention and segregation involving special social services. This historic concept or image of disability as a medical and social issue explains why disability has generally not been perceived as a human rights issue in the same way as gender or race.² Whenever human rights doctrine and disability were associated in the past, the focus was more on ICESCR rights than on ICCPR rights. This approach is reflected in the fact that the United Nations Disability Unit, which is located in the Division for Social Policy and Development, has no counterpart in the human rights machinery. It is further mirrored in State policy, since disability is often dealt with by social welfare ministries instead of being mainstreamed as an issue of concern to all government departments. Moreover, the international disability community itself overlooked the work of the Human Rights Committee during the United Nations Decade of Disabled Persons. In the first book to be published on the United Nations human rights machinery and disabled persons, Gerard Quinn made the following observation:

It is perhaps time that the disability community paid [the same] attention to civil and political rights as it does ... to economic and social rights. Rather, one's focus should ideally be on both sets of rights simultaneously.”³

4.1.2 Specific ICCPR rights and disability

The various civil and political rights contained in the ICCPR can be divided into four clusters:⁴ (a) rights that refer to human existence, (b) liberty rights, (c) associational rights and (d) political rights. All categories are of relevance to disabled people. As we know from the two reports produced by United Nations human rights bodies on disabled persons,⁵ all these rights are frequently violated in the case of persons with disabilities.

¹ For example the Declaration on the Rights of Disabled Persons, 1975. See Gerard Quinn, “The International Covenant on Civil and Political Rights”, *Human Rights and Disabled Persons*, T. Degener and Y. Koster-Dreese (eds.) (Dordrecht, Martinus Nijhoff, 1995), p. 81.

² *Ibid.*, p. xii.

³ *Ibid.* p. 81.

⁴ *Ibid.* p. 83.

⁵ See *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder*, report by Mrs. Erica-Irene Daes, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, 1986, United Nations publication, Sales No. E.85 XIV.9; see also *Human Rights and Disabled Persons*, report by Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of

(a) *ICCPR rights - protecting human existence and the integrity of the person in the context of disability*

The most fundamental right in the first group is the right to life (article 6). In developing countries the mortality rate of disabled children is often higher because they are the last to be fed or taken care of. In developed countries the right to life is affected by “euthanasia” practices such as withholding life-saving treatment from a newborn child with disabilities. Another important right in this context is the right to freedom from torture and other cruel, inhuman or degrading treatment and punishment (article 7). In particular, this article prohibits medical or scientific experimentation without free consent. Gerard Quinn has identified four circumstances in which these rights are relevant to disability.⁶ First, disability is often a result of human rights violations such as war crimes, torture or degrading or cruel treatment and punishment. Second, services for disabled persons provided by or under the auspices of the State may violate article 7 because they are degrading or inhumane. For example, a violation may occur if disabled persons are “warehoused” in institutions. Gerard Quinn even argues that:

a deliberate policy to treat persons with disabilities under separate arrangements simply for the sake of administrative convenience might amount to second class citizenship and is thus at least arguably “degrading” as per article 7.”⁷

Third, article 7 may be violated if disabled persons are placed in an inappropriate environment, for instance subjected to an ordinary prison regime as a convicted person. Inaccessibility of sanitary facilities or the impossibility of leaving a cell may amount to degrading treatment. Lastly, article 7 rights are relevant in the context of medical treatment and research. Disabled persons are often the target of medical or scientific experimentation. The requirement of free and informed consent is often ignored in practice. Persons with intellectual impairments, who are sometimes deemed unable to give consent, are a particularly vulnerable group. The “Principles for the protection of persons with mental illness and the improvement of mental health care” adopted by the United Nations General Assembly in 1991⁸ give valuable guidance for the interpretation of article 7 in the context of institutionalized disabled persons. The Principles prohibit certain kinds of treatment such as sterilization and psychosurgery and other forms of irreversible medical “therapy” in the case of involuntary patients. They give detailed information on instances in which free and informed consent for medical treatment is necessary.

(b) *ICCPR liberty rights and disability*

The right to liberty and security of person (article 9) is relevant in the context of civil commitment of the mentally ill. Under what circumstances may disabled or mentally ill persons be committed to a mental health facility? If the commitment is involuntary, what procedures should be followed? Is it enough for a certified doctor to decide that

Discrimination and Protection of Minorities, United Nations, 1993, United Nations publication, Sales No. E.92.XIV.4.

⁶ Degener and Koster-Dreese, *Human Rights and Disabled Persons*, p. 84.

⁷ Ibid. p. 84.

⁸ General Assembly resolution 46/119 of 17 December 1991. In this connection, see the Daes report (footnote 5 above).

commitment is medically necessary or should a judge be involved? What constitute legitimate grounds for the infringement of liberty rights? Are therapeutic arguments sufficient or should it first be established that the person to be committed presents a danger to him/herself or to others? Again, the “Principles for the protection of persons with mental illness” provide invaluable guidance. They require involuntary admission decisions to be taken by qualified mental health practitioners who are monitored and controlled by judicial or other independent and impartial review bodies. Legitimate grounds for involuntary commitment are immediate harm to the individual or others, or a serious deterioration in his/her condition.⁹ In addition, the Principles strictly regulate legal capacity decisions and standards of care and treatment.

Several other liberty rights under the ICCPR are important in civil commitment cases or in criminal cases in which the accused is disabled. Article 10 stipulates that “[a]ll persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.” Article 14 states that “[a]ll persons shall be equal before the courts and tribunals.” Both article 14 and article 15 recognize important rights in the context of criminal proceedings such as the right to a fair hearing, including “to have the free assistance of an interpreter if he cannot understand or speak the language used in court” (article 14(3)(f)).

Another important human right for disabled persons is contained in article 16: “Everyone shall have the right to recognition everywhere as a person before the law.” This is a key due process right in the context of both civil and criminal commitment. Disabled persons, whether legally competent or incapacitated, must not be treated as mere objects in any official proceedings. In addition, article 16 may serve, in the area of bioethics, as a “safety net” for the protection of the human rights of disabled persons. There seems to be a danger of redefining the “person” in the context of euthanasia in such a way as to exclude severely disabled persons.¹⁰

Two further liberty rights recognized in the ICCPR demonstrate that more is at stake than detention issues. Freedom from slavery and servitude (article 8) is an important right for disabled persons both within and outside institutions. The United Nations Sub-Commission on the Promotion and Protection of Human Rights¹¹ has established a Working Group on Contemporary Forms of Slavery that deals with human organ trafficking, the sale of women and children and the international sex trade.¹² Disabled persons are among the victims. Violations of article 8 may also occur in “sheltered workshops”, which offer employment to persons with disabilities. Disability groups have claimed that the working conditions in such facilities and the lack of legal protection for employees amount to conditions of slavery.¹³ Useful human rights

⁹ Principles 16 and 17.

¹⁰ See Helga Kuhse and Peter Singer, *Should the Baby Live? The Problem of Handicapped Infants* (New York, Oxford University Press, 1985).

¹¹ A subsidiary body of the United Nations Commission on Human Rights.

¹² For information on the Working Group on Contemporary Forms of Slavery see <http://www.unhchr.ch/html/menu2/i2slavwg.htm>.

¹³ See Susanne von Daniels, Theresia Degener et.al. (eds.) *Krüppel-Tribunal: Menschenrechtsverletzungen im Sozialstaat* (Cologne, Pahl-Rugenstein, 1983).

standards for sheltered workshops which could serve as interpretative guidelines for article 8 have been developed by the International Labour Organization (ILO).¹⁴

Lastly, the right to liberty of movement (article 12) includes the right to move around freely within a State and freedom to choose one's residence. To implement this human right for their disabled citizens, States parties may need to reconsider their public transportation and housing policies. The provision of such transport is not an ICCPR but an ICESCR issue. It highlights the interdependence and indivisibility of the two sets of rights, especially in the disability context.

(c) *ICCPR associational and other rights in the context of disability*

Social cooperation rights are rights that protect the need of all human beings to cooperate, to live in a community with others and to live as members of a social group. Freedom of association (article 22), family rights (article 23), the right to be protected as a child (article 24) and the right to privacy (article 17) fall within this cluster. It is open to debate whether the right to privacy really belongs in the group of social cooperation rights if it is interpreted as a right to be left alone. However, article 17 also covers privacy within the family and home and protects a person's honour and reputation, all of which are relevant to social life.

The right to privacy is a human right that is often neglected in the context of disability. Disabled persons frequently have to accept the involvement of many others in their private lives (doctors, therapists, personal assistants, etc.). The right to privacy is therefore difficult to protect, especially in an institutional setting. As it is based on the assumption of respect for autonomy and human dignity, it may be argued that article 17 of the Covenant is of special importance to disabled individuals.

The same applies to family rights (article 23) such as the right to marry and found a family and equality rights between spouses. These rights are violated if disabled persons are prevented from marrying for eugenic reasons. Compulsory sterilization practices also violate article 23 rights. The Despouy report notes that disabled persons are victims of such human rights violations in some countries.¹⁵ Disabled parents (i.e. disabled mothers) often experience discrimination and feel that States neglect them in their family programmes.¹⁶ The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by the General Assembly in 1993¹⁷, which is one of the most important human rights instruments for disabled people, may be used as a source of interpretative guidance on article 23 in the context of disability. Rule 9 describes disabled persons' requirements for equal rights to sexual relationships, marriage and parenthood. Article 24 of the Covenant states that the child has a right "to such measures of protection as are required by his status as a

¹⁴ See the ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159) and ILO Recommendation No 168 of 1983.

¹⁵ See the Despouy report (footnote 5 above).

¹⁶ See, for example, Michelle Wates and Rowen Jade (eds.) *Bigger than the Sky: Disabled Women on Parenting* (London, The Women's Press, 1999); Gisela Hermes (ed.) *Krücken, Babies und Barrieren. Zur Situation behinderter Eltern in der Bundesrepublik* (Kassel, bifos e.V., 1998); Barbara Duncan, Rosangela Berman-Bieler (eds.) *International Leadership Forum for Women with Disabilities. Final Report* (New York, Rehabilitation International, 1997).

¹⁷ General Assembly resolution 48/96 of 20 December 1993.

minor, on the part of his family, society and the State”. The article also includes an anti-discrimination clause which, interestingly, does not cover disabled children.

The right to association (article 22) raises the issue of access to public and private places where people meet. Disabled individuals need to have the opportunity to join political, social or cultural associations and to form their own organizations. Rule 18 of the Standard Rules draws attention to the important role that disability organizations play in the development of disability policy.

(d) *ICCPR political rights in the context of disability*

Last but not least, the ICCPR enshrines classical political rights, such as the right to freedom of thought (article 18) and freedom of opinion (article 19), the right of peaceful assembly (article 21), the right to take part in the conduct of public affairs (article 25) and equality rights (articles 2, 3 and 26).

Freedom of thought and freedom of opinion (articles 18 and 19) are commonly reduced to freedom of religion in the context of disability. While it is true that many disabled persons are religious, failure to consider disabled people as political citizens is a form of stereotyping. However, to become politically aware, it is essential to have access to general political debate in society. Media and lobby groups play an important role in political discourse. Some persons with disabilities, such as deaf and blind persons, are often deprived of this opportunity because of communication barriers. Yet article 19 states that the right to freedom of expression includes “freedom to seek, receive and impart information”.

The right of assembly (article 21) and the right to take part in public affairs (article 25) again raise issues of access to places where political life is played out. The right to vote (article 25), as a classic democratic right, is of central importance to the realization of freedom of thought and expression. But if polling stations are inaccessible to wheelchair users or if the election material is available in print version only, how can an election be considered to be held “by universal and equal suffrage and ... by secret ballot, guaranteeing the free expression of the will of the electors”? Similar concerns arise in connection with laws that prohibit all mentally disabled persons from voting.¹⁸

Representation of disabled persons in political parties, parliaments and other bodies is another form of political participation, but it is still the exception.

The most important implication of article 25 for disabled persons may be that every citizen is entitled to “have access, on general terms of equality, to public service in his country”. Gerard Quinn notes that this right can be read in two ways: “One might read it in such a way as to ensure that all persons can partake equally of their civic obligations which are associated with citizenship. The right to serve on a jury is one good example.¹⁹ One may also read it more expansively to guarantee a right of access

¹⁸ See Despouy report, para. 43.

¹⁹ See, for example, *Donald Galloway v. Superior Court of the District of Columbia*, 1993 US Dist. LEXIS 3314, 16 March 1993.

to public services.”²⁰ The latter interpretation is an interesting one for countries that have not enacted anti-discrimination laws for disabled citizens containing a right of access to public services, places and buildings.

The right to equality is one of the oldest and most fundamental human rights norms. The guarantee of equality is reflected in several provisions of the ICCPR but three clauses specifically address the issue: articles 2, 3 and 26. Article 3 requires gender equality and articles 2 and 26 prohibit discrimination on grounds such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. While disability is not mentioned explicitly, there is a broad consensus that disabled persons are covered by the term “other status”.²¹ The right to equality is one of the most important human rights for disabled persons. During the United Nations Decade of Disabled Persons (1983 – 1992), the international disability community emphasized that discrimination is the main reason for the exclusion of disabled people from the mainstream of society and for their relative poverty. Disability discrimination is singled out as the most rampant and fundamental human rights violation in the Despouy report.²² To interpret the ICCPR equality clauses in terms of disability, it may be useful to refer to the Standard Rules, which state that:

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.²³

4.2 Enforcement and interpretation of the ICCPR in the context of disability

The Human Rights Committee (HRC) is composed of 18 independent experts whose mandate consists in monitoring the implementation of the ICCPR in States parties. They are elected by the States parties for a four- year term, consideration being given to equitable geographical distribution of membership (articles 31 and 32 of the Covenant). Article 28 stipulates that the HRC “shall be composed of nationals of the States parties to the present Covenant who shall be persons of high moral character and recognized competence in the field of human rights”.

4.2.1 Working methods of the Human Rights Committee

The HRC meets three times a year for three weeks, once in New York and twice in Geneva. Its working methods are as follows.

²⁰ Degener and Koster-Dreese, *Human Rights and Disabled Persons*, p. 91.

²¹ Ibid., Aart Hendriks, “The significance of equality and non-discrimination for the protection of the rights and dignity of disabled persons”, p. 40.

²² Despouy report, p. 25.

²³ United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, paras 25 and 26.

First, the HRC reviews the reports submitted periodically by States parties. The initial report must be submitted within a year of the entry into force of the Covenant in the State concerned. Thereafter, States parties are required to submit reports on the basis of periodicity determined by the Committee. On examining the reports, the HRC can draw attention to matters of concern or make observations and recommendations. As it has no powers of enforcement, it views the examination of reports as an occasion for engaging in a “constructive dialogue” with States parties with a view to improving the human rights situation.²⁴

Second, the HRC reviews individual complaints or State complaints. Both procedures are based on a claim that a State party has violated the rights enshrined in the ICCPR. Individual complaints can be made by citizens of State parties that have ratified the first Optional Protocol. State complaints can be made between States that have made a declaration under article 41, which provides for this procedure. While the latter complaint procedure has never been used,²⁵ the number of individual complaints has increased enormously.²⁶ While the HRC can determine that a State party has violated the human rights enshrined in the ICCPR, it cannot enforce its views vis-à-vis the State concerned.²⁷

To facilitate interpretation of the ICCPR, the HRC adopts “general comments”. These comments are not binding on States parties but provide useful guidance on how to interpret the various Covenant provisions.²⁸ As of November 2001, the HRC had adopted 29 general comments reflecting experience gained from its reviews of State party reports or its consideration of complaints. The Committee described the purpose of general comments in its 1994 report:

General comments ... do not purport to ... attribute any priority among the different aspects [of the Covenant] in terms of implementation. They are intended to make the Committee’s experience available for the benefit of all States parties so as to promote more effective implementation of the Covenant; to draw their attention to insufficiencies disclosed by a large number of reports; to suggest improvements in the reporting procedures to clarify the requirements of the Covenant; and to stimulate the activities of States parties and international organizations in the promotion and protection of human rights.²⁹

NGOs are not allowed to take part in the discussions of the HRC but they can submit written information and so-called “parallel” reports to the Committee. NGOs participate actively in the Working Group of the HRC that meets prior to each session. The Working Group on reports is composed of five members and their primary mandate is to prepare “lists of issues” on State party reports under consideration.

²⁴ See Henry J. Steiner and Philip Alston, *International Human Rights in Context: Law, Politics Morals* (Oxford University Press, 1996), p. 506

²⁵ *Ibid.*, p. 536.

²⁶ Anne F. Bayefsky, *The United Nations Human Rights Treaty System: Universality at the Crossroads* (York University Press, 2001), p. 26

²⁷ Steiner and Alston, *International Human Rights in Context*, p. 537

²⁸ *Ibid.*, p. 524.

²⁹ *Official Records of the General Assembly, Forty-ninth Session, Supplement No. 40 (A/49/40)*, vol.I, para. 50.

4.2.2 ICCPR general comments and disability

Unlike the ICESCR Committee, the HRC has no specific general comment on disabled persons. Each general comment addresses a specific article of the Covenant. Some more recent comments have replaced older ones. The following four make some mention of disabled persons:

- General Comment No. 8 of 1982 on the right of liberty and security of person (article 9);³⁰
- General Comment No. 19 of 1990 on protection of the family, the right to marry and the equality of spouses (article 23);³¹
- General Comment No. 20 of 1992, which replaces General Comment No. 7 concerning the prohibition of torture and cruel, inhuman or degrading treatment or punishment (article 7);³² and
- General Comment No. 25 of 1996 on the right to take part in the conduct of public affairs, the right to vote and to be elected, and the right to equal access to public service (article 25).

(a) ICCPR General Comment No. 8 (liberty and security of person) and disability

General Comment No. 8 stresses that article 9, paragraph 1 (the right to liberty and security of person):

is applicable to all deprivations of liberty, whether in criminal cases or in other cases such as, for example, mental illness, vagrancy, drug addiction, educational purposes, immigration control, etc. It is true that some of the provisions of article 9 ... are only applicable to persons against whom criminal charges are brought. But the rest, and in particular the important ... right to control by a court of the legality of the detention, applies to all persons deprived of their liberty by arrest or detention. Furthermore, States parties have ... also to ensure that an effective remedy is provided in other cases in which an individual claims to be deprived of his liberty in violation of the Covenant.

In paragraph 4, the HRC addresses preventive detention:

Also if so-called preventive detention is used, for reasons of public security, it must be controlled by the same provisions, i.e. it must not be arbitrary, and must be based on grounds and procedures established by law, ... information of the reasons must be given ... and court control of the detention must be available ... as well as compensation in the case of a breach.

General Comment No. 8 contains no reference to disability-specific human rights instruments that could offer guidance in interpreting the applicability of article 9 to detained persons with disabilities. A cross-reference to two other soft-law

³⁰ See “Compilation of general comments and general recommendations adopted by human rights treaty bodies“ (HRI/GEN/1/Rev.5).

³¹ Ibid.

³² Ibid.

instruments, the 1971 Declaration on the Rights of Mentally Retarded Persons³³ and the 1975 Declaration on the Rights of Disabled Persons,³⁴ might have proved useful. Although they have no direct bearing on the interpretation of the Covenant, both refer to the ICCPR in their preambles and contain useful paragraphs on the restriction of human rights by detention.³⁵

(b) *ICCPR General Comment No. 19 (family, marriage) and disability*

While General Comment No. 19 does not explicitly refer to a disabled person's right to marry and found a family, paragraphs 4 and 5 make some useful statements in this regard:

4. ... States parties' reports should indicate whether there are restrictions or impediments to the exercise of the right to marry based on special factors such as degree of kinship or mental incapacity. ...

5. The right to found a family implies, in principle, the possibility to procreate and live together. When States parties adopt family planning policies, they should be compatible with the provisions of the Covenant and should, in particular, not be discriminatory or compulsory. ...

The issue of the right to marry is a real one for many persons with disabilities, especially women with intellectual impairments.³⁶ The wording of General Comment No. 19 is therefore useful, but a clear statement that disability per se should never be regarded as a legitimate ground for sterilization and restrictions on marriage would have been even more helpful.

It is noteworthy that none of the twelve general comments adopted by the HRC during the United Nations Decade of Disabled Persons (1982-1993) refers specifically to the rights of disabled persons.

(c) *General Comment No. 20 (torture) and disability*

General Comment No. 20 relating to torture and cruel, inhuman or degrading treatment or punishment makes no explicit mention either of disabled persons but includes some statements that are of importance to them.

2. The aim of the provisions of article 7 of the International Covenant on Civil and Political Rights is to protect both the dignity and the physical and mental integrity of the individual. It is the duty of the State party to afford everyone protection through legislative and other measures as may be necessary against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity. ...

³³ General Assembly resolution 2856 (XXVI) of 20 December 1971, reproduced in Degener and Koster-Dreese, *Human Rights and Disabled Persons*, pp. 371 ff.

³⁴ General Assembly resolution 3447 (XXX) of 9 December 1975 reproduced in Degener and Koster-Dreese, *Human Rights and Disabled Persons*, pp. 373 ff.

³⁵ Paras. 6 and 7 of the 1971 Declaration and paras. 4, 10 and 11 of the 1975 Declaration.

³⁶ See T. Degener, "Disabled women and international human rights", *Women and International Human Rights Law*, Kelly D. Askin and Doreen M. Koenig (eds.), vol. 3, (Ardsley NY, Transnational, 2001), pp. 267 – 293.

7. Article 7 expressly prohibits medical or scientific experimentation without the free consent of the person concerned. The Committee notes that the reports of States parties generally contain little information on this point. More information should be given to the need and means to ensure observance of this provision. The Committee also observes that special protection in regard to such experiments is necessary in the case of persons not capable of giving valid consent, and in particular those under any form of detention or imprisonment. Such persons should not be subjected to any medical or scientific experimentation that may be detrimental to their health.

General Comment No.20 thus raises two important points with regard to the meaning of article 7 for disabled persons.

First, and most importantly, States parties have a clear legal responsibility for violations of human rights that occur in private institutions for disabled persons. This point is of great significance in the light of the trend toward privatization of such services worldwide. Second, disabled persons who are not capable of giving valid consent should be protected against any medical or scientific experimentation. Both points are important for the human rights protection of persons with disabilities.

The human rights of disabled persons can also be violated in the context of social service provision. Not only is it difficult to expose the perpetrators but the act itself is often not considered to be a human rights violation because the author is not a State official. General Comment No. 20 suggests that it is and offers valuable guidance in relation to the medical and scientific experimentation to which disabled persons are often subjected.

This subject was hotly debated in Europe when the European Convention on Human Rights and Biomedicine was adopted in 1997. Article 17 of this regional treaty allows non-therapeutic medical research to be carried out on persons incapable of giving valid consent. Disability groups in many European countries such as Germany³⁷ and the United Kingdom protested against the Convention. Some scholars have argued that the article 17 provision is incompatible with article 7 of the ICCPR, arguing that the latter prevails under international law.³⁸

(d) *ICCPR General Comment No. 25 (voting, right to take part in public affairs) and disability*

General Comment No. 25 is the first HRC comment that specifically addresses disabled persons – in three of its twenty-seven paragraphs:

4. Any conditions which apply to the exercise of the rights protected by article 25 should be based on objective and reasonable criteria. ... For example, established mental incapacity may be a ground for denying a person the right to vote or to hold office.

10. ... It is unreasonable to restrict the right to vote on the ground of physical disability or to impose literacy, educational or property requirements. ...

³⁷ For an overview of the German debate see T. Degener, “Chronologie der Bioethik-Konvention und ihre Streitpunkte”, *Kritische Vierteljahresschrift für Gesetzgebung und Rechtswissenschaft*, vol. 1 (1998), pp.7-33.

³⁸ A. Hendriks, “Article 17 of the European Convention on Human Rights and Biomedicine: incompatible with international human rights law?”, *Kritische Vierteljahresschrift für Gesetzgebung und Rechtswissenschaft*, vol. 1 (1998), p. 116.

20. An independent electoral authority should be established to supervise the electoral process and to ensure that it is conducted fairly, impartially and in accordance with established laws which are compatible with the Covenant. ... Assistance provided to the disabled, blind or illiterate should be independent. Electors should be fully informed of these guarantees.

These interpretations offer significant guidance for the inclusion of disabled persons in the electoral process. The Comment establishes that physical disability may never be a legitimate ground for restricting the right to vote. Neither may any intellectual disability be considered a reason for denying a person the right to vote or to hold office. Such action is permissible only in cases of established mental incapacity. The Comment further states that persons assisting disabled voters must be neutral, their only task being to preserve the independence of the voter. The same would hold true for technical adjustments such as ensuring accessibility and privacy of voting space.

These comments clearly have implications for the manner in which elections are run. Sometimes disabled persons are denied the right to vote even though their functional limitation does not affect their decision-making. Voting assistance to disabled persons is sometimes given by family members or others on whom the disabled person depends. This raises issues of privacy and autonomy and in any event leaves the disabled person susceptible to manipulation.

General Comment No. 25 fails to give detailed guidance on the kind of information that States parties should include in their reports and the degree of detail required. For example, are inaccessible polling stations a violation of article 25 of the Covenant? Have blind people a right to receive voting material in Braille or on tape? Are deaf people entitled to sign language interpretation? Some statements in the Comment, however, may serve as arguments to respond to all these questions:

11. States must take effective measures to ensure that all persons entitled to vote are able to exercise that right. ...

12. ... Information and materials about voting should be available in minority languages. Specific methods, such as photographs and symbols, should be adopted to ensure that illiterate voters have adequate information on which to base their choice. ...

Hence it may be argued that States need to ensure that disabled persons have access to polling stations. Sign language and Braille may even be considered minority languages. If this argument is rejected on the grounds that disabled persons are not recognized as a minority within the meaning of article 27 of the Covenant, it could be argued that deaf and blind people are in a similar situation to persons using a minority language and are thus entitled to equal treatment. The reference to the “specific methods, such as photographs and symbols” that are needed to accommodate illiterate persons shows that States parties have a duty to adjust information and voting materials to cater for different forms of communication.

General Comment No. 25 is silent on the meaning of article 25, subparagraph (c), of the Covenant for disabled persons. The right to equal access to public service may be read either restrictively or expansively. To date the HRC has read it restrictively as a right of equal access to public service positions in terms of “appointment, promotion, suspension and dismissal.”³⁹ While affirmative measures “may be taken in appropriate

³⁹ General Comment No. 25, para. 23.

cases to ensure there is equal access to public service for all citizens”,⁴⁰ disabled persons are not specifically mentioned.

Access is one of the main subjects addressed in the Standard Rules⁴¹ - an instrument adopted by the General Assembly just three years before the HRC adopted General Comment No. 25. It would have been useful if the General Comment had taken them into account.

4.3 An evaluation of the operation of the ICCPR in the context of disability

4.3.1 State reporting and disability under the ICCPR

The following methodology was used in evaluating the way in which the HRC and States parties deal with disability as a human rights issue under the ICCPR.

All available State party reports submitted since 1993 were reviewed in the light of disability issues. It is well known that there is a huge backlog of State party reports that are either overdue or have been submitted but not yet been reviewed by the treaty bodies.⁴²

In addition, all available ICCPR documents relating to State party reports dated 1993 or later were reviewed from a disability perspective. These documents are categorized as follows:

- “Lists of issues” are documents that identify areas of concern in the light of a preliminary analysis of State party reports. These documents are usually prepared by a working group that meets prior to HRC sessions. The issues identified are addressed when the report is examined in the presence of the State party representatives.
- “Concluding observations” are HRC documents issued at the end of the process and reflect the dialogue between the HRC members and States parties on the State party report. The reports are examined in the presence of representatives of the Government and conclude with the adoption of “concluding observations”.
- “Summary records” contain a detailed summary of HRC proceedings.

The year 1993 was chosen as a starting point because of the adoption that year of the Standard Rules by the United Nations General Assembly. The Standard Rules were adopted to some extent as a substitute for a binding human rights treaty on disability and are thus regarded as the most important United Nations human rights instrument on disability.⁴³ While monitoring of the Standard Rules takes place outside the United Nations human rights machinery in the framework of the Commission for Social Development, all United Nations bodies are required to cooperate with the Special

⁴⁰ Ibid.

⁴¹ See, for example, Rule 5: “States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. ...”

⁴² See Bayefsky, *The United Nations Human Rights Treaty System*, p. 7.

⁴³ See Degener and Koster-Dreese, *Human Rights and Disabled Persons*, p. 12

Rapporteur in monitoring their implementation.⁴⁴ Furthermore, 1993 marked the end of the United Nations Decade of Disabled Persons, which was supposed to raise awareness of disability issues among States Members of the United Nations and United Nations agencies.

4.3.2 An overview of State party reports and disability under the ICCPR

Of the 114 State party reports reviewed, 76 (67 per cent) made some reference to disability issues. This surprisingly positive result becomes less impressive if one takes a closer look at the content of the references.

The majority of State party reports (57 per cent) mention disabled persons in connection with three or fewer articles of the ICCPR. Only 7 per cent refer to disabled persons in connection with seven or more of the twenty-seven human rights protected by the Covenant.

The most frequently cited provisions are article 23 (family rights) and article 24 (children's right to protection). Some 43 per cent of State party reports refer to these provisions. However, the reference hardly ever contains information about disabled persons' right to marry and procreate, or disabled children's right to mainstream education⁴⁵ or to protection from exploitation. The references commonly contain information about family benefits for disabled children or similar social welfare issues. The next most frequently cited provisions of the Covenant with respect to disabled persons are articles 2 and 26 (equality and non-discrimination). A further 32 per cent of reports state that equality laws have been adopted under which disabled persons are also or exclusively protected.

This finding matches our earlier research on disability reform laws globally.⁴⁶ It was found that more than forty countries adopted disability discrimination laws during the last decade or earlier. Twenty-four of these countries mentioned the fact in their State party reports to the HRC. Not many reports contained detailed information about the new laws and their implementation. Examples of good practice in this regard are the reports of Australia,⁴⁷ Canada,⁴⁸ Finland,⁴⁹ China (on Hong Kong Special Administrative Region),⁵⁰ the United Kingdom,⁵¹ and the United States.⁵² These State party reports contain useful information about the goals of modern anti-discrimination laws on disability, the areas covered and their implementation.

⁴⁴ Standard Rules, chap. IV: "Monitoring mechanism", para. 7.

⁴⁵ With the notable exception of the initial report of Zimbabwe (CCPR/C/74/Add.3).

⁴⁶ T Degener and G. Quinn, "A survey of international, comparative and regional disability law reform", forthcoming in *Disability Rights: Transforming National and International Law*, Disability Rights Education Defense Fund (DREDF) (ed.), (NY: Transnational).

⁴⁷ Third periodic report (CCPR/C/AUS/98/3).

⁴⁸ Fourth periodic report (CCPR/C/103/Add.5).

⁴⁹ Fourth periodic report (CCPR/C/95/Add.6).

⁵⁰ Initial report (CCPR/C/HKSAR/99/1/Add.1).

⁵¹ Fifth periodic report (CCPR/C/United Kingdom/99/5).

⁵² Initial report (CCPR/C/81/Add.4).

The majority of State party reports (54 per cent) refer briefly to disabled persons as one among several groups, usually together with women and children. Only 30 per cent of the reviewed State party reports include statements relating exclusively to disabled persons.

Other than addressing social welfare measures and equality laws, State party reports tend to refer to disabled persons in connection with civil commitment and the compulsory treatment of mentally ill or intellectually impaired persons, treatment of disabled defendants and prisoners, voting rights, marriage and divorce law, immigration law and medical experimentation.

With respect to civil commitment and (compulsory) treatment of disabled persons, State party reports reflect an awareness that very serious human rights issues are at stake. Thus, most reports that raise issues under article 7 (torture/inhuman treatment), article 9 (liberty and security of person) or article 10 (detention) cite mental health legislation that provides some kind of procedural safeguard. However, State party reports often merely cite the laws without giving any information on how the procedure is actually implemented (e.g. whether judicial review is applicable or whether detention and compulsory treatment decisions are left to the discretion of doctors).⁵³ There is a considerable amount of good practice in the system. The State party reports of Denmark,⁵⁴ the United Kingdom (on Hong Kong),⁵⁵ Israel,⁵⁶ the Netherlands,⁵⁷ and the United States,⁵⁸ are notable for the human rights approach adopted to civil commitment legislation.

Reports usually address the subject of disabled defendants in judicial proceedings under article 14 (equality before the courts). A significant number of State party reports display an overprotective attitude in that legal representation is mandatory for disabled defendants, regardless of whether they are able to defend themselves.⁵⁹

Very few State party reports address the issue of the human rights of disabled prisoners or the treatment of disabled defendants. Notable examples of good practice in this regard are the reports of the Czech Republic, Denmark and the United Kingdom. The initial report of the Czech Republic and the second periodic report of Ireland⁶⁰ frankly acknowledge that State prisons are unable to accommodate disabled prisoners.⁶¹ Denmark reports that the State has established a training programme for police officers on how to deal with disabled persons.⁶² In the United Kingdom a

⁵³ See, for example, the fourth periodic report of Poland (CCPR/C/95/Add.8), paras. 60 ff.

⁵⁴ Third periodic report of Denmark (CCPR/C/64/Add.11).

⁵⁵ Fourth periodic report of the United Kingdom (Hong Kong) (CCPR/C/95/Add.5), para. 123.

⁵⁶ Initial report of Israel (CCPR/C/81/Add.13), paras 227 ff.

⁵⁷ Third periodic report of the Netherlands (CCPR/C/NET/99/3) paras. 54 to 57 and paras. 77 to 81.

⁵⁸ Initial report of the United States (CCPR/C/81/Add.4), paras. 172 ff., paras. 247 ff. and paras. 280 ff.

⁵⁹ Initial report of Slovakia (CCPR/C/81/Add.9), para. 49.

⁶⁰ CCPR/C/IRL/98/2, para. 408. This report is unique in that the information about inaccessible prisons comes from NGOs that are cited in the State party report.

⁶¹ CCPR/C/CZE/2000/1, para. 209.

⁶² Fourth periodic report of Denmark (CCPR/C/DNK/99/4). para. 73.

common standard of conduct has been laid down for all staff working in prisons which also refers to disabled inmates.⁶³

A minority of State party reports mention disabled persons' right to vote under article 25 (right to vote, access to public service). However, not all of these reports reflect an understanding that disabled persons are citizens with equal political rights. Thus, some merely state that people with intellectual impairments are denied the right to vote.⁶⁴ Others seem to find it sufficient to permit physically disabled voters to bring along their own assistants or demand that persons needing adjustments in the voting process notify the electoral board.⁶⁵ Only four State parties report positive action taken by the federal or local government to make the voting process accessible to disabled persons.⁶⁶ One reports that such affirmative measures are limited to people who are unable to walk, while blind, deaf or otherwise disabled persons have to bring their own assistants.⁶⁷

Where State party reports mention disabled persons in the context of their domestic immigration laws under article 12 (rights of aliens), it is usually to state that disability is a legal ground for denial of permission to immigrate. The small number of States that admit to such judicial discrimination against disabled persons tend not to perceive such discrimination as a human rights issue.

Three State party reports – those of Australia, the Netherlands and the United States – address the issue of scientific or medical experimentation. While Australia's third periodic report states that "in principle" such interventions are only carried out on persons who can give informed consent,⁶⁸ the initial report of the United States reveals that (non-therapeutic) medical or scientific experimentation has been carried out on persons without their consent. These practices are described as illegal and are said to be under investigation.⁶⁹ The third periodic report of the Netherlands states that, under certain circumstances, non-therapeutic experimentation may be carried out on persons incapable of giving informed consent.⁷⁰

One State party report – the fourth periodic report of Finland – treats the right to use sign language as a human rights issue under article 27 of the Covenant (minority rights) and notes that the Finnish constitution was amended accordingly in 1995.⁷¹

Overall, the review of 114 State party reports to the HRC shows that the majority of States (63 per cent) still tend to approach the human rights of disabled persons under

⁶³ Fourth periodic report of the United Kingdom (CCPR/C/95/Add.3), para. 131.

⁶⁴ See, for example, the fourth periodic report of the United Kingdom (Dependent Territories (Guernsey) CCPR/C/95/Add.10), para.19.

⁶⁵ See, for example, the third periodic report of Venezuela (CCPR/C/VEN/98/3), para. 386 and the initial report of the former Yugoslav Republic of Macedonia (CCPR/C/74/Add.4), para. 542.

⁶⁶ Fourth periodic report of Canada (CCPR/C/103/Add.5) paras. 244 ff.; initial report of Israel (CCPR/C/81/Add.13) para. 808; initial report of the United States (CCPR/C/81/Add.4) para. 754; fourth periodic report of Italy (CCPR/C/103/Add.4) para. 195.

⁶⁷ Fourth periodic report of Italy (CCPR/C/103/Add.4), para. 195.

⁶⁸ CCPR/C/AUS/98/3, para. 383.

⁶⁹ Initial report of the United States (CCPR/C/ 81/Add. 4), paras. 178 ff.

⁷⁰ CCPR/C/NET/99/3.

⁷¹ CCPR/C/95/Add.6, para. 118.

the Covenant from a medical or welfare angle. A minority of reports (38 per cent) adopt an approach based more on civil and political rights.

An outstanding example of good practice is the third periodic report of Australia, which provides a comprehensive overview of federal and state disability discrimination law and which also refers to disabled Australians in connection with nine substantive rights covered by the ICCPR.⁷² The report deals extensively with such matters as anti-discrimination law in the context of disability, the relationship between abortion law and disability, mental health legislation, civil and criminal commitment, medical research and scientific experiments, jury service, protection of legal personality, support measures for families with disabled children, and disability discrimination in the area of education, voting rights, public employment and staff selection.

The report reflects an awareness that legislation alone is not sufficient for the realization of human rights. Australia's third periodic report gives an admirably clear picture of the situation and refers candidly to problems such as the exclusion of disabled persons from jury service.

4.3.3 An evaluation of how disability issues are handled in the dialogue between the HRC and States parties

To analyse how disability issues were dealt with in the dialogue between HRC members and State representatives, all available documents since 1993 in the categories "list of issues", "summary records", "concluding observations" and "annual reports" were reviewed.

(a) Disability in HRC lists of issues

Three out of thirty-three "list of issues" documents raised disability issues. Two concerned requests to the State party – the United Kingdom (concerning the Crown Dependent Territory of Jersey) and Guyana – to provide information about legislation and policy prohibiting discrimination against disabled persons and other groups (women, homosexuals, old persons) who are covered by article 26 of the Covenant (non-discrimination).⁷³ The third document raised an issue relating exclusively to disabled persons. In connection with the consideration of the second periodic report of the Syrian Arab Republic, the State party was asked to "elaborate on article 70b of the Law on the Judiciary pursuant to which disabled persons are denied access to posts in the judiciary."⁷⁴

(b) Disability issues in HRC summary records

Of 381 "summary records" relating to HRC sessions, 58 (15 per cent) included some reference to disabled persons. While disabled persons were dealt with mostly as one of several groups mentioned (usually women and usually in connection with

⁷² CCPR/C/AUS/98/3.

⁷³ CCPR/C/68/L/UKCD and CCPR/C/68/L/GUY.

⁷⁴ CCPR/C/71/L/SYR.

discrimination), 13 summary records (3 per cent) made explicit reference to issues relating to disabled persons. The subjects dealt with were capital punishment, voting rights, welfare benefits and support services for disabled family members, sterilization, legal protection, status of disabled persons in society, abortion law, detention and corporal punishment, disabled children, amputation as criminal punishment, and scientific and medical experiments.

HRC members rarely request detailed information about involuntarily institutionalized disabled persons. Nor do they tend to initiate a dialogue with State representatives regarding circumstances in which there seems to be no “court control of the detention” (General Comment No. 8). HRC members seem to be reluctant to enforce General Comment No. 25, which states that disabled persons should have equal voting rights and that voting assistance should be truly independent. General Comment No. 25 has much untapped potential in the context of disability. The issue of disabled persons seems to be brought into the dialogue more often by State representatives than HRC members. Sometimes the summary records contain no comments by members even where the reports themselves reveal discrimination, as in the case of immigration laws prohibiting disabled persons from immigration. We wish to emphasize that none of the above is due to any lack of interest on the part of HRC members but, more probably, to the weight of other competing priorities.

It is laudable that HRC members often mention disabled persons in the context of article 26 of the Covenant (non-discrimination). These initiatives are welcome. But the summary records also show that the dialogue between the Committee and States parties tends not to focus on positive examples of cases in which disability discrimination or mental health laws adhere to human rights principles. Such a dialogue might give HRC members a deeper insight into disability matters and it could usefully alert States parties to innovative thinking.

The review of available summary records showed that the HRC not only asked questions but also expressed explicit concern regarding the enjoyment of human rights by disabled persons in four cases. When considering the third periodic report of Cyprus, the HRC expressed concern about a law under which the use of force against an intellectually disabled person was not deemed to be a punishable offence.⁷⁵ During its consideration of Japan’s fourth periodic report, HRC members welcomed the abolition of a law on the compulsory sterilization of disabled women. However, the Committee was concerned that the Government had not yet paid compensation to approximately 16,000 disabled women who had been sterilized between 1949 and 1995.⁷⁶ When reviewing the initial report of the United States, the HRC raised concerns about the execution of intellectually disabled persons.⁷⁷

(c) Disability issues in HRC concluding observations

Purely as a matter of fact, disability issues do not figure prominently in the concluding observations of the HRC.

⁷⁵ CCPR/C/SR.1648, para. 20.

⁷⁶ CCPR/C/SR.1716, para. 30.

⁷⁷ CCPR/C/SR.1405, para. 56.

Of 153 reviewed documents, only 10 (7 per cent) mentioned the human rights of disabled persons. The countries referred to were Australia,⁷⁸ Austria,⁷⁹ Canada,⁸⁰ the United Kingdom (on Hong Kong),⁸¹ Ireland, Japan, Korea⁸², Lithuania⁸³, Netherlands and the United States. Of these nine concluding observations, five welcomed the disability laws or measures adopted by the respective State. Four (3 per cent) included critical statements or recommendations. With respect to the United States, for example, the HRC expressed concern that in some States non-therapeutic research was undertaken involving incapacitated persons. In addition, it expressed regret that in some cases there appeared to have been a lack of protection of the mentally retarded from the death penalty.⁸⁴

With regard to Ireland's second periodic report, the HRC recommended that further action should be taken to ensure

the full and equal enjoyment of Covenant rights by disabled persons, without discrimination, in accordance with article 26 ...⁸⁵

With regard to Japan's fourth periodic report, the Committee,

while acknowledging the abolition of forced sterilization of disabled women, regrets that the law has not provided for a right of compensation to persons who were subjected to forced sterilization, and recommends that the necessary legal steps be taken.⁸⁶

Great concern was expressed by the HRC regarding euthanasia and medical research in the context of the third periodic report of the Netherlands:

(d) The Committee, having taken full note of the monitoring task of the review committee, is also concerned about the fact that it exercises only an *ex post* control, not being able to prevent the termination of life when the statutory conditions are not fulfilled.

The State party should re-examine its law on euthanasia and assisted suicide in the light of these observations. It must ensure that the procedures employed offer adequate safeguards against abuse or misuse, including undue influence by third parties. The *ex ante* control mechanism should be strengthened. The application of the law to minors highlights the serious nature of these concerns. The next report should provide detailed information as to what criteria are applied to determine the existence of a "voluntary and well-considered request", "unbearable suffering" and "no other reasonable alternative". It should further include precise information on the number of cases to which the new Act has been applied and on the relevant reports of the review committee. The State party is asked to keep the law and its application under strict monitoring and continuing observation.

⁷⁸ *Official Records of the General Assembly, Fifty-fifth Session, Supplement No. 40 (A/55/40)*, vol I, paras. 498 – 528.

⁷⁹ CCPR/C/79/Add.103.

⁸⁰ CCPR/C/79/Add.105.

⁸¹ CCPR/C/79/Add.57.

⁸² CCPR/C/79/Add.114.

⁸³ CCPR/C/79/Add.87.

⁸⁴ CCPR/C/79/Add.50, paras. 286 ff and para. 281.

⁸⁵ *Official Records of the General Assembly, Fifty-fifth Session, Supplement No. 40 (A/55/40)*, vol I, para. 450.

⁸⁶ CCPR/C/79/Add.102, para. 31.

6. The Committee is gravely concerned at reports that new-born handicapped infants have had their lives ended by medical personnel.

The State particularly should scrupulously investigate any such allegations of violations of the right to life (article 6 of the Covenant), which fall outside the law on euthanasia. The State particularly should further inform the Committee on the number of such cases and on the results of court proceedings arising out of them⁸⁷.

The HRC thus adopted a different and much more critical standpoint on the issue than the Council of Europe.

4.4 Disability as a human rights issue in the complaints procedures under the first Optional Protocol to the ICCPR

4.4.1 Disability issues in case law under the Optional Protocol

At every session the HRC also considers individual complaints about violations of the Covenant. The complaint procedure can be used only if the State in question has ratified the first Optional Protocol to the ICCPR. In such cases, individual citizens or their representatives can claim (in the form of a “communication”) to be a victim of the infringement by a State party of any of the rights set forth in the Covenant. The HRC reviews these cases on the basis of written information only. The complainant and the State party concerned have an opportunity to put forward their version of events and to argue the case, but there are no oral hearings before the Committee.

The HRC considers communications in closed meetings. Only its final decisions – called “Views” – are available to the public. The Committee first decides whether the communication is admissible. If it is deemed to be admissible, the HRC proceeds to assess whether the State party has violated the ICCPR. Where it finds that there has been a violation, it often indicates in its “Views” what action should be taken by the State party in order to remedy the situation.⁸⁸ Although these “Views” on individual complaints are not enforceable, they are nevertheless of legal value. They do not constitute case law in the strict legal sense because the HRC is not a court like, for example, the European Court of Human Rights. But the Committee is the only United Nations body with a mandate to interpret the ICCPR in the context of individual complaints and it has developed a rich jurisprudence on Covenant provisions over the years.

If a communication is admitted under the first Optional Protocol, the HRC often presents legal arguments interpreting relevant ICCPR provisions in the context of the case before it. While the concluding observations on a State party’s periodic report reflect the HRC’s opinions on the overall implementation of the Covenant in that State, the “Views” reflect the Committee’s interpretation of the application of certain articles of the ICCPR to specific situations.

⁸⁷ CCPR/CO/72/NET.

⁸⁸ For further details on individual complaints procedures under the ICCPR see Steiner and Alston, *International Human Rights Law in Context*, p. 535, and Bayefsky, *The United Nations Human Rights Treaty System*, p. 25 ff.

The individual complaints procedure under the first Optional Protocol to the Covenant is not widely known and cases are distributed very unevenly in geographical terms. During the first 15 years, only 468 complaints were received from a total of 36 States parties.⁸⁹ More recently, the number of complaints has grown dramatically but their geographical distribution remains uneven.⁹⁰

For the purposes of this study, 344 HRC documents dealing with both the admissibility and the merits of complaints were examined. Of these 344 cases, 8 communications, or 2 per cent, dealt with disability issues. The complaints concerned issues such as employment discrimination,⁹¹ discrimination relating to compensation of war veterans,⁹² discrimination relating to welfare benefits⁹³ and torture or inhuman and degrading treatment.⁹⁴ All but two of these cases were declared inadmissible.

In one of the disability complaints deemed admissible – *Hamilton v. Jamaica* (1999), the HRC adopted an interesting and robust view on the application of article 10 of the Covenant (treatment of detained persons with humanity) to disabled prisoners.⁹⁵ The case essentially involved the treatment and conditions of confinement of a disabled prisoner on death row. He was paralysed in both legs and experienced extreme difficulty in slopping out his cell and climbing onto his bed. It was argued before the HRC that his rights under articles 7 and 10 of the Covenant had been violated because the prison authorities had failed to take his disability into account and make proper arrangements for him. In essence, he argued that the absence of “reasonable accommodation” of his condition violated the ICCPR. The HRC agreed and stated that:

8.2...the conditions described...are such as to violate the author's right to be treated with humanity and with respect for the inherent dignity of the human person, and are therefore contrary to article 10, paragraph 1.

...

9. The Human Rights Committee, acting under article 5, paragraph 4, of the Optional Protocol to the International Covenant on Civil and Political Rights, is of the view that the facts before it disclose a violation of articles 10, paragraph 1, 9, paragraph 3, and 14, paragraph 3 (c), of the Covenant.

⁸⁹ Torkel Opsahl, “The Human Rights Committee”, *The United Nations and Human Rights*, Philip Alston (ed.) (New York: Oxford University Press 1992), p. 421.

⁹⁰ Bayefsky, *The United Nations Human Rights Treaty System*, p. 27.

⁹¹ *Nicolov v. Bulgaria*, communication No 824/1998, decision adopted by the Committee on 13 April 2000 (CCPR/C/68/D/824/1998); *Cziklin v. Canada*, communication No 741/1997, decision adopted by the Committee on 5 August 1999 (CCPR/C/66/D/741/1997).

⁹² *Drake et al. v. New Zealand*, communication No. 601/1994, decision adopted by the Committee on 29 April 1997 (CCPR/C/59/D/601/1994); *Atkinson et al. v. Canada*, communication No 573/1994, decision adopted by the Committee on 9 November 1995 (CCPR/C/55/D/573/1994).

⁹³ *R.E.d.B. v. Netherlands*, communication No 548/1993, decision adopted by the Committee on 5 November 1993 (CCPR/C/49/D/548/1993).

⁹⁴ *Hamilton v. Jamaica*, communication No. 616/ 1995, Views adopted by the Committee on 28 July 1999 (CCPR/C/66/D/616/1995); *Hart v. Australia*, communication No 947/2000, decision adopted by the Committee on 27 October 2000 (CCPR/C/70/D/947/2000); *Kehler v. Germany*, communication No. 834/ 1998, decision adopted by the Committee on 2 April 2001 (CCPR/C/71/D/834/1998).

⁹⁵ *Hamilton v. Jamaica*.

10. In accordance with article 2, paragraph 3 (a), of the Covenant, the State party is under an obligation to provide Mr. Hamilton with an effective remedy, entailing compensation and placement in conditions that take full account of his disability. The State party is under an obligation to ensure that similar violations do not occur in the future.

The Views of the HRC in this case have important implications for the application of the Covenant to disabled persons. First, the case illustrates that disabled persons' human rights are not only affected in the context of social welfare and health. Like non-disabled citizens, disabled persons experience human rights violations in various roles, as prisoners, as voters, as employees, as family members, etc. Second, the Committee's Views send an important signal that the rights laid down in the ICCPR are applicable to all. Article 10 states that all detained individuals have a right to be treated with humanity and respect. It follows that States parties are not permitted to differentiate negatively between disabled and other prisoners. Third, the outcome indicates that the HRC was operating on some unstated philosophy of "reasonable accommodation". It follows that States parties should recognize that there are prisoners with different needs and that they have to adjust their systems to accommodate those needs. Lastly, the HRC's Views at least imply a rejection of the view that civil and political rights have no implications for the positive treatment of prisoners. The concept of negative human rights, the argument goes, only means that the State has to refrain from certain actions which amount to human rights violations. And if a disabled individual does not adjust to the conditions under which human rights are usually exercised, it is the individual's problem and not the State's. The outcome in *Hamilton v. Jamaica* goes a long way towards viewing people with disabilities as rights-holders and not as problems. This understanding of human rights in the context of disability has won support not only from the HRC. The European Court of Human Rights heard a similar case in 2001 involving a disabled woman who had been committed to a prison in the United Kingdom for a couple of days. The Court considered that

to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment contrary to article 3 [of the European Convention for the Protection of Human Rights and Fundamental Freedoms]⁹⁶

Another disability case on which the HRC adopted a merits decision was that of *Clement Francis v Jamaica* (communication No. 606/1994). The complainant was convicted of murder in 1980 and sentenced to death. He remained on death row until murder was reclassified as a non-capital offence in 1992. Among other things, he complained that his mental health had substantially deteriorated as a result of the stress of waiting for the execution of the death penalty and in the absence of appropriate psychiatric attention. It was alleged that the circumstances of his incarceration therefore amounted to cruel, inhuman or degrading treatment and a lack of respect for his dignity contrary to article 7 and article 10, paragraph 1. To a certain extent, the essence of the complaint was that the conditions of confinement caused the onset of a disability. In its Views, the HRC found, inter alia, violations of article 7 and article 10, paragraph 1. It stated that:

⁹⁶ *Price v. the United Kingdom*, Judgment of the European Court of Human Rights (Third Section on Application No. 33394/96, 10 July 2001), para. 30.

Whereas the psychological tension created by prolonged detention on death row may affect persons in different degrees, the evidence before the Committee ... indicates that his mental health seriously deteriorated during incarceration on death row. Taking into consideration the author's description of the prison conditions, including his allegations about regular beatings inflicted on him by warders, as well as the ridicule and strain to which he was subjected during the five days he spent in the death cell awaiting execution in February 1988, which the State party has not effectively contested, the Committee concludes that these circumstances reveal a violation of Jamaica's obligations under articles 7 and 10, paragraph 1, of the Covenant⁹⁷.

The HRC is thus conscious of how poor conditions of incarceration can themselves give rise to disability. It follows that the HRC would be just as watchful over the conditions of detention of persons whose disability predated their incarceration.

It is interesting that such robust human rights decisions on disability arise in the context of prisons. Many prison inmates are actually persons with either physical or mental disabilities. The area of prisoners' rights is, of course, much more developed than that of the human rights of persons with disabilities. The fact that disability issues are beginning to emerge in the context of prisons is a welcome development.

4.5 Conclusions on the ICCPR and disability

4.5.1 Conclusions

The dominant theme of the disability rights movement is freedom and participation and not welfare. The ICCPR is all about engineering space for human freedom and enabling the human spirit to flourish. One would therefore logically expect the ICCPR monitoring mechanism to play a major role in advancing the freedom rights of persons with disabilities.

However, our review of the relevant United Nations documents shows that general awareness of the applicability of the ICCPR to disabled persons needs to be developed. This finding is reflected in the general comments adopted by the HRC. Four out of twenty-nine general comments include some reference to disabled persons. Important provisions of the ICCPR, such as the right to equality, the right to freedom of movement, the right of peaceful assembly, the right to freedom of information, and family rights have not thus far been interpreted by the HRC in its general comments in relation to disabled persons. The general comments that refer to disabled persons fail to do so comprehensively.

While the number of reports that mention disabled persons is higher than expected, a closer look reveals that the references are generally marginal. The majority of references contain information on social benefits for families with disabled children or other welfare issues. Thus, the medical and welfare approach to disability tends to prevail even in the context of a treaty concerning civil and political rights.

⁹⁷ *Francis v. Jamaica*, Communication No. 606/1994, Views adopted by the Committee on 3 August 1995 (CCPR/C/54/D/606/1994), para. 9.2.

States parties tend not to recognize persons with disabilities as a distinct group protected by the ICCPR. Most State party reports refer to disabled persons only when other minority groups are mentioned. Laudable exceptions are the reports of Australia,⁹⁸ Canada,⁹⁹ Finland,¹⁰⁰ China (on Hong Kong Special Administrative Region),¹⁰¹ the United Kingdom¹⁰² and the United States.¹⁰³ All of these countries have enacted comprehensive anti-discrimination or human rights laws covering persons with disabilities. They have made the shift to the human rights perspective on disability.

There is some evidence of increasing involvement or consultation of disability NGOs by States parties in the preparation of reports.¹⁰⁴ The dialogue between the HRC and State representatives could be developed with respect to disabled persons. The HRC tends not to react even when a State party report reveals blatant examples of judicial discrimination against disabled persons. This is due, no doubt, to competing demands on its time and attention.

The subject of disabled persons is often brought into the dialogue by State representatives. There is very little evidence that members of the HRC receive parallel reports from disability NGOs. Only one parallel report was mentioned – regarding the second periodic report of Ireland.¹⁰⁵

It appears that the HRC itself took the highly commendable initiative on euthanasia and medical experimentation. Its concluding observations with respect to euthanasia practices and medical research on persons unable to give informed consent are extremely laudable. They show that the HRC is able to take the opposite view from regional intergovernmental human rights organizations. The Council of Europe has adopted a different approach to medical research. The 1997 Convention on Human Rights and Biomedicine allows non-therapeutic medical research to be carried out on persons incapable of giving valid consent (article 17).

Lastly, it is striking just how few communications relating to the human rights of disabled persons have been submitted under the first Optional Protocol. Lack of awareness of the procedure among disabled persons and disability NGOs may be one of the main reasons why it is so rarely used in the context of disability.

Hamilton v. Jamaica provides solid evidence that the HRC realizes the potential of the ICCPR in the disability context. So far, the complaint procedure has not been used to a great extent in the context of disability. But it is highly likely that the number of disability communications will increase in the years ahead as awareness of its existence spreads throughout the disability community.

⁹⁸ Third periodic report (CCPR/C/AUS/98/3).

⁹⁹ Fourth periodic report (CCPR/C/103/Add.5).

¹⁰⁰ Fourth periodic report (CCPR/C/95/Add.6).

¹⁰¹ Initial report (CCPR/C/HKSAR/99/1/Add.1).

¹⁰² Fifth periodic report (CCPR/C/UK/99/5).

¹⁰³ Initial report (CCPR/C/81/Add.4).

¹⁰⁴ Second periodic report (CCPR/C/IRL/98/2).

¹⁰⁵ CCPR/C/SR.1846.

Paradoxically, the ICCPR remains an underdeveloped human rights instrument for persons with disabilities. This is paradoxical because people with disabilities are primarily seeking the same freedom and liberty enjoyed by all. Perhaps the reason for this underdevelopment is related to the perception that disability issues are primarily the concern of social policy, welfare and health care. If so, then the current use of the ICCPR in the context of disability simply mirrors common perceptions in society. However, with the worldwide shift towards equal rights and participation, one can foresee even greater use being made of the ICCPR in the future. It certainly has great potential as a means of stimulating the worldwide process of disability law reform currently under way.

Chapter 5

Disability and social justice: the International Covenant on Economic, Social and Cultural Rights

Anna Bruce, Gerard Quinn, Padraic Kenna

Purpose and outline of the chapter

The International Covenant on Economic, Social and Cultural Rights (ICESCR) was concluded in 1966 after almost 20 years of drafting. It entered into force 10 years later in 1976. As of 8 February 2002, 145 States had ratified the Covenant. This chapter assesses the current use and future potential of the ICESCR in the context of disability. It is divided into four sections.

The first section provides a brief overview of the ICESCR and its enforcement mechanism, which involves the scrutiny of State party reports by the Committee on Economic, Social and Cultural Rights (ICESCR Committee). The second section reviews the relevance of ICESCR rights in the context of disability. The third assesses how the ICESCR system currently operates in that context, drawing on two sets of case studies.

In the first set of case studies, the treatment of disability in 20 State party reports is examined in terms of four key rights for people with disabilities (the right to non-discrimination, the right to work, the right to education and the right to cultural participation). The second set of case studies is more focused in that it examines the treatment of all ICESCR rights as they relate to disability in the light of 7 recent State party reports. It looks for any discernible patterns since the adoption of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) by the General Assembly and the adoption of General Comment No. 5 (1995) on disability by the ICESCR Committee. It also looks at how the Committee has been responding to the disability aspects of the various State party reports examined.

The fourth section presents our conclusions on the current use of the ICESCR with respect to disability and our suggestions as to how its considerable potential in this regard can be maximized.

5.1 An overview of the International Covenant on Economic, Social and Cultural Rights¹

5.1.1 Introduction to the International Covenant on Economic, Social and Cultural Rights

There are many ways of characterizing ICESCR rights. From the peculiar perspective of disability, the rights protected by the ICESCR might usefully be grouped as follows:

(a) Overarching right to non-discrimination

The right to non-discrimination (article 2)
The right to equality between men and women (article 3)

(b) Rights that facilitate participation

The right to education (articles 13-14)
The right to health (article 12)

(c) Rights to participate in the workplace

The right to work (article 6)
The right to just and favourable conditions of work (article 7)
The right to form and join trade unions (article 8)

(d) Other ICESCR rights and disability

The right to social security (article 9)
The right to protection of the family, mothers and children (article 10)
The right to an adequate standard of living (article 11)
The right to take part in cultural life (article 15)

The implementation of the ICESCR in States parties is monitored by the ICESCR Committee, which examines State party reports. Interestingly, and in contrast to the other United Nations treaty monitoring bodies, the Committee was not established pursuant to a provision of the ICESCR treaty but derives its existence from a resolution of the Economic and Social Council. The Committee was created in 1985 and began its work in 1987, taking over as the third successive body to monitor the implementation of the Covenant.

¹ For an introduction to the ICESCR and the ICESCR Committee, see United Nations Fact Sheet No.16 (Rev.1), *The Committee on Economic, Social and Cultural Rights*. See generally Alston and Quinn, "The nature and scope of States parties' obligations under ICESCR" *Human Rights Quarterly*, vol. 9 (1987), pp. 156-229; M. Craven., *The International Covenant on Economic, Social and Cultural Rights* (Oxford, Clarendon Press, 1995); Eide et al. *Economic, Social and Cultural Rights – A Textbook* (Dordrecht: Martinus Nijhoff, 1995); S. Leckie, "The ICESCR: catalyst for change in a system needing reform", *The Future of UN Human Rights Treaty Monitoring*, Alston and Crawford (eds.) (Cambridge University Press, 2000); "Maastricht Guidelines on Violations of ESCR", *Human Rights Quarterly*, vol. 20 (1998), pp. 691-704.

The Committee performs its task of monitoring the implementation of the ICESCR during two or three sessions each year held in Geneva, Switzerland. It is composed of 18 members who serve as independent experts. The members are nominated by States parties and elected for a renewable four-year term by the Economic and Social Council.

The elaboration of an Optional Protocol allowing for a system of complaints under the ICESCR was recommended by the World Conference on Human Rights in 1993. A draft optional protocol amending the ICESCR has been proposed by the Committee. If adopted, it would enable individuals or groups to lodge complaints with the ICESCR Committee.²

Article 16 of the ICESCR states:

The States Parties...undertake to submit...reports on the measures which they have adopted and the progress made in achieving the observance of the rights recognized herein.

Within two years of the entry into force of the Covenant in a State party, and every five years thereafter, the State concerned is required to submit a report to the Committee. The report should illustrate the extent to which each right in the Covenant is realized and the measures taken to give it effect.³

When the Committee receives a State party report, a Working Group reads it and sends a written request for additional information (list of issues) to the State party. The State party in turn submits a written reply (reply to the list of issues), answering the questions raised by the Working Group. Finally, the report is discussed at a meeting between representatives of the State party's Government and the ICESCR Committee, the main points of which are recorded in the summary records. The Committee then draws conclusions about the State party's performance in terms of its obligations under the Covenant and publishes them as "concluding observations". The observations offer guidance for the further implementation of the Covenant by the State party concerned. They may contain more specific recommendations or comments and may also highlight good practice.

If a State party fails to meet its reporting obligations, the Committee may invite it to submit the missing report. In the absence of a response, it may proceed to consider the status of economic, social and cultural rights in the State party concerned in the light of all available information.

5.1.2 The role of general comments under the ICESCR

From its third session, the Committee began to adopt general comments in response to a request from the Economic and Social Council. The purpose of such comments is to assist States parties in fulfilling their reporting obligations.

More specifically, the Committee endeavours through general comments:

² See the report of the Committee on Economic, Social and Cultural Rights to the Commission on Human Rights on a draft optional protocol for the consideration of communications in relation to the International Covenant on Economic, Social and Cultural Rights (E/CN.4/1997/105, annex).

³ Details of the reporting record of each State party is available on the OHCHR web site.

To make the experience gained so far through the examination of States' reports available for the benefit of all States parties in order to assist and promote their further implementation of the Covenant; to draw the attention of States parties to insufficiencies disclosed by a large number of reports; to suggest improvements in the reporting procedures; and to stimulate the activities of the States parties, international organizations and the specialized agencies concerned in achieving progressively and effectively the full realization of the rights recognized in the Covenant.⁴

While general comments are not legally binding as such, they represent an authoritative interpretation of the Covenant.

As of January 2002, the Committee had issued 14 general comments⁵: 1. Reporting by States parties (1989); 2. International technical assistance measures (1990); 3. The nature of States parties' obligations (1990); 4. The right to adequate housing (1991); 5. Persons with disabilities (1994); 6. The economic, social and cultural rights of older persons (1995); 7. The right to adequate housing: forced evictions (1997); 8. The relationship between economic sanctions and respect for economic, social and cultural rights (1997); 9. The domestic application of the Covenant (1998); 10. The role of national human rights institutions in the protection of economic, social and cultural rights (1998); 11. Plans of action for primary education (1999); 12. The right to adequate food (1999); 13. The right to education (1999); and 14. The right to the highest attainable standard of health (2000).

General Comment No. 5, which deals specifically with ICESCR rights as they relate to persons with disabilities, is addressed below. While disability is not generally mentioned in the other general comments, they nevertheless often refer to "vulnerable and marginalized groups". This undoubtedly includes persons with disabilities.

5.2 The general application of the ICESCR in the context of persons with a disability

5.2.1 General State party obligations under the ICESCR

The general legal obligations of States parties to the ICESCR are spelled out in article 2, paragraph 1, which requires States parties

to take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

According to the ICESCR Committee, the measures a State has to take to meet its obligations under each Covenant right may be divided into three levels or types:

⁴ See the report on the twenty-second, twenty-third and twenty-fourth sessions of the Committee on Economic, Social and Cultural Rights, *Official Records of the Economic and Social Council, Supplement No. 2* (E/2001/22), p. 25.

⁵ See the "Compilation of general comments and general recommendations adopted by human rights treaty bodies" (HRI/GEN/1/Rev.5).

obligations *to respect, to protect and to fulfil*.⁶ For example, the obligation to *respect* the right to education requires States to refrain from adopting any measures that would hinder or prevent the enjoyment of education. The obligation to *protect* the right to education requires them to ensure that no other actor interferes with the enjoyment of education. Lastly, the obligation to *fulfil*, the extent of which is subject to the wording of each right, requires States to fulfil or provide for the realization of the right to education.

While the obligation to realize the full enjoyment of the Covenant rights is progressive and conditioned by available resources, the obligation to guarantee that each right is enjoyed by everyone without discrimination and to take steps towards the realization of rights is immediate.⁷

General Comment No. 3 states that such steps must be “deliberate, concrete and targeted” and that they must be taken within “a reasonably short time” after the Covenant’s entry into force for a particular State.⁸ States are required to “move as expeditiously and effectively as possible” towards the full realization of each right under the Covenant.⁹ The legality of any deliberately retrogressive measure must be justified by reference to the realization of the totality of rights provided for in the Covenant.¹⁰

According to the Committee, even though the obligations imposed by the ICESCR are largely obligations of conduct (i.e. to take steps), each State party has “a minimum core obligation” to satisfy the “minimum essential levels of each of the rights” under the Covenant.¹¹ If a State wishes to attribute its failure to discharge this obligation to a lack of resources, “it must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.”¹²

General Comment No. 3 notes the importance of international cooperation and assistance for the realization of the rights in the Covenant and states that the phrase “available resources” includes those available through international cooperation and assistance.¹³ It also underlines that

even in times of severe resources constraint ... the vulnerable members of society can and indeed must be protected by the adoption of relatively low-cost targeted programmes.¹⁴

⁶ These levels or types have been explored by the Committee in the context of the right to education, the right to food and the right to health.

⁷ General Comment No. 3, The nature of States parties’ obligations, para. 1.

⁸ Ibid., para. 2.

⁹ Ibid., para. 9.

¹⁰ Ibid.

¹¹ Ibid. para. 10. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, *prima facie*, failing to discharge its obligations under the Covenant.

¹² Ibid.

¹³ Ibid., para. 13.

¹⁴ Ibid., para. 12.

With regard to the types of steps that States parties must take, the Committee emphasizes that while the adoption of legislative measures is often indispensable for the realization of the Covenant rights, States' obligations are not exhausted until all appropriate measures have been taken to ensure the realization of a right.¹⁵ Such measures include, inter alia, administrative, financial, educational and social measures, as well as the provision of effective remedies for alleged violations of ICESCR rights.¹⁶

Even when "available resources" are demonstrably inadequate, States parties must still strive to ensure the widest possible enjoyment of the relevant rights under the circumstances. If a State claims that it is unable to meet even its minimum obligations because of a lack of resources, it must at least be able to demonstrate that every effort has been made to use all resources that are at its disposal in an effort to satisfy, as a matter of priority, these minimum obligations.

5.2.2 The disability perspective: General Comment No. 5 as a bridge to the United Nations Standard Rules

General Comment No. 5 is important for three reasons.

First of all, it provides an explicit bridge to the United Nations Standard Rules for the interpretation of ICESCR rights in the context of disability, stating that:

[t]he Standard Rules are of major importance and constitute a particularly *valuable reference guide* in identifying more precisely the relevant obligations of States parties under the Covenant..¹⁷

(emphasis added)

The United Nations Standard Rules are therefore one of the main sources of guidance in interpreting Covenant rights in the context of disability. Other instruments mentioned in General Comment No. 5 are the World Programme of Action concerning Disabled Persons,¹⁸ the Guidelines for the Establishment and Development of National Coordinating Committees on Disability or Similar Bodies,¹⁹ and the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.²⁰

Second, General Comment No. 5 amplifies the meaning of States parties' obligations under the ICESCR in the context of disability. Importantly, its overall philosophy is one of equality and active participation. It recognizes that:

[t]hrough neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation, persons with disabilities have very often been prevented from exercising their economic, social or cultural rights on an equal basis with persons without

¹⁵ Ibid., paras. 3 and 4.

¹⁶ General Comment No. 9, The domestic application of the Covenant, paras. 2 and 3.

¹⁷ General Comment No. 5, Persons with disabilities, para. 7.

¹⁸ General Assembly resolution 37/52 of 3 December 1982.

¹⁹ United Nations document A/C.3/46/4, annex I.

²⁰ General Assembly resolution 46/119 of 17 December 1991, annex.

disabilities. The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.²¹

With regard to State party obligations vis-à-vis the actions of private parties, it states:

[in] the absence of Government intervention there will always be instances in which the operation of the free market will produce unsatisfactory results for persons with disabilities, either individually or as a group, and in such circumstances it is incumbent on Governments to step in and take appropriate measures to temper, complement, compensate for, or override the results produced by market forces.²²

According to General Comment No. 5, States parties must also ensure that the enjoyment of rights by persons with disabilities is not hampered by third-party actors in the private sphere. Non-public entities, including private employers and private suppliers of goods and services, must “be subject to both non-discrimination and equality norms in relation to persons with disabilities”.²³ If States parties fall short of this, “the ability of persons with disabilities to participate in the mainstream of community activities and to realize their full potential as active members of society will be severely and often arbitrarily constrained.”²⁴

States parties are urged 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.²⁵

On the question of preferential or special treatment, General Comment No. 5 states that:

States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability.²⁶

In a sense, it conceptualizes ICESCR rights as “enablers” for an active life. General Comment No. 5 notes that the specific measures that States parties have to take in order to implement their obligations in the context of disability are “essentially” the same as those corresponding to any other obligations. They must include “general, as well as specially designed, laws, policies and programmes”²⁷ and they must be developed in cooperation with representatives of persons with disabilities.²⁸ The specific measures needed to realize the rights of persons with disabilities include:

the need to ascertain, through regular monitoring, the nature and scope of the problems existing within the State; the need to adopt appropriately tailored policies and programmes to

²¹ General Comment No. 5, para. 15.

²² Ibid., para. 12.

²³ Ibid., para. 11.

²⁴ Ibid.

²⁵ Ibid., para. 9.

²⁶ Ibid., para. 5.

²⁷ Ibid., para. 6.

²⁸ Ibid., para. 14.

respond to the requirements thus identified; the need to legislate where necessary and to eliminate any existing discriminatory legislation; and the need to make appropriate budgetary provisions or, where necessary, seek international cooperation and assistance.²⁹

With regard to legal measures, General Comment No. 5 notes that such measures are not enough to ensure equal enjoyment of rights for persons with disabilities. It refers in this connection to Rule 1 of the Standard Rules which requires States “to take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution”.³⁰

General Comment No. 5 also reiterates Rule 4 of the Standard Rules:

it is also necessary to ensure that “support services, including assistive devices” are available “for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights”.³¹

According to the Committee,

[w]herever possible, appropriate personal assistance should be provided in this connection. Such assistance should be undertaken in a manner and spirit which fully respect the human rights of the person(s) concerned.³²

In sum, the philosophy of General Comment No. 5 is geared towards using ICESCR rights to achieve independence, autonomy and participation.

The third significant aspect of General Comment No. 5 is its review of the implications of each ICESCR right for disability. Reference is made below to the relevant passages.

5.2.3 The State party reporting process and disability

There are three sources of guidance on what State party reports should contain.

The first is General Comment No. 1 on reporting by States parties, which was adopted by the Committee in 1989. The Comment gives general instructions on the information to be provided on all Covenant rights. The second source is the “revised general guidelines regarding the form and contents of reports to be submitted by States parties under articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights” adopted by the Committee in 1991.³³ This document gives more detailed guidance on the kind of information that States parties should include in their periodic reports. The various general comments, including General Comment No. 3, constitute a third source of guidance on reporting obligations inasmuch as general comments generally either amplify the meaning of certain rights or relate them directly to one or more groups of persons.

²⁹ Ibid., para. 13.

³⁰ Ibid., para. 11.

³¹ Ibid., para. 33.

³² Ibid.

³³ E/C.12/1991/1.

Reporting obligations differ from right to right because of the difference in the underlying obligations. What follows is an account of general reporting obligations followed by a more specific account of the relevance of each of the rights protected by the ICESCR to disability.

In General Comment No. 1 (1989) on reporting by States parties, the Committee established seven goals for the ICESCR reporting system. Though general, they are of considerable relevance to reporting on disability.

The first goal is to ensure that national legislation, administrative rules and procedures, and practices are in conformity with the Covenant rights and obligations.³⁴ This goal relates specifically to initial reports submitted after accession.

The second goal is to ensure that the State regularly monitors the level of enjoyment of each right. Of particular relevance is the requirement that any national statistics gathered or processed must pay particular attention to “vulnerable or disadvantaged groups”.³⁵ If a State party does not have the capacity to undertake the monitoring process, it should, according to General Comment No. 1, state this in its report and indicate the nature and extent of any international assistance that would enable it to fulfil its obligations.³⁶

The third goal is to enable States parties to demonstrate that they have adopted policies and programmes to implement the rights contained in the Covenant.³⁷ Reports should indicate why a certain measure, for example of a legal, financial or administrative nature, was considered to be the most appropriate means of realizing the right in question.³⁸ In addition to legislation, measures that might be considered appropriate would include the provision of judicial remedies in respect of ICESCR rights which may, in accordance with the national legal system, be considered justiciable. The Committee notes, for example, that the enjoyment of rights without discrimination will often be appropriately promoted, in part, through the provision of judicial or other effective remedies.³⁹

The fourth goal of the reporting process is to encourage public scrutiny of government policies at the national level and to encourage the involvement of other actors from the economic, social and cultural sectors.⁴⁰ This is important in the disability context since it provides a rights-based perspective on the relevant national disability reform process.

The fifth goal is to establish a basis in terms of which the Committee and States parties can evaluate the progressive realization of economic, social and cultural rights over time.

³⁴ General comment No. 1, Reporting by States parties, para. 2.

³⁵ Ibid., para. 3.

³⁶ Ibid.

³⁷ Ibid., para. 4.

³⁸ General Comment No. 3, The nature of States parties' obligations, para. 4.

³⁹ Ibid., para. 5.

⁴⁰ General Comment No. 1, para. 5.

The sixth objective is to allow the State party to identify difficulties and obstacles to the realization of economic, social and cultural rights.⁴¹ No State is perfect and all States can learn from one another.

The seventh and last goal of the reporting process is to enable the Committee to facilitate the exchange of information among States parties and to develop a better understanding of the common problems they face.⁴²

In addition to General Comment No. 1, the Committee has adopted more detailed reporting guidelines⁴³ indicating the desired format and content of periodic reports.

The revised reporting guidelines list questions under each right. Importantly, they explicitly request information from States parties relating to the enjoyment of the following ICESCR rights by persons with disabilities:

- Article 6 (the right to work);
- Article 9 (the right to social security);
- Article 10 (the right to protection of the family, mothers and children);
- Article 13 (the right to education).

Moreover, the revised reporting guidelines request information about certain categories of persons including “vulnerable groups”, which can be assumed to include persons with disabilities.⁴⁴ They also ask for information that is indirectly relevant to the enjoyment of rights by persons with disabilities but does not refer to them specifically, for example the text of anti-discrimination legislation relating to economic, social and cultural rights in the State party.⁴⁵

5.3 The relevance of specific ICESCR rights in the context of disability

This section identifies the relevance of individual ICESCR rights in the context of disability.

5.3.1 The overarching right to non-discrimination

The relevant non-discrimination norm is a linchpin of the ICESCR. It plays an overarching role in ensuring the equal and effective enjoyment of all ICESCR rights. Its importance in the context of disability cannot be overemphasized.

- (a) *The general non-discrimination norm in the context of disability:
article 2*

Under article 2, paragraph 2, of the ICESCR, the States parties:

⁴¹ Ibid., para. 8.

⁴² Ibid., para. 9.

⁴³ E/C.12/1991/1..

⁴⁴ Under articles 2, 6, 7, 9, 10, 11-13 and 15.

⁴⁵ E/C.12/1991/1, guidelines on article 2, para. 2.

undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or *other status*.

(emphasis added)

According to General Comment No. 5, disability falls under the heading “other status” and is thus treated by the Committee as a ground in respect of which discrimination is prohibited.⁴⁶ The General Comment defines disability-based discrimination 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.⁴⁷

(emphasis added)

It should be noted that the above passage uses the term “reasonable accommodation” which is common in most comparative disability discrimination law.

General Comment No. 5 notes that the legal situation of persons with disabilities around the world calls for “comprehensive anti-discrimination legislation”. Such legislation should not be limited to judicial remedies, but also provide for “social-policy programmes which enable persons with disabilities to live an integrated, self-determined and independent life”.⁴⁸ Presumably, the legislation should incorporate the key concept of “reasonable accommodation”. Protection against discrimination should cover both the public and the private sphere of society.⁴⁹ Every differentiation in treatment based on disability that has a negative impact on the enjoyment of economic, social and cultural rights constitutes a *prima facie* violation of the Covenant.

(b) *The right to equality between men and women in the context of disability: article 3*

Article 3 of the ICESCR expands on the general prohibition of discrimination in article 2 by requiring States parties to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights. It should be seen as a statement of the importance of gender equality.

General Comment No. 5 notes that females with disabilities are often treated as “genderless” human beings and that the “double discrimination suffered by women with disabilities is often neglected”.⁵⁰ States parties are urged by the Committee to address the situation of women with disabilities as a high priority.⁵¹ The Committee

⁴⁶ Ibid., para. 5.

⁴⁷ Ibid., para. 15.

⁴⁸ Ibid., para. 16.

⁴⁹ Ibid., para. 11.

⁵⁰ General Comment No. 5, para. 19.

⁵¹ Ibid.

thus urges States to recognize and counteract the effects of multiple discrimination based on gender and disability.

General Comment No. 6 on the economic, social and cultural rights of older persons recognizes the discrimination risk associated with the combination of age and disability.⁵²

The right to non-discrimination does not give persons with disabilities the right to set minimum standards. In countries where the realization of rights such as the right to education or the right to health is limited even for the able-bodied population, the right to non-discrimination is not sufficient to guarantee persons with disabilities immediate adequate realization of such rights.

However, the ICESCR is not merely about the non-discriminatory enjoyment of economic, social and cultural rights. It is also concerned with floor standards for the enjoyment of such rights. For example, in General Comment No. 4 on the right to adequate housing, the Committee states that disadvantaged groups, such as “the physically disabled” and “the mentally ill” must enjoy “full and sustainable access to adequate housing resources” and that “housing law and policy should take fully into account the special housing needs of these groups.”⁵³ States are required to “give due priority to those social groups living in unfavourable conditions by giving them particular consideration”.⁵⁴ The substantive content of these rights is examined below.

5.3.2 ICESCR rights that facilitate participation

ICESCR rights can play a vitally important role in helping to prepare people with disabilities for a life of active citizenship and participation. In this regard, the importance of the right to education for people with disabilities cannot be overstated. It provides them with the means to lead a life of participation. Moreover, it educates others to be tolerant of the difference of disability. The right to health is important in itself. But it also important in that it primes people with disabilities to lead a life of active participation. Indeed, the ICESCR Committee has itself established a direct link between the right to health and participation.

(a) *The right to education in the context of disability (article 13)*

Article 13 states that:

1. The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.

⁵² General Comment No. 6, The economic, social and cultural rights of older persons, paras. 5 and 41.

⁵³ General Comment No. 4, The right to adequate housing, paras. 6 and 8 (e).

⁵⁴ *Ibid.*, para. 11.

2. The States Parties to the present Covenant recognize that, with a view to achieving the full realization of this right:

- (a) Primary education shall be compulsory and available free to all;
- (b) Secondary education in its different forms, including technical and vocational secondary education, shall be made generally available and accessible to all by every appropriate means, and in particular by the progressive introduction of free education;
- (c) Higher education shall be made equally accessible to all, on the basis of capacity, by every appropriate means, and in particular by the progressive introduction of free education;
- (d) Fundamental education shall be encouraged or intensified as far as possible for those persons who have not received or completed the whole period of their primary education;
- (e) The development of a system of schools at all levels shall be actively pursued, an adequate fellowship system shall be established, and the material conditions of teaching staff shall be continuously improved.

3. The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to choose for their children schools, other than those established by the public authorities, which conform to such minimum educational standards as may be laid down or approved by the State and to ensure the religious and moral education of their children in conformity with their own convictions.

4. No part of this article shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principles set forth in paragraph 1 of this article and to the requirement that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

The 1991 revised reporting guidelines indicate that States parties should report on disability under article 13.

General Comment No. 13 on the right to education (1999)⁵⁵ states that the right to education encompasses the following elements: availability, accessibility, acceptability and adaptability. Accessibility is further asserted to have three overlapping dimensions: (a) non-discrimination, (b) physical accessibility and (c) economic accessibility.

General Comment No. 13 cites the failure to eliminate legal and de facto discrimination in the field of education and the failure to introduce free primary education as examples of violations of the right to education.⁵⁶ According to the Committee, the obligation to guarantee that the right to education is exercised without discrimination is immediate.⁵⁷ Consequently, the “minimum core obligation” of the right to education includes the right of access to public educational institutions and programmes on a non-discriminatory basis.⁵⁸ In addition, temporary special measures

⁵⁵ General Comment No. 13, The right to education, paras. 36 and 16 (e).

⁵⁶ Ibid. para. 59.

⁵⁷ Ibid., para. 43.

⁵⁸ Ibid., para. 57.

designed to bring about de facto equality for disadvantaged groups in the context of education are not to be regarded as discriminatory provided that they meet certain requirements.⁵⁹

In General Comment No. 5 the ICESCR Committee recognizes that persons with disabilities can best be educated in the general education system. Reiterating Rule 6 of the Standard Rules, the Committee notes that:

States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in *integrated settings*.⁶⁰

(emphasis added)

The implementation of an integrated approach requires States parties to make available the necessary equipment and support in order to “bring persons with disabilities up to the same level of education as their non-disabled peers”.⁶¹ The Committee mentions by way of example that sign language should be recognized as a separate language to which children should have access and whose importance should be acknowledged in their overall social environment.⁶²

While the Committee concedes in General Comment No. 13 that “[i]n some circumstances, separate educational systems or institutions for groups defined by the categories in article 2 (2) shall be deemed not to constitute a breach of the Covenant,” this concession is best interpreted in the light of the clear affirmation by the Committee in General Comment No. 5 that persons with disabilities are best educated in an integrated educational system.⁶³

In General Comment No. 13 the Committee notes that:

States parties must closely monitor education - including all relevant policies, institutions, programmes, spending patterns and other practices - so as to identify and take measures to redress any de facto discrimination.⁶⁴

Also relevant in the context of disability is States parties' obligation to disaggregate educational data by prohibited grounds of discrimination. This implicitly includes disability.⁶⁵ General Comment No. 13 requires States parties to “remove gender and other stereotyping which impedes the educational access of girls, women and other disadvantaged groups”.⁶⁶ While the focus here is on gender, the obligation to remove stereotyping is relevant in the context of disability.

The theme of the comparable provision of the United Nations Standard Rules – Rule 6 – is equality and participation. It focuses on the integration of children with

⁵⁹ Ibid., para. 32.

⁶⁰ General Comment No. 5, para. 35.

⁶¹ Ibid.

⁶² Ibid.

⁶³ General Comment No. 13, para. 33.

⁶⁴ Ibid., para. 37.

⁶⁵ Ibid.

⁶⁶ Ibid., para. 55.

disabilities into the mainstream of the education system and the provision of adequate teaching and support devices and services. States should have a “clearly stated policy, understood and accepted at the school level and by the wider community,” on the provision of education to persons with disabilities in the mainstream education system.⁶⁷

Pursuant to Rule 6, integrated education and community-based programmes should be seen as complementary approaches to providing cost-effective education and training for persons with disabilities. Communities should be encouraged by national community-based programmes to develop local education for persons with disabilities.⁶⁸ According to Rule 6, special education may be considered but should be aimed at preparing students for the general education system. The quality of special education should reflect the same standards and ambitions as mainstream education, and, at a minimum, be allocated the same share of resources. The Rule mentions the possibility of the “current” appropriateness of special education in some instances, for example for persons with “particular communication needs”. The education of such persons should be aimed at providing effective communication skills and ensuring maximum independence.⁶⁹ Consideration should be given to the needs of people with communication disabilities, including the use of sign language in the education of deaf children, in their families and communities.⁷⁰

The overall themes of article 13 in the context of disability are non-discrimination, integration and the provision of adequate support and access.

(b) *The obligation to adopt a plan of action for primary education in the context of disability (article 14)*

Article 14 states that:

Each State Party to the present Covenant which, at the time of becoming a Party, has not been able to secure in its metropolitan territory or other territories under its jurisdiction compulsory primary education, free of charge, undertakes, within two years, to work out and adopt a detailed plan of action for the progressive implementation, within a reasonable number of years, to be fixed in the plan, of the principle of compulsory education free of charge for all.

General Comment No. 11 does not explicitly stipulate that the plan should cover primary education for children with disabilities. Among various prohibited grounds for discrimination, it mentions only gender.⁷¹ Still, as the core obligations of article 13 include the provision of all forms and levels of education without discrimination and the obligation to provide compulsory primary education free of charge, it is reasonable to presume that States parties are under an obligation to cater for children with disabilities in their plan of action under article 14.⁷² The Committee notes that:

⁶⁷ Rule 6.(6(a)).

⁶⁸ Rule 6 (7).

⁶⁹ Rule 6 (8-9).

⁷⁰ Rule 5 (7 and 8).

⁷¹ General Comment No. 11, Plans of action for primary education, para. 6.

⁷² General Comment No. 13, para. 57.

Plans of action prepared by States parties to the Covenant in accordance with article 14 are especially important as the work of the Committee has shown that the lack of educational opportunities for children often reinforces their subjection to various other human rights violations.⁷³

This argument applies with considerable force in the context of children with disabilities.

Rule 6, paragraph 1, of the Standard Rules states that:

[e]ducation for persons with disabilities should form an integral part of national educational planning, curriculum development and school organization.⁷⁴

In addition, Rule 6, paragraph 4, stipulates that:

[i]n States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.⁷⁵

There is, therefore, strong support for the view that children with disabilities should be included in plans of action for primary education.

(c) The right to health in the context of disability (article 12)

The right to health is important in itself for people with disabilities. But it also serves a more instrumental function in helping to prime people with disabilities for a life of active participation in the mainstream.

Article 12 of the Covenant reads as follows:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
 - (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
 - (b) The improvement of all aspects of environmental and industrial hygiene;
 - (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
 - (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

According to General Comment No. 14 on the right to the highest attainable standard of health (2000), the core obligations include the following:

[t]o adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy

⁷³ General Comment No. 11, para. 4.

⁷⁴ Rule 6 (1).

⁷⁵ Rule 6 (4).

and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, *shall give particular attention to all vulnerable or marginalized groups*.⁷⁶

(emphasis added)

While General Comment No. 14 does not list the groups in question, persons with disabilities normally fall into the above category.

According to General Comment No. 14, the right to health includes:

a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.⁷⁷

Thus, achievement of the right to health is linked by the Committee to the achievement of a broad range of attendant rights and other social supports:

the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement ... address integral components of the right to health.⁷⁸

The right to health contains the following elements; availability, accessibility, acceptability and quality.⁷⁹ The General Comment expressly mentions persons with disabilities under the heading of accessibility, noting that

health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ... persons with disabilities.⁸⁰

According to the Committee, treatment of a disability is “preferably [provided] at community level”.⁸¹

It notes that:

States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services, especially with respect to the core obligations of the right to health.⁸²

⁷⁶ General Comment No. 14, The right to the highest attainable standard of health, para. 43 (f).

⁷⁷ Ibid., para. 4.

⁷⁸ Ibid., para. 3.

⁷⁹ Ibid., para. 12.

⁸⁰ Ibid.

⁸¹ Ibid., para. 17.

⁸² Ibid., para. 19.

As stated in General Comment No. 5, disability is one such prohibited ground of discrimination.⁸³ That Comment adopts an integrationist approach, reiterating Rule 2, paragraph 3, of the Standard Rules which states that:

States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.⁸⁴

In the context of the right of non-discrimination with respect to health, General Comment No. 14 expressly mentions “adequate access to buildings” as an inherent part of the right to health for persons with disabilities.⁸⁵ The Committee also stresses that States are obliged to ensure that the “private providers of health services and facilities comply with the principle of non-discrimination in relation to persons with disabilities”.⁸⁶

The obligation to guarantee that the right to health is enjoyed by all persons, including persons with disabilities, without discrimination is immediate. Failure in this respect constitutes a failure to implement the core content of the Covenant and thus, *prima facie*, a violation.⁸⁷ The Committee notes that:

many measures, such as most strategies and programmes designed to eliminate health-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information.⁸⁸

Issues such as the selective non-treatment of persons with disabilities can be dealt with under the notion of non-discrimination. The Committee recalls General Comment No. 3, which states that “even in times of severe resource constraints, the vulnerable members of society must be protected by the adoption of relatively low-cost targeted programmes.”⁸⁹

Importantly, a direct link is forged in General Comment No. 5 between the right to health and the achievement of the goal of participation. Paragraph 34 states that persons with disabilities have the right to receive social and medical services, including orthopaedic devices:

which enable persons with disabilities to become independent, prevent further disabilities and support their social integration.

In General Comment No. 5 the Committee refers to the United Nations General Assembly Declaration on the Rights of Disabled Persons and the World Programme of Action concerning Disabled Persons. In the context of rehabilitation services, it reiterates Rule 3 of the Standard Rules which states that these services should enable persons with disabilities “to reach and sustain their optimum level of independence

⁸³ General Comment No. 5, para. 5.

⁸⁴ *Ibid.*, para. 34.

⁸⁵ General Comment No. 14, para. 12 (b).

⁸⁶ *Ibid.*, para. 26.

⁸⁷ *Ibid.*, paras. 30, 43, 47.

⁸⁸ *Ibid.*, para. 18.

⁸⁹ *Ibid.*

and functioning”. Thus, the Committee clearly sees independence and participation in society as major objectives of the right to health in the context of disability.

General Comment No. 5 states that all services for persons with disabilities “should be provided in such a way that the persons concerned are able to maintain full respect for their rights and dignity”.⁹⁰ In General Comment No. 14 the Committee lists some of the freedoms inherent in the right to health, including “the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation”.⁹¹ While persons with disabilities are not explicitly mentioned in this context, these freedoms have a special significance for them.

On the question of participation in decision making, General Comment No. 14 notes that

the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12.⁹²

Within the category of “persons with disabilities”, General Comment No. 14 singles out children, stating that “[c]hildren with disabilities should be given the opportunity to enjoy a fulfilling and decent life and to participate within their community.”⁹³ As regards older persons, the Committee notes the importance of “physical as well as psychological rehabilitative measures aimed at maintaining the functionality and autonomy of older persons”.⁹⁴

In the context of mental health care, the Committee notes that “coercive medical treatments” are only to be applied in “exceptional cases” and “should be subject to specific and restrictive conditions, respecting best practices and applicable international standards, including the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care.”⁹⁵ States are also required to ensure “the promotion and support of the establishment of institutions providing counselling and mental health services, with due regard to equitable distribution throughout the country”.⁹⁶

The provision of the United Nations Standard Rules corresponding to article 12 of the Covenant is Rule 2 which states that:

States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.⁹⁷

⁹⁰ General Comment No. 5, para. 34.

⁹¹ General Comment No. 14, para. 8.

⁹² Ibid., para. 54.

⁹³ Ibid., para. 22.

⁹⁴ Ibid., para. 25. See also General Comment No. 6, The economic, social and cultural rights of older persons, paras. 5, 33, 40-42.

⁹⁵ General Comment No. 14, para. 34.

⁹⁶ Ibid., para. 36.

⁹⁷ Rule 2 (3).

States should also ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.⁹⁸

In order to fulfil these obligations, States should work towards the provision of programmes run by multidisciplinary teams, facilitating

early detection, assessment and treatment of impairment [which] could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.⁹⁹

Rule 2 requires States to ensure:

that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.¹⁰⁰

Ongoing and up-to-date training should also be provided to prevent health care personnel from giving inappropriate advice to parents, thus restricting options for their children.¹⁰¹ At the local level, community workers should receive training for the early detection of impairments, the provision of primary assistance and referral to appropriate services.¹⁰²

According to Rule 3 on rehabilitation:

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.¹⁰³

All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.¹⁰⁴

National rehabilitation programmes should cover all types of disabilities and be based on “the actual individual needs of persons with disabilities and on the principles of full participation and equality”.¹⁰⁵ Such programmes should cover, inter alia, “basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance”.¹⁰⁶ While all rehabilitation services should be available locally, special time-limited rehabilitation courses may be organized in residential form.¹⁰⁷

According to Rule 3, persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services and to involve

⁹⁸ Rule 2 (6).

⁹⁹ Rule 2 (1).

¹⁰⁰ Rule 2 (4).

¹⁰¹ Rule 2 (5).

¹⁰² Rule 2 (2).

¹⁰³ Rule 3.

¹⁰⁴ Rule 3 (3).

¹⁰⁵ Rule 3 (1).

¹⁰⁶ Rule 3 (2).

¹⁰⁷ Rule 3 (5).

themselves in rehabilitation, “for instance as trained teachers, instructors or counsellors”.¹⁰⁸ Organizations of persons with disabilities should be involved in the formulation and evaluation of rehabilitation programmes.¹⁰⁹

What is striking about the Committee's approach to the right to health in the context of disability is the direct link it establishes between the achievement of health and other rights, and between health and active participation, its emphasis on non-discrimination, which can be highly relevant in the context of selective treatment for people with disabilities, and its emphasis on human dignity and autonomy.

5.3.3 Rights to participate in the workplace

Work provides the material means for a life of independence. Access to work in the mainstream employment sector is therefore of crucial importance to people with disabilities as are the associated rights to just and favourable conditions of work and freedom of association. Workplaces must often be adjusted so that they reasonably accommodate workers with disabilities in order to ensure equal effective access to the right to work.

(a) *The right to work in the context of disability (article 6)*

Article 6 reads as follows:

1. The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.
2. The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

The 1991 revised reporting guidelines explicitly state that States parties should report on disability under article 6.

The Committee notes in General Comment No. 5 that the realization of the right to work for persons with disabilities will require the elimination of “prominent and persistent” discrimination as well as:

the physical barriers that society has erected in areas such as transport, housing and the workplace which are then cited as the reason why persons with disabilities cannot be employed.¹¹⁰

It is therefore not enough to address discrimination. It is also necessary to deal with other barriers to work. According to General Comment No. 5, States should actively support the integration of persons with disabilities into the regular labour market and:

¹⁰⁸ Rule 3 (4) and (6).

¹⁰⁹ Rule 3 (7).

¹¹⁰ General Comment No. 5, paras. 20 and 22.

develop policies which promote and regulate flexible and alternative work arrangements that *reasonably accommodate* the needs of disabled workers.¹¹¹

(emphasis added)

States must also ensure that lack of access to transportation does not greatly reduce the chances of persons with disabilities of “finding suitable, integrated jobs, taking advantage of educational and vocational training, or commuting to facilities of all types”.¹¹² Thus, General Comment No. 5 requires States parties to make employment accessible to workers with disabilities.

The General Comment concedes that sheltered employment may be suitable for some persons with disabilities, but adds that the confinement of persons with a certain category of disability to certain occupations or to the production of certain goods may violate the right freely to choose or accept work.¹¹³ The aim of such sheltered and supported employment should always be employment in the open labour market.¹¹⁴ The use of “therapeutical treatment” which amounts to forced labour may be considered a violation of the right to work.¹¹⁵

According to General Comment No. 5, “technical and vocational guidance and training programmes” required under article 6 (2)

should reflect the needs of all persons with disabilities, take place in integrated settings, and be planned and implemented with the full involvement of representatives of persons with disabilities.¹¹⁶

Reiterating Rule 7 of the Standard Rules, the General Comment notes that rural workers have the same right as urban workers to find “productive and gainful employment”.¹¹⁷ According to the Standard Rules, action programmes to promote the employment of persons with disabilities should include measures to provide persons with disabilities with training, placement and ongoing support such as personal assistance and interpreting services, measures to design and adapt workplaces to make them accessible to persons with disabilities and measures to support the use of new technology and the development of assistive devices, tools and equipment.¹¹⁸

According to Rule 7, States should actively support the integration of persons with disabilities into open employment by measures such as:

vocational training, incentive-oriented quota schemes, reserved or designated employment, loans or grants for small business, exclusive contracts or priority production rights, tax concessions, contract compliance or other technical or financial assistance to enterprises employing workers with disabilities.¹¹⁹

¹¹¹ Ibid., para. 22.

¹¹² Ibid., para. 23.

¹¹³ Ibid., para. 21.

¹¹⁴ Ibid., para. 20.

¹¹⁵ Ibid., para. 21.

¹¹⁶ Ibid., para. 24.

¹¹⁷ Ibid., para. 22.

¹¹⁸ Rule 7 (3).

¹¹⁹ Rule 7 (2).

As employers, States should create favourable conditions for the employment of persons with disabilities in the public sector and take measures to include persons with disabilities in training and employment programmes in the private and informal sectors.¹²⁰ Employers in general should be encouraged to make reasonable adjustments to accommodate persons with disabilities.¹²¹ Rule 7 recognizes that empowering persons with disabilities is not enough to ensure that they enjoy the right to work. States must also educate other persons by initiating and supporting "public awareness-raising campaigns designed to overcome negative attitudes and prejudices concerning workers with disabilities".¹²² This is an important point since considerable resistance may be met with from fellow workers.

Rule 7 addresses the need for participation by organizations of persons with disabilities, stressing that they must be consulted by States, workers' organizations and employers "concerning all measures to create training and employment opportunities, including flexible hours, part-time work, job-sharing, self-employment and attendant care for persons with disabilities".¹²³ These are, in a sense, different forms of "reasonable accommodation".

The themes running through the ICESCR right to work in the context of disability are therefore, broadly speaking, non-discrimination (interpreted to require "reasonable accommodation"), a strong preference for mainstream employment in the open labour market and adequate protections for those in sheltered employment.

(b) *The right to just and favourable conditions of work in the context of disability (article 7)*

Article 7 reads as follows:

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of just and favourable conditions of work which ensure, in particular:

- (a) Remuneration which provides all workers, as a minimum, with:
 - (i) Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work;
 - (ii) A decent living for themselves and their families in accordance with the provisions of the present Covenant;
- (b) Safe and healthy working conditions;
- (c) Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than those of seniority and competence;
- (d) Rest, leisure and reasonable limitation of working hours and periodic holidays with pay, as well as remuneration for public holidays

¹²⁰ Rule 7 (5) and (8).

¹²¹ Rule 7 (2).

¹²² Rule 7 (4).

¹²³ Rule 7 (9).

According to General Comment No. 5, the right to just and favourable conditions of work applies just as much in sheltered employment as it does in the open labour market.¹²⁴

Read in conjunction with article 2 (2), the right to just and favourable conditions of work is to be accorded to everyone without discrimination. States parties must ensure that workers with disabilities are not discriminated against regarding wages or other conditions of work.¹²⁵ General Comment No. 5 notes that States parties have a responsibility to ensure that disability is not an excuse for paying less for equal work or for imposing substandard working conditions.¹²⁶

According to Rule 7 of the Standard Rules,

States, workers' organizations and employers should cooperate to ensure equitable recruitment and promotion policies, employment conditions, rates of pay, measures to improve the work environment in order to prevent injuries and impairments and measures for the rehabilitation of employees who have sustained employment-related injuries.¹²⁷

Broadly speaking, therefore, the main theme of article 7 in the context of disability is non-discrimination with respect to pay and working conditions in both sheltered and open employment.

(c) *The right to form and join trade unions in the context of disability (article 8)*

Article 8 reads:

1. The States Parties to the present Covenant undertake to ensure:

(a) The right of everyone to form trade unions and join the trade union of his choice, subject only to the rules of the organization concerned, for the promotion and protection of his economic and social interests. No restrictions may be placed on the exercise of this right other than those prescribed by law and which are necessary in a democratic society in the interests of national security or public order or for the protection of the rights and freedoms of others;

(b) The right of trade unions to establish national federations or confederations and the right of the latter to form or join international trade-union organizations;

(c) The right of trade unions to function freely subject to no limitations other than those prescribed by law and which are necessary in a democratic society in the interests of national security or public order or for the protection of the rights and freedoms of others;

(d) The right to strike, provided that it is exercised in conformity with the laws of the particular country.

2. This articles hall not prevent the imposition of lawful restrictions on the exercise of these rights by members of the armed forces or of the police or of the administration of the State

¹²⁴ General Comment No. 5, para. 25.

¹²⁵ Ibid.

¹²⁶ Ibid.

¹²⁷ Rule 7 (6).

3. Nothing in this article shall authorize States Parties to the International Labour Organisation Convention of 1948 concerning Freedom of Association and Protection of the Right to Organize to take legislative measures which would prejudice, or apply the law in such a manner as would prejudice, the guarantees provided for in that Convention.

General Comment No. 5 notes that article 8, in conjunction with other rights, emphasizes “the importance of the right of persons with disabilities to form their own organizations” for the protection and promotion of economic and social interests.¹²⁸

Furthermore, these organizations “should be consulted regularly by government bodies and others in relation to all matters affecting them; it may also be necessary that they be supported financially and otherwise so as to ensure their viability.”¹²⁹

Trade union rights are important for all disabled workers and perhaps more so for those in sheltered employment. Problems may arise if traditional trade unions refuse to accept members with disabilities or if there is resistance to the organization of workers in sheltered work environments.

5.3.4 Other ICESCR rights and disability

A range of other substantive social, economic and cultural rights also have important roles to play in preparing people with disabilities for a life of participation. They should not merely be thought of as ends in themselves but also as tools for the liberation of people with disabilities.

(a) *The right to social security in the context of disability (article 9)*

Article 9 reads:

The States Parties to the present Covenant recognize the right of everyone to social security, including social insurance.

The 1991 revised reporting guidelines require States parties to report on disability under article 9.

In General Comment No. 5 the Committee notes the particular importance of social security and income-maintenance schemes for persons with disabilities. It reiterates Rule 8 (1) of the Standard Rules:

States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities.¹³⁰

According to the Committee, such support should:

reflect the special needs for assistance and other expenses often associated with disability and ... also cover individuals (who are overwhelmingly female) who undertake the care of a person with disabilities.¹³¹

¹²⁸ General Comment No. 5, para. 26.

¹²⁹ Ibid.

¹³⁰ Ibid., para. 28.

In reiterating the Standard Rules, General Comment No. 5 makes the important point that persons with disabilities who have not previously been employed have the right to social security. Importantly, it notes that the:

[i]nstitutionalization of persons with disabilities, unless rendered necessary for other reasons, cannot be regarded as an adequate substitute for the social security and income-support rights of such persons.¹³²

This anti-institutionalization language is quite strong.

The provision of the Standard Rules corresponding to article 9 of the Covenant is Rule 8, according to which:

States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities.¹³³

This support should cover the extra costs of disability and costs incurred by those caring for persons with disabilities.¹³⁴ States should ensure that general social welfare schemes do not exclude or discriminate against persons with disabilities.¹³⁵

According to Rule 8, social security systems should include incentives to restore income-earning capacities and provide or support vocational training and placement services. Social security programmes should also provide incentives to seek employment.¹³⁶ Income support should be maintained until the disabling condition disappears and the person concerned achieves adequate and secure income. Social protection systems should not discourage persons with disabilities from seeking employment.¹³⁷

Important themes in the Committee's approach to the right to social security in the context of disability are recognition of the extra costs of disability, avoidance of institutionalization and using social support to enable people with disabilities to lead an active life.

(b) *The right to protection of the family, mothers and children in the context of disability (article 10)*

Article 10 reads as follows:

The States Parties to the present Covenant recognize that:

1. The widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while

¹³¹ Ibid.

¹³² Ibid., para. 29

¹³³ Rule 8 (1).

¹³⁴ Rule 8 (1 and 3).

¹³⁵ Rule 8 (2).

¹³⁶ Rule 8 (4 and 5).

¹³⁷ Rule 8 (6).

it is responsible for the care and education of dependent children. Marriage must be entered into with the free consent of the intending spouses.

2. Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.

3. Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation. Their employment in work harmful to their morals or health or dangerous to life or likely to hamper their normal development should be punishable by law. States should also set age limits below which the paid employment of child labour should be prohibited and punishable by law.

General Comment No. 5 requires States parties to endeavour to ensure that persons with disabilities can, when they so wish, live with their families. Importantly, it also requires them to ensure that “laws and social policies and practices” do not impede the realization of the rights of persons with disabilities to marry and form a family.¹³⁸ In addition, persons with disabilities should have access to “necessary counselling services in order to fulfil their rights and duties within the family”.¹³⁹

General Comment No. 5 reiterates Rule 9(2) of the Standard Rules, stating that “persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.”¹⁴⁰ It then stresses that “[t]he needs and desires in question should be recognized and addressed in both the recreational and the procreational contexts.”¹⁴¹ While the Committee notes that these rights are commonly denied to both sexes, it mentions explicitly that “[w]omen with disabilities also have the right to protection and support in relation to motherhood and pregnancy.”¹⁴² It follows that

[b]oth the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2).¹⁴³

General Comment No. 5 also notes that article 10 (3) of the Covenant (which is reinforced by the corresponding provisions in the Convention on the Rights of the Child) entitles children with disabilities to special protection from exploitation, abuse and neglect.¹⁴⁴ This is important for all children with disabilities but especially for those who reside in institutions.

The provision of the Standard Rules corresponding to article 10 of the Covenant is Rule 9, according to which:

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

¹³⁸ General Comment No. 5, para. 30.

¹³⁹ Ibid.

¹⁴⁰ Ibid., para. 31.

¹⁴¹ Ibid.

¹⁴² Ibid.

¹⁴³ Ibid.

¹⁴⁴ Ibid., para. 32.

Rule 9 states that persons with disabilities should not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. They must have equal access to family planning methods and information in accessible form on the sexual functioning of their bodies. States should remove all “unnecessary obstacles” to the adoption or fostering of a person with a disability.¹⁴⁵ It is incumbent on States to promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons (especially girls and women) with disabilities. Part of this obligation involves encouraging the media to tackle negative attitudes.¹⁴⁶ As persons with disabilities are particularly vulnerable to sexual and other forms of abuse in the family and institutions, they need to be educated on how to avoid, recognize and report such abuse.¹⁴⁷

In the context of special protection for children with disabilities, Rule 4 on support services states that the special needs of girls and boys with disabilities should influence the design, durability and age-appropriateness of assistive devices and equipment.¹⁴⁸

The main themes of the right to family life under article 10 of the ICESCR in the context of disability are the right to intimate association, the right to marry and found a family, the right to special protection for vulnerable children, and the need to ensure respect for privacy and the dignity of the person.

The main themes of the Committee’s approach to article 10 in the context of disability are accessibility, non-discrimination and participation.

(c) *The right to an adequate standard of living in the context of disability (article 11)*

Article 11 reads as follows:

1. The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international cooperation based on free consent.

2. The States Parties to the present Covenant, recognizing the fundamental right of everyone to be free from hunger, shall take, individually and through international cooperation, the measures, including specific programmes, which are needed:

(a) To improve methods of production, conservation and distribution of food by making full use of technical and scientific knowledge, by disseminating knowledge of the principles of nutrition and by developing or reforming agrarian systems in such a way as to achieve the most efficient development and utilization of natural resources;

¹⁴⁵ Rule 9 (1).

¹⁴⁶ Rule 9 (3).

¹⁴⁷ Rule 9 (4).

¹⁴⁸ Rule 4 (5).

(b) Taking into account the problems of both food-importing and food-exporting countries, to ensure an equitable distribution of world food supplies in relation to need.

According to General Comment No. 5, the right to an adequate standard of living in the context of disability entails the fulfilment of basic material needs such as adequate food, housing and clothing.¹⁴⁹ It further states that persons with disabilities may have “particular clothing needs, so as to enable them to function fully and effectively in society”.¹⁵⁰ Again, in the Committee's view the link between Covenant rights and the achievement of the goal of participation is plain.

General Comment No. 12 on the right to adequate food states that food must be accessible to everyone, without discrimination, including “the physically disabled” and “the mentally ill”.¹⁵¹ According to the Committee, “whenever an individual or group is unable, for reasons beyond their control, to enjoy the right to adequate food by the means at their disposal, States have the obligation to fulfil (provide) that right directly.”¹⁵² Furthermore, General Comment No. 12 states that:

[e]ven where a State faces severe resource constraints, whether caused by a process of economic adjustment, economic recession, climatic conditions or other factors, measures should be undertaken to ensure that the right to adequate food is especially fulfilled for *vulnerable population groups and individuals*.¹⁵³

(emphasis added)

According to General Comment No. 12, States parties are required to draw up a national strategy on the realization of the right to food. Such a strategy should “give particular attention to the need to prevent discrimination in access to food or resources for food”.¹⁵⁴ Violations of the right to food are stated to include “denial of access to food to particular individuals or groups, whether the discrimination is based on legislation or is proactive”.¹⁵⁵

Housing rights are particularly important for people with disabilities. General Comment No. 4 (1991) on the right to adequate housing states that disadvantaged groups, such as “the physically disabled” and “the mentally ill” must have “full and sustainable access to adequate housing resources” without discrimination, and that “housing law and policy should take fully into account the special housing needs of these groups.”¹⁵⁶ States are required to “give due priority to those social groups living in unfavourable conditions by giving them particular consideration”.¹⁵⁷

¹⁴⁹ General Comment No. 5, para. 33.

¹⁵⁰ Ibid.

¹⁵¹ General Comment No. 12, para. 13.

¹⁵² Ibid., para. 15.

¹⁵³ Ibid., para. 28.

¹⁵⁴ Ibid., para. 26.

¹⁵⁵ Ibid., para. 19.

¹⁵⁶ General Comment No. 4, para. 8 (e).

¹⁵⁷ Ibid., para. 11.

The adequacy of housing, in the view of the Committee, is determined in part by “social, economic, cultural, climatic, ecological and other factors”.¹⁵⁸ Everyone has the right to “live somewhere in security, peace and dignity”.¹⁵⁹ As regards location, General Comment No. 4 asserts that “[a]dequate housing must be in a location which allows access to employment options, health-care services, schools, child-care centres and other social facilities.”¹⁶⁰

General Comment No. 4 emphasizes the interrelatedness of the right to housing and other human rights such as the right to non-discrimination, the right to freedom of expression, the right to freedom of association, the right to freedom of residence, the right to participate in public decision-making and the right not to be subjected to arbitrary or unlawful interference with one's privacy, family, home or correspondence.¹⁶¹ Thus, in the case of persons with disabilities, fulfilment of the right to adequate housing entails providing housing that gives the individual access to equal participation in the political, social, economic and cultural spheres of society.

According to Rule 5 of the Standard Rules on accessibility, which deals with access to the physical environment, including housing, “States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society.” States are required to introduce programmes of action to make the physical environment accessible to persons with disabilities and to take measures to remove obstacles to participation. Such measures should include the development of standards and guidelines, and due consideration should be given to the enactment of:

legislation to ensure accessibility to various areas in society, such as housing, buildings, public transport services and other means of transportation, streets and other outdoor environments.¹⁶²

States should also include accessibility requirements from the outset in the design and construction of the physical environment, and:

ensure that architects, construction engineers and others who are professionally involved in the design and construction of the physical environment have access to adequate information on disability policy and measures to achieve accessibility.¹⁶³

Organizations of persons with disabilities should be involved from the beginning in the planning of public construction projects and should be consulted on the development of standards and norms of accessibility.¹⁶⁴

(d) *The right to cultural participation in the context of disability*
(article 15)

Article 15 reads as follows:

¹⁵⁸ Ibid., para. 8.

¹⁵⁹ Ibid., para. 7.

¹⁶⁰ Ibid., para. 8(f).

¹⁶¹ Ibid., para. 9.

¹⁶² Rule 5(a) (1).

¹⁶³ Rule 5(a) (2 and 3).

¹⁶⁴ Rule 5(a) (4).

1. The States Parties to the present Covenant recognize the right of everyone:
 - (a) To take part in cultural life;
 - (b) To enjoy the benefits of scientific progress and its applications;
 - (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science and culture.
3. The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research and creative activity.
4. The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and cooperation in the scientific and cultural fields.

Read in conjunction with article 2 (2), this right is to be accorded to everyone without discrimination.

General Comment No. 5 reiterates Rule 10, paragraphs 1 and 2, of the Standard Rules, noting that:

States should ensure that persons with disabilities have the opportunity to utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community, be they in urban or rural areas. ... States should promote the accessibility to and availability of places for cultural performances and services ...¹⁶⁵

According to the General Comment, article 15 applies to places for recreation, sports and tourism.¹⁶⁶ To facilitate the equal participation of persons with disabilities in culture, it urges States parties to inform and educate the general public about disability. This education should:

dispel prejudice or superstitious beliefs ... and the general public should be educated to accept that persons with disabilities have the same rights as anyone else to use restaurants, hotels, recreation centres and cultural venues.¹⁶⁷

General Comment No. 5 also notes that communications barriers must be eliminated to ensure that persons with disabilities can exercise their right to equal participation in cultural life. The Committee refers to the 1992 "Review by the Secretary-General of the implementation of the World Programme of Action concerning Disabled Persons and the United Nations Decade of Disabled Persons" which gives the following examples of useful measures:

the use of talking books, papers written in simple language and with clear format and colours for persons with mental disability, [and] adapted television and theatre for deaf persons.¹⁶⁸

¹⁶⁵ General Comment No. 5, para. 36.

¹⁶⁶ Ibid.

¹⁶⁷ Ibid., para. 38.

¹⁶⁸ Ibid., para. 37.

As cited above, Rule 10 of the Standard Rules requires States to ensure that persons with disabilities can participate equally in the creation and the enjoyment of culture. Activities such as dance, music, literature, theatre, plastic arts, painting and sculpture must be open to persons with disabilities, and places such as theatres, museums, cinemas and libraries should be accessible. States should develop and use the necessary technology to make literature, films and theatre accessible to persons with disabilities.¹⁶⁹ Rule 11 of the Standard Rules requires States to ensure that persons with disabilities have equal opportunities for recreation and sport. Places for recreation and sports, such as hotels, beaches, sports arenas and gym halls, should be accessible to persons with disabilities, and measures such as projects to develop accessibility should be taken.¹⁷⁰ Sports organization should be encouraged, together with organizations of persons with disabilities, to develop opportunities for persons with disabilities to participate in sports activities.¹⁷¹ The instruction and training provided to persons with disabilities should be of the same quality as that provided to able-bodied persons.¹⁷² In some cases, special arrangements or special games are needed. States should encourage persons with disabilities to participate in national and international events.¹⁷³ In the context of tourism, the services of tourist authorities, travel agencies, hotels, voluntary organizations and others should be offered to persons with disabilities, taking into account any special needs. Suitable training should be provided to assist in this process.¹⁷⁴

The right to culture is important for people with disabilities since it enables them to influence the way in which they are portrayed and gives them access to society's cultural products including sports, cinema and theatre.

5.4 Case studies on the current use of the ICESCR in the context of disability

Two sets of case studies are presented here.

The first is an evaluation of how 20 reports by 15 States parties to the Covenant treat the issue of disability.¹⁷⁵ The 15 States (Algeria, Germany, Guatemala, Iraq, Morocco,

¹⁶⁹ Rule 10 (1-3).

¹⁷⁰ Rule 11(1).

¹⁷¹ Rule 11 (3 and 5).

¹⁷² Rule 11 (4).

¹⁷³ Rule 11 (3).

¹⁷⁴ Rule 11 (2).

¹⁷⁵ Algeria: initial report, 1994 (E/1990/5/Add. 22); second periodic report 2000 (E/1990/6/Add. 26);

Germany: third periodic report, 1996 (E/1994/104/Add. 14), fourth periodic report, 2000 (E/C.12/4/Add. 3);

Guatemala: initial report, 1995 (E/1990/5/Add. 24);

Iraq: second periodic report, 1993 (E/1990/7/Add. 15);

Morocco: second periodic report, 1998 (E/1990/6/Add. 20);

Nepal: initial report, 1999 (E/1990/5/Add. 45);

Nigeria: initial report, 1996 (E/1990/5/Add. 31);

Panama: second periodic report, 1999 (E/1990/6/Add. 24);

Republic of Korea: initial report, 1993 (E/1990/5/Add. 19);

Nepal, Nigeria, Panama, Republic of Korea, Senegal, Sweden, Ukraine, United Kingdom, Yugoslavia and Zimbabwe) were chosen on the basis of availability of documentation and the aim of relatively even geographical distribution. To trace progress over time, two successive reports from each of five States parties were included (Algeria, Germany, Sweden, Ukraine and United Kingdom).¹⁷⁶

The second set of case studies takes a closer look at seven recent State party reports, covering all Covenant rights, and considers the Committee's response to the presence or absence of references to disability in these reports. It gives a fuller picture not just of how States parties view their ICESCR obligations with respect to persons with disabilities but also of the Committee's interaction with States parties. The seven State party reports are from Germany, Japan, Mexico, the Russian Federation, Senegal, Sweden and the Syrian Arab Republic. Again, the criteria for selection were availability of material, recent submission of a report and the aim of achieving a relatively even geographical spread.

5.4.1 Broad view: four key rights in 20 State party reports

(a) *The right to non-discrimination (article 2(2))*

The concepts of equality and non-discrimination are not explicitly mentioned in the context of disability in most the reports analysed.

Only one report (Sweden, fourth periodic report) mentions the creation of a law specifically and solely targeting disability discrimination (in the field of employment). Germany refers to the insertion of disability as a prohibited ground for discrimination in the Constitution (third periodic report) and, in a section dealing with homosexual relationships, mentions disability in passing as one of many unlawful grounds for discrimination (fourth periodic report). The United Kingdom states that in the Cayman Islands disability is one of the prohibited grounds for discrimination in Labour Law (fourth periodic report). In the context of legal protection against discrimination in employment, Algeria mentions that “disabled persons who cannot be employed in normal working conditions shall be entitled to sheltered work or, where necessary, places in sheltered workshops and to special training” (initial report).

As regards the integration, inclusion and equal participation of persons with a disability in society, just over half of the reports analysed (ten States parties) refer to

Senegal: second periodic report, 1999 (E/1990/6/Add. 25);

Sweden: third periodic report, 1994 (E/1994/104/Add. 1); fourth periodic report, 2000 (E/C.12/4/Add. 4);

Ukraine: third periodic report, 1994 (E/1994/104/Add. 4); fourth periodic report, 1999 (E/C.12/4/Add. 2);

United Kingdom: second periodic report, 1993 (Dependent Territories: E/1990/7/Add. 16); fourth report, 2000 (Overseas Territories: E/C.12/4/Add. 5);

Yugoslavia: second periodic report, 1998 (E/1990/6/Add. 22);

Zimbabwe: initial report, 1995 (E/1990/5/Add. 28).

¹⁷⁶ The second periodic report of the United Kingdom concerns the United Kingdom and its Dependent Territories and deals only with articles 13 to 15. The fourth periodic report concerns its Overseas Territories and covers all Covenant rights.

problems in this regard and/or explicitly mention either a policy or a specific measure to deal with them (Algeria, initial report; Germany, third and fourth periodic reports; Morocco, second periodic report; Panama, second periodic report; Republic of Korea, initial report; Sweden, third periodic report; Ukraine, third periodic report; United Kingdom, second periodic report (in connection with Isle of Man and Montserrat); Yugoslavia, second periodic report; Zimbabwe, initial report). Four reports mention a policy or a measure taken to eliminate societal barriers in the form of an inaccessible social environment (Republic of Korea, initial report; Ukraine, third periodic report; United Kingdom, fourth periodic report (in connection with the Falkland Islands); Yugoslavia, second periodic report).

Three reports explicitly mention equality/equal opportunities as a goal in the context of persons with disabilities (Germany, third periodic report; Morocco, second periodic report; Republic of Korea, initial report) and only one report mentions the need for the elimination of prejudice against persons with a disability (Republic of Korea, initial report).

Although Sweden's fourth periodic report improves on the previous report by citing a non-discrimination law in the field of employment, there is no clearly discernible progress under the heading of disability in most State parties between one report and the next.

In sum, fewer than half the reports analysed explicitly mention equality and non-discrimination in the context of disability and just over half mention participation and inclusion of persons with disabilities. It seems that these two key messages of General Comment No. 5 have not percolated through to the point where they influence all (or even most) policies and measures relating to disability in the areas covered by the ICESCR.

(b) The right to work (articles 6 and 7)

The aspect of the right to work that has been most instrumental in the shift towards a human rights perspective in the context of disability is access for persons with a disability to mainstream employment.

In addition to the two reports that mention non-discrimination laws in the area of employment (Sweden and the United Kingdom (Cayman Islands)), eleven reports (nine States parties) mention efforts to increase employment opportunities for persons with a disability (Algeria, first and second periodic reports; Germany, fourth periodic report; Guatemala, initial report; Iraq, second periodic report; Republic of Korea, initial report; Sweden, third and fourth periodic reports; Ukraine, third periodic report; Yugoslavia, second periodic report). The most commonly reported measures are vocational rehabilitation and training and placement, or creation of work opportunities. While many reports mention the integration of persons with disabilities into working life, they do not specify whether they are referring to mainstream or sheltered employment.

The right to vocational rehabilitation and to find suitable work is often dealt with in the context of persons with disabilities who have previously worked (e.g. those who have had accidents in the workplace).

Sweden's fourth periodic report mentions financial assistance to persons with disabilities to make specific workplaces accessible to them.

Five reports (three States parties) provide statistics for employed/unemployed persons with disabilities (Germany, third periodic report; Sweden, third and fourth periodic reports; Ukraine, third and fourth periodic reports). But only Sweden's fourth periodic report answers the vital question of what proportion of persons with disabilities are employed/unemployed.

Generally speaking, therefore, reports do not indicate the extent to which persons with disabilities participate in the mainstream workplace. While many mention steppingstones to this goal such as different forms of social and economic support, references to the integration of persons with disabilities into working life do not explicitly relate to mainstream employment, and non-discrimination laws are rare.

(c) The right to education (article 13)

The most important aspect of the right to education in the context of promoting a change of approach to disability is the inclusion of persons with disabilities in the general education system.

Most reports (except for Algeria, second periodic report; Germany, fourth periodic report; Guatemala, initial report; Nigeria, initial report; Ukraine, fourth periodic report) refer in some way to formal education of persons with disabilities (which is not taken here to include shorter targeted vocational education).

The majority of reports deal with the education of persons with disabilities mainly (and sometimes solely) in the context of special educational facilities. Only four explicitly mention the importance, and their active pursuance, of a policy of inclusion of persons with disabilities in the general education system (Morocco, second periodic report; Panama, second periodic report; United Kingdom, second periodic report (Isle of Man); Zimbabwe, initial report).

Three reports mention the establishment of special units connected to general schools for persons with disabilities (United Kingdom, second periodic report (Cayman Islands, Isle of Man), fourth periodic report (Gibraltar); Yugoslavia, second periodic report). One report mentions personal educational assistants for children with disabilities but does not say whether this occurs in special or general schools (United Kingdom, fourth periodic report (St. Helena)).

Three reports provide statistics on the number of special schools and/or students (Iraq, second periodic report; Republic of Korea, initial report; Yugoslavia, second periodic report).

Germany mentions the provision of transport adapted to individual needs as a means of equalizing opportunities between children with disabilities and able-bodied children (third periodic report).

Only one report touches on the physical accessibility of educational establishments (United Kingdom, fourth periodic report (Falkland Islands)).

Ukraine's fourth periodic report mentions a legal right for everyone to free primary education, regardless, inter alia, of health, but does not explicitly mention disability (fourth periodic report).

Most reports mention children only in connection with education in the context of disability.

To sum up, while some States parties espouse the objective of achieving integrated education, the provision of integrated education for persons with disabilities (with all its attendant planning and logistical problems) is not the norm or the reality in many States.

(d) Right to cultural participation (article 15)

The right to cultural participation covers both the enjoyment and the creation of culture. The creation of culture is the sharing of a perception of reality or a specific point of view. Cultural expression has a particular value for those whose perspectives were not communicated in the past or were ignored. Both the right to create culture and the right to take part in cultural life enhance the visibility of persons with disabilities in society and thus assist in changing perceptions of disability.

Only one report (Yugoslavia, second periodic report) mentions persons with disabilities in the context of article 15. It provides information regarding both the participation in culture and the creation of culture by persons with disabilities.

Under the heading of participation, the report mentions theatre groups involving persons with disabilities and "social groups" attached to organizations for persons with disabilities. Some of these organizations receive minor government grants. According to the report, most mainstream cultural venues are still inaccessible to persons with disabilities. With regard to the creation of culture, the report mentions the publication of magazines by organizations of persons with disabilities, the creation of a school of poetry by persons with disabilities and fashion design for persons with disabilities.

All in all, the fact that only one report mentions persons with disabilities in the context of the right to culture indicates that many States parties have not yet taken fully on board the general goals of participation and independence. This poor record is deeply disappointing, as achievement of a right to culture clearly has the potential to produce a multiplier effect.

(e) Conclusions

A comprehensive account of the situation of persons with disabilities under the ICESCR would include: (a) a general policy statement based on the criteria of equality, inclusion and participation and a social definition of disability; (b) an account of how this perspective is applied and realized in the context of each right; and (c) an assessment of the extent to which these rights are currently enjoyed by persons with disabilities. None of the reports analysed comes close to fulfilling these requirements. Measured against the above benchmarks, the coverage of persons with disabilities is, at best, piecemeal. Moreover, in most cases it is not clearly and explicitly based on a policy such as the one described above.

Many reports mention persons with disabilities in the same breath as other groups of persons perceived as “innocent, vulnerable or dependent” (Nigeria, initial report) such as “orphans, helpless women, the aged, the disabled and incapacitated persons” (Nepal, initial report). As a result, discrimination and lack of enjoyment of rights is obscured for each of these groups by an image of inherent helplessness, implying the need for charity rather than empowerment and justice.

In most cases, the terms disability and handicap are used interchangeably¹⁷⁷ and offensive terminology¹⁷⁸ such as “mentally retarded”¹⁷⁹ is commonplace. However, more recent reports indicate that there has been some improvement in this regard.

More often than not, the concept of rights is absent from descriptions of measures to meet the needs of persons with disabilities. In the reports analysed, no reference is made to the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities or to the ICESCR Committee’s General Comment No. 5. There is only one reference to the International Year of the Disabled (Republic of Korea, initial report) and one to the World Programme of Action concerning Disabled Persons (Algeria, initial report). Three reports mention the creation of national institutions to further the rights of persons with disabilities (Guatemala, initial report; Morocco, second periodic report; Sweden, fourth periodic report).

All of the above suggests that States parties to the ICESCR have not fully internalized the move to a rights-based perspective on disability. The problem is not a lack of normative clarity in the ICESCR. Perhaps greater levels of NGO involvement – both in the drafting of States reports and in the work of the ICESCR Committee – could provide leverage for change in the right direction.

5.4.2 Close-up view: coverage of all rights in the context of disability in seven recent State party reports

It will be recalled that the 1991 revised reporting guidelines specifically request States parties to report on disability under articles 6 (work), 9 (social security), 10 (family) and 13 (education).

(a) Germany - fourth periodic report (2000)

The State party’s report

Germany's fourth periodic report under the ICESCR was published in 2000.¹⁸⁰

¹⁷⁷ But see Sweden, fourth periodic report, correcting the use of the term handicap in the previous report.

¹⁷⁸ See, for example, Algeria, second periodic report (disabled and maladjusted persons); Iraq, second periodic report (totally disabled/totally handicapped); Nepal, initial report (the disabled and incapacitated persons); Republic of Korea, initial report (physical or mental defect); Zimbabwe, initial report (natural deformity),

¹⁷⁹ See, for example, Iraq, second periodic report (mentally, psychologically and physically retarded); Panama, second periodic report; Sweden, third periodic report; Ukraine, third periodic report; United Kingdom second periodic report (Gibraltar) (retarded); Zimbabwe, initial report.

¹⁸⁰ E/C.12/4/Add.3.

Disability is mentioned in the context of articles 6 (the right to work), 10 (the right to protection of the family, mothers and children) and 11 (the right to an adequate standard of living).

Under article 6 (the right to work), the report refers under the heading “Measures to integrate people with disabilities into working life” to a memorandum entitled “The Integration of Disabled Persons in the Federal Republic of Germany”. It emphasizes that the measures outlined in the memorandum also apply to the new Länder. The memorandum sets out in 16 chapters the range of support facilities available to people with disabilities. They include some far-reaching measures for the integration of people with disabilities into the workforce.

A special effort is reportedly being made on behalf of “young disabled persons in East Germany” with a view to implementing the agreement reached at the European Union Employment Summit in Luxembourg in 1997. In accordance with the aim agreed at the Summit, Germany states that it plans to offer a “new start” to “every single disabled person” before he or she has been out of work for twelve months. Together with unemployed persons in general, 20 per cent of unemployed “disabled people” are to be offered vocational training under this plan. Germany also reports on a “pilot project” to evaluate whether an extension of the “particular promotion of hiring and employing disabled persons from the compensation levy budget” to cover “fixed-term employment contracts” can make employers more prepared to employ “severely disabled persons”.

Under article 10 (the right to protection of the family, mothers and children), the German report states that child benefits are payable for “children who, because of a disability, are unable to support themselves”.

Under article 11 (the right to an adequate standard of living), Germany notes that 33.1 per cent of the expenditure for “benefits to help cover living costs” in 1997 was spent on “integration assistance for disabled persons”. In 1997, some 38 per cent of people receiving assistance for “persons in special circumstances” were recipients of “integration assistance for disabled persons”.

The Committee's list of issues

The list of issues¹⁸¹ mentions disability in the context of two articles, article 6 (the right to work) and article 15 (the right to cultural participation).

Under article 6, the Committee wished to be informed about “any action taken, pursuant to the memorandum ‘The Integration of Disabled Persons in the Federal Republic of Germany’”.

Under article 15, the Committee requested information about “the benefits and assistance” given to, inter alia, “persons with disabilities ... to participate in, and benefit from, the cultural activities of the State party”.

The State party's reply to the list of issues

The reply to the list of issues was not available at the time of writing.

¹⁸¹ E/C.12/Q/GER/2.

The summary records

The summary records of the meetings in respect of Germany¹⁸² show that the issue of disability was not raised during the Committee's discussions with the State party.

The Committee's concluding observations

There is no reference to disability in the Committee's concluding observations.¹⁸³

*(b) Japan - second periodic report (1998)**The State party's report*

Japan's second periodic report under the ICESCR was published in 1998.¹⁸⁴

The report mentions disability in the context of articles 6 (the right to work), 9 (the right to social security), 10 (the right to protection of the family, mothers and children), 12 (the right to health) and 13 (the right to education).

Under the heading "General comments" and the subheading "Status and rights of foreigners", the report mentions "welfare allowances for persons with disability" and "special allowances for persons with disability" as examples of benefits that do not require Japanese nationality. Under the subheading "Measures for the socially disadvantaged", the report presents a general policy statement on the situation of persons with disabilities. In 1995, Japan enacted the "Government Action Plan for Persons with Disabilities" designed to implement the "New Long-Term Programme for Government Measures for Persons with Disabilities" enacted in 1993. According to the report, the Action Plan has seven goals: "(a) Living in communities as ordinary citizens; (b) Promoting the social independence of persons with disabilities; (c) Promoting a barrier-free society; (d) Targeting the quality of life (QOL); (e) Assuring security in living; (f) Removing psychological barriers; and (g) Promoting international cooperation and exchanges."¹⁸⁵

The Action Plan is said to be "based on the principle of rehabilitation, which aims to restore all human rights to those in all stages of the life cycle, and of normalization, which strives to create a society where the daily lives and activities of persons with disabilities are equal in quality to those without disabilities".¹⁸⁶

Under article 6, the report notes the importance of providing "detailed and considerable vocational guidance and vocational placement according to the person's capability and aptitude".¹⁸⁷ It states that a job-seeking registration system for persons with disabilities has been established. Figures are provided showing an increase in both persons registered

¹⁸² E/C.12/2001/SR.48 and 49.

¹⁸³ E/C.12/1/Add.68.

¹⁸⁴ E/1990/6/Add.21.

¹⁸⁵ E/1990/6/Add.21, para. 12.

¹⁸⁶ Ibid.

¹⁸⁷ Ibid., para. 26.

as job-seekers and persons having found employment. The report recognizes that the number of applicants with disabilities exceeds the number of employment opportunities.

Under article 9 (the right to social security), the report refers to a “disability pension” under two different pension schemes. The “National Pension Scheme” is open to all residents and its size is dependent on the degree of disability. The “Employees' Pension Insurance Scheme” is based on contributions, the size of which depends on a person's monthly salary, period of contribution and degree of disability. When a worker is injured or falls ill at work, s/he is entitled to medical compensation, long-term health care and “temporary”, “long-term” or “permanent” disability compensation benefit.

Under article 10 (right to protection of the family, mothers and children), the report refers to a Law concerning the Provision of the Special Child-Rearing Allowance, which provides for the payment of compensation to the parent or guardian rearing a “child with a mental or physical disability”. The monthly allowance depends on the degree of disability. The total number of recipients stood at 130,000 in March 1997. Under the Child Welfare Law, the Government also reportedly provides medical aid and equipment for “children with potential disabilities”.

Under the heading “Protection of children”, the report notes that the Government has taken active steps to reinforce “the prevention, early diagnosis and early medical care of the mentally or physically disabled”.¹⁸⁸ It describes measures such as “the placing of disabled children in institutions for mentally disabled children, schools for mentally disabled children, institutions for physically disabled children, institutions for blind children, institutions for children with auditory/speech disabilities, and institutions for severely handicapped children, or enabling them to commute to such institutions”.¹⁸⁹ In October 1996, there were 816 “facilities for disabled children” attended by approximately 38,000 children. The report further states that “home welfare measures such as counselling and guidance at child guidance centres and welfare offices and the dispatching of home helpers are also vigorously promoted.”¹⁹⁰

Under article 12 (the right to health), it is reported that the Mental Hygiene Law was renamed the Law concerning Mental Health and Welfare for the Mentally Disabled in 1995 to improve rehabilitation and protection facilities for “mentally disabled persons”. The policy on mental health and welfare of “the mentally disabled has been changing from a system of hospitalization in mental hospitals to a system of community care”.¹⁹¹ As regards access to medical care, “the Government pays part of the medical expenses for patients hospitalized on the orders of the prefectural governors and for outpatients.”¹⁹² The Government also subsidizes the construction and management of rehabilitation institutions for the “mentally disabled” and provides counselling by doctors and social workers at health centres.

The Law for the Welfare of Physically Disabled Persons is said to provide for medical care and rehabilitation. Children with “physical disabilities” or with “diseases that

¹⁸⁸ Ibid., para. 128.

¹⁸⁹ Ibid.

¹⁹⁰ Ibid.

¹⁹¹ Para. 197.

¹⁹² Para. 196.

might cause disabilities if left untreated” are provided with medical care under the Child Welfare Law.

Under article 13 (the right to education), the report mentions “a small number of infirm people” who are unable to go to ordinary schools and receive “basic education”. These students subsequently have the option of entering higher-level schools.

The Committee’s list of issues

In its list of issues the Committee requested information under article 6 (the right to work) on “the implementation of the provisions of the Covenant concerning the employment of persons with disabilities in Japan”.¹⁹³

The State’s reply to the list of issues

In its reply to the list of issues,¹⁹⁴ Japan states that various measures are being implemented with a view to requiring employers to hire persons with physical or intellectual disabilities. Companies with more than 56 employees are expected to hire more than 1.8 per cent of their employees from among people with disabilities. A figure of 1.48 per cent was recorded for 1999.¹⁹⁵ Various grants are reportedly given to employers and the Government’s aim is to promote the “independence of persons with disabilities in their vocational life by providing vocational rehabilitation”.¹⁹⁶

With regard to access to culture, the Government outlines its policies of making facilities such as museums and theatres accessible to “the aged and physically handicapped”. Loans and government support are provided for research and development relating to appliances and telecommunication/broadcasting services “which facilitate greater benefits to the aged, handicapped or those who look after them”.¹⁹⁷

The summary records

In response to questions, a Japanese representative referred to incentives to encourage employment of the “handicapped”. OECD figures were cited to show that only 2.4 per cent of children attend special educational institutions in Japan, which is a relatively low level by international standards.¹⁹⁸

The Committee’s concluding observations

In its concluding observations, the Committee expressed concern that discrimination against persons with disabilities continued to exist in Japan, particularly in relation to labour and social security rights.¹⁹⁹

¹⁹³ E/C12/Q/JAP/1, para. 13.

¹⁹⁴ HR/ICESCR/NONE/2001/16.

¹⁹⁵ Ibid. section III, paras. 1 and 2.

¹⁹⁶ Ibid.

¹⁹⁷ Ibid., reply to questions on article 15.

¹⁹⁸ Ibid., para. 43.

¹⁹⁹ E/C.12/1/Add.67, para. 25.

The Committee recommended that Japan abolish discriminatory provisions in its legislation and adopt a law against discrimination relating to persons with disabilities. It also urged the State to speed up the employment rate for persons with disabilities in the public sector where legislation existed.²⁰⁰

(c) *Mexico - third periodic report (1997)*

The State party's report

Mexico's third periodic report under the ICESCR was published in 1997.²⁰¹

Disability is mentioned in the context of articles 2 (the right to non-discrimination), 6 (the right to work), 7 (the right to just and favourable conditions of work), 9 (the right to social security), 10 (the right to protection for the family, mothers and children), 11 (the right to an adequate standard of living), 12 (the right to health) and 13 (the right to education).

Under article 2 (the right to non-discrimination), the report notes that it has taken measures “for the benefit of the poorer social groups”, including action to combat “malnutrition, morbidity and mortality due to infectious and parasitic diseases”.

Under article 6 (the right to work), the State party report mentions disability in the context of a training programme for the disabled which provided training for 726 persons during 1995.

Under article 7 (the right to just and favourable conditions of work), the Mexican report states that incapacity rates due to accidents at work have been reduced.

Under article 9 (the right to social security), the report deals with two social insurance schemes. One is compulsory, and concerns “State workers” and their families. The other is voluntary and concerns everyone else, provided that they can afford to pay the contributions. These schemes cover medical services, “[c]ompensation for occupational accidents” and “pensions in respect of incapacity to work”.

Under article 10 (right to protection of the family, mothers and children), the report mentions that children of a socially insured person “who cannot support themselves owing to a chronic illness or physical or mental deficiency”, are entitled to medical care and/or cash benefits. Under the heading “Situation of orphaned, abandoned and disabled children and young persons, and those deprived of their family environment, and street children”, the reports describes Mexico’s cooperation with UNICEF to provide a “basic food, nutrition, health and sanitation package”. In addition, the Government reports taking measures to provide vulnerable children with “shelter and food, medical, psychological and learning-disability treatment, and cultural, sports and recreational activities, as well as education and training, including work training”.

²⁰⁰ Ibid., para 52.

²⁰¹ E/1994/104/Add.18.

The national assistance policy to “promote the welfare of the disabled and incorporate them in development”²⁰² reportedly uses both public and private resources to “initiate a process of change in which the disabled will be the protagonists of their own development”.²⁰³

Under article 11 (the right to an adequate standard of living), the report mentions malnutrition as a cause of “mental retardation”.

Under article 12 (the right to health), it estimates that “9 per cent of the population suffers from mental subnormality and that 2 to 4 per cent have learning difficulties”.²⁰⁴ The report also mentions that health care for mothers and new-borns addresses “prevention of mental defects due to congenital hypothyroidism”.²⁰⁵

With regard to article 13 (the right to education), the report notes that the new approach to education for persons with disabilities is now informed by “a new vision of the integration of disabled children in the regular school system”²⁰⁶. A national programme “to promote the welfare and social integration of disabled persons and incorporate them in development”²⁰⁷ was established in 1995. Special education needs are catered for in schools in the general education system by means of special “operational and administrative units”. At the same time, “special-education schools” and “new social integration centres” are encouraged. The report mentions the provision of training to upgrade the skills of personnel working with children with “special education needs”. Public educational institutions run “extensive programmes of special education for disabled children”. Mention is made of the creation of a “disability registry” which provides information on children with disabilities in pre-school, primary and secondary education in all the country's public and private schools. These figures are provided in the report (2.9 million children aged 0-17 have some disability) and disaggregated according to the type of disability and number of children involved.

According to the report, 16.3 per cent of the 154,321 trainee teachers in public institutions in 1995 were following a course on “special education”.

A coalition of 91 Mexican NGOs submitted a parallel report²⁰⁸ to Mexico's third periodic report which makes no mention of disability.

The Committee's list of issues

In its list of issues,²⁰⁹ the Committee asked the State party about the measures it had taken to “establish appropriate, non-discriminatory working conditions for the disabled” with reference to article 7 of the Covenant.²¹⁰

Summary records

²⁰² Ibid.

²⁰³ Ibid.

²⁰⁴ Ibid., para. 326.

²⁰⁵ Ibid., para. 387.

²⁰⁶ Ibid., para. 244.

²⁰⁷ Ibid., para. 449.

²⁰⁸ E/C.12/1999/NGO/3.

²⁰⁹ E/C.12/Q/MEX/1.

²¹⁰ Ibid., para. 22.

According to the summary records,²¹¹ a Mexican representative stated that the national Senate was considering the possibility of ratifying ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159) and of acceding to the Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities. Fund-raising events were frequently held for disabled people.²¹²

The Committee's concluding observations

The concluding observations on Mexico's third periodic report make no mention of disability.²¹³

(d) Russian Federation – third periodic report (2000)

The State party's report

The third periodic report of the Russian Federation under the ICESCR was published in 1995.²¹⁴

Disability is mentioned in the context of articles 6 (the right to work), 7 (the right to just and favourable conditions of work), 9 (the right to social security), 11 (the right to an adequate standard of living), 12 (the right to health) and 13 (the right to education).

Under article 6 (the right to work), the report notes that the number of disabled women in the workplace declined by 80,000 during the reference period (1991-1992). It also notes that 55 persons are “injured and become disabled” every day as a result of work-related accidents.

Under article 7 (the right to just and favourable conditions of work), the problem of unsafe working conditions is elaborated on. The report states that in order to relieve the critical social situation in the Russian Federation, wages, pensions and allowances for, inter alia, “the disabled” are reviewed once a quarter. The report also mentions measures adopted to ensure the vocational rehabilitation of “the disabled”.

Under article 9 (the right to social security), the Constitution of the Russian Federation reportedly ensures social security in the case of “disability”. Workers are stated to be entitled to “temporary incapacity benefits” when they cannot work owing to injury or illness. This provision also covers the situation “when artificial limbs have to be provided”.²¹⁵ A disability pension is paid to workers who can no longer work because of a disability. The amount of the pension, and the eligibility for additional benefits, are dependant on the number of years worked and the person's need for care.

²¹¹ E/C.12/1999/SR.44, 45 and 46.

²¹² E/C.12/1999/SR.46 para. 67.

²¹³ E/C.12/1/Add.41.

²¹⁴ E/1994/104/Add.8.

²¹⁵ Ibid., para. 116.

Allowances are also paid to “able-bodied persons” who care for someone incapable of working.

Under article 11 (the right to an adequate standard of living), article 7 of the Constitution of the Russian Federation reportedly spells out the State's obligation to “provide State support” for, inter alia, “the disabled”. According to the report, assistance in the form of cash grants and assistance in kind are provided, inter alia, to “families with disabled children”. Pensions are reportedly paid for “disabled children”. Up to the age of 16 “disabled children” are entitled to free medical care. The Russian Federation reports that every year measures are taken to provide summer holidays for, inter alia, disabled children.

Under article 12 (the right to health), the Russian Federation reports a “humanization” of health legislation through a “strengthening of the rights and guarantees of its application”. Particular attention is paid to “the least protected segments of the population”, including “the disabled”.

Under article 13 (the right to education), the report claims that “the State satisfies not only the educational requirements of ordinary members of society but also those of handicapped citizens for whom special educational arrangements are made.”

The Committee's list of issues

In its list of issues the Committee inquired about the effectiveness of the measures for the vocational rehabilitation of the disabled.²¹⁶

It also asked a question under article 3 about the protection of working women, young persons and the disabled.²¹⁷

The State party's reply to the list of issues

No record of a reply by the State party could be located at the time of writing.

*The summary records*²¹⁸

Referring to the issue of disability, a representative of the Russian Federation mentioned the lack of up-to-date rehabilitation equipment. He also referred to tax advantages and technical advice that the Government offered to companies to increase the employment of people with disabilities.²¹⁹

The Committee's concluding observations

The concluding observations mention disability in the context of employment. Under the heading “Positive aspects”, the Committee “notes with appreciation that

²¹⁶ E/C.12/Q/RUS.1, para 23.

²¹⁷ Ibid., para. 9.

²¹⁸ E/C.12/1997/SR.11, 12, 13 and 14.

²¹⁹ E/C.12/1997/SR.13, para. 56.

employers are given tax incentives for the hiring of disabled persons to facilitate their access to gainful employment.”²²⁰

(e) *Senegal – second periodic report (1999)*

The State party's report

Senegal's second periodic report under the ICESCR was published in 1999.²²¹

Disability is mentioned in the context of articles 11 (the right to an adequate standard of living), 12 (the right to health) and 13 (the right to education).

Under article 11 (the right to an adequate standard of living), the report mentions the prevention of disability.

Under article 12 (the right to health), the reports states that nearly 2 per cent of the population is “disabled” and “among them, rural disabled persons account for 90 per cent”.²²² This has led the Ministry of Health to “revitalize its rural health programme to improve coverage for patients”.²²³

Under article 13 (the right to education), the report refers to the provision of “special education”, which is described as covering “the medical, psychological and pedagogical needs of children whose normal schooling and training is rendered difficult because of a physical or other disability”.²²⁴

The Committee's list of issues

In its list of issues, the Committee requested information on all measures being implemented by the State party to protect and fulfil the economic, social and cultural rights of ethnic and religious minorities, people with disabilities, older people and foreigners.²²⁵

Disability is also referred to in relation to the benefits and assistance given to certain groups to enable them to participate in and benefit from cultural activities.²²⁶

The State party's reply to the list of issues

No replies were received by the Committee.

The Committee's concluding observations

The concluding observations on Senegal²²⁷ expressed regret that the State party had not provided written replies to the list of issues.

²²⁰ E/C.12/1/Add. 3, para.7.

²²¹ E/1990/6/Add. 25.

²²² E/1990/6/Add. 25, para. 82.

²²³ Ibid.

²²⁴ Ibid., para. 109.

²²⁵ E/C.12/Q/SEN/1, para. 8.

²²⁶ Ibid., para. 42.

²²⁷ E/C.12/1/Add.62.

The Committee expressed concern at “the lack of adequate protection and facilities for people with disabilities who are unable to participate in many occupations due to physical barriers and lack of equipment and training opportunities”.²²⁸

(f) *Sweden – fourth periodic report (2000)*

The State party’s report

Sweden's fourth periodic report under the ICESCR was published in 2000.²²⁹

Disability is mentioned in the context of article 6 (the right to work), article 9 (the right to social security), article 11 (the right to an adequate standard of living) and article 13 (the right to education).

Under article 6 (the right to work), the Swedish report notes the continuing need for measures to create job opportunities for disadvantaged groups, including “the disabled”. One such measure is “workplace introduction” under which the employer pays a small sum and the worker receives a “training allowance” from the State. Another measure mentioned in the report is the enactment of the Act against Discrimination of Persons with Functional Impairment at Work in 1999. This law is monitored by the Ombudsman for Disabled People, who can bring cases of discrimination before the Swedish Labour Court.

Other legal instruments mentioned in the context of persons with disabilities are

the Law on Employment Protection and the Work Environment Act. According to the report, “[s]everely disabled people receive individual support”.²³⁰ It notes the difficulties faced by “[p]eople with functional disabilities” in competing in the open labour market. Their unemployment rate is reported as 50 per cent, compared with 28 per cent for the population as a whole. The report notes that the achievement of employment for people with disabilities is not only a matter of ensuring the entry of “disabled persons” into the labour market but also of supporting participation and preventing dropout.

Under article 9 (the right to social security), the Swedish report refers to the fact that it is a party to the ILO Invalidity, Old-Age and Survivors' Benefits Convention, 1967 (No. 128). It mentions a care allowance available to parents of “disabled children” who are in need of care. Under the heading “Other disability benefits” the report mentions a “disability allowance” that may be paid to a person who has “a functional impairment or a long-lasting illness” and who requires technical aids or equipment to be able to work or return to work.

Under article 11 (the right to an adequate standard of living), Sweden notes that there are disparities between residential areas regarding, inter alia, the number of “disability pensions” paid. The report also notes that the labour market crises of the 1990s were particularly hard for, inter alia, “the disabled”. Under the heading “Standard of living

²²⁸ Ibid., para. 17.

²²⁹ E/C.12/4/Add.4.

²³⁰ Ibid., para. 72.

and living conditions for the elderly and disabled”, it notes that these two categories have traditionally experienced financial and social difficulties.

Since 1992, Swedish municipalities are reported as being responsible for the provision of long-term services and care to people in these categories, including both home care and “special needs housing”. The report provides detailed figures from 1993 for people receiving care, support or other services from municipal councils under the Act concerning Support and Service for Persons with Certain Functional Impairments. The most common service received is “counselling and other personal support”. This law, and the Act on Compensation for Assistance in force since 1 January 1994, are reported to have “extended the rights of people with disabilities”.

Under the heading “Statistics on poverty in Sweden”, the report notes that “disability pensioners” were among those who lost out most during the increase in poverty in the 1990s. It also mentions that “[p]eople suffering from mental illness” make up an increased percentage of the 10,000 homeless persons in Sweden.

Referring to Sweden’s third periodic report published in 1994, the report observes that the term “handicapped” used in that report has now been replaced by “disabled” or “people with disabilities”.

The report refers to difficulties facing people with disabilities under article 11 (the right to an adequate standard of living).

Under article 13 (the right to education), the report notes that a new curriculum for compulsory schools has been adopted which includes “special schools and compulsory special schools for the intellectually disabled”.

The Committee's list of issues

In its list of issues the Committee requested information about people with disabilities in relation to article 15 (the right to take part in cultural life and enjoy the benefits of scientific progress):

Please provide updated information on the benefits and assistance given, in general, to the population, and , in particular, to young persons, students, older people, people with disabilities, and the most disadvantaged and marginalizes groups.²³¹

The State party's reply to the list of issues

The reply to the list of issues refers to an interdepartmental action plan for human rights to be drawn up by the Ministry for Democratic Issues and Public Administration. A baseline study of Sweden’s international legal obligations, including those relating to the “rights of disabled persons” is said to have been prepared.

In response to a specific question raised by the Committee, Sweden replies that 25 grants have been made to a programme to develop culture for people with different

²³¹ E/C.12/Q/SWE/2, para. 35.

disabilities, to improve adult education for people with disabilities and to enhance their access to literature, films and the media.

The Committee's concluding observations

The concluding observations do not mention persons with disabilities.²³²

(g) Syrian Arab Republic – second periodic report (1999)

The State party's report

The Syrian Arab Republic's second periodic report under the ICESCR was published in 1999.²³³

Disability is mentioned in the context of articles 9 (the right to social security), 10 (the right to protection of the family, mothers and children), 11 (the right to an adequate standard of living), and 12 (the right to health).

The Syrian Arab Republic mentions that it has “adopted the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities”.²³⁴ In addition, it celebrates the International Day of Disabled Persons, the “Day of the Blind” and the “Week of the Deaf”. The report states that all “Arab and international conventions and social action strategies reaffirm the prevailing attitude under which the disabled are regarded as a social category requiring attention and various forms of care conducive to their integration into the socio-economic development process.”²³⁵

Under article 9 (the right to social security), the Syrian Arab Republic refers to a disability pension and additional benefits for workers who become disabled in connection with their employment. In the case of persons with disabilities who have not previously been employed, the State “undertakes to provide for every citizen and his family in the event of ... disability”.²³⁶

Under article 10 (right to protection of the family, mothers and children), the Syrian Arab Republic reports on a number of issues concerning persons with disabilities under the heading “the disabled”. The Syrian Constitution stipulates that the State shall provide for “every citizen and his family” in the case, inter alia, of “disability”.

According to the report, the Syrian Arab Republic shows great concern for the “problem of the disabled”. Many “institutions, schools and centres” have been established “in order to cater for the welfare, education and rehabilitation of the various categories of disabled persons”. These establishments provide “rehabilitation, training and employment services” to enable persons with disabilities to “integrate into society and participate in the socio-economic development process”.²³⁷

²³² E/C.12/1/Add. 70.

²³³ E/1994/104/Add.23.

²³⁴ E/1994/104/Add.23, para. 142.

²³⁵ Ibid., para. 130.

²³⁶ Ibid., para. 59.

²³⁷ Ibid., para. 131.

Some “charitable institutions and associations” for the “physically disabled” are listed in the report. They include schools and a rehabilitation centre which “provides disabled persons with guidance and training in occupations suited to their condition and their abilities” free of charge.²³⁸ The aim of these institutions is to enable persons with disabilities to utilize their remaining capacities and to facilitate their social adaptation and integration.²³⁹ Legislation regulating the establishment and operation of such institutions “for each type of disability” is said to have been enacted. There is also legislation providing for the employment of “blind persons”. The report lists a number of “national associations concerned with the physically disabled”.

Public bodies are reportedly required to employ a quota of 4 per cent of “disabled persons”. The Ministry of Social Affairs and Labour is responsible for the “care of the disabled” and for the supervision of “voluntary charitable associations” that provide services for persons with disabilities. The Ministry has organized various training courses for the staff of institutions catering for the “social welfare of various categories of disabled persons” as well as for families with “disabled members”.

According to the report, “a community-based rehabilitation project for disabled persons” is being implemented in cooperation with the ILO “in order to stimulate public awareness concerning the serious problems faced by disabled persons and to provide them with opportunities through small production projects”.²⁴⁰

The Syrian Arab Republic reports that its Central Statistical Office, in cooperation with the United Nations Children's Fund, is conducting a joint field survey of “disabled persons under 18 years of age in the Syrian Arab Republic in order to ascertain their number, their geographical distribution and their distribution by age, sex and type of disability”.²⁴¹

Under article 11 (the right to an adequate standard of living), the report indicates that the State and non-governmental organizations provide social services for “indigent families and disadvantaged social categories” such as “the disabled”.

The Committee's list of issues

In its list of issues, the Committee requested, under article 9, statistical information concerning, inter alia, disability pensions.²⁴² Details of laws and ordinances in this area were also requested together with information on how they were applied in practice.

Information was requested under article 12 on the actual situation in the field of mental health, including the estimated numbers of mentally ill, how they were cared for and by whom.²⁴³

²³⁸ Ibid., para. 136 (c).

²³⁹ Ibid., para. 136.

²⁴⁰ Ibid., para. 140.

²⁴¹ Ibid., para. 141.

²⁴² E/C.12/Q/SYR/1, para. 17.

²⁴³ Ibid., para. 27.

The State party's reply to the list of issues

In its reply to the questions regarding article 9,²⁴⁴ the State party referred to the health and education benefits and social services provided to people over 60 years of age by a new National Committee for Care. The issue of benefits for people with disabilities was not directly addressed.

No information was provided regarding people with mental illness or disability. There was, however, a lengthy reference to provisions of the Syrian Penal Code concerning beggars and vagrants. Under articles 596–604 of the Code, anyone found begging or seeking charity may be confined for up to six months. Moreover, “anyone who engages in begging after leaving a charitable institution in which he was being cared for shall be liable, even if incapacitated, to the above-mentioned penalty of detention.”²⁴⁵

The summary records

One member of the Committee noted that although the report provided detailed information on various categories of disabled people, no mention was made of those who were wholly dependent on others.²⁴⁶

With regard to article 6, a Syrian representative cited the example of disabled students who had been encouraged to study law and become lawyers despite the initial resistance of the Law Society. More generally, he stated that “there were a large number of benevolent societies in the private sector providing food, health care and pharmaceuticals to the handicapped.”²⁴⁷

Commenting on health care (article 12), a Syrian representative stated that “special care was given to both the partially and seriously disabled. The severely disabled were not ignored, but enjoyed full protection, especially from associations for the disabled, which catered for their health, nutritional and other needs. They were cared for by special staff who visited the day-care centres where they lived if no care was available at home.”²⁴⁸

The Committee's concluding observations

The issue of disability was not specifically referred to in the concluding observations except in the context of general concerns about the system of social security and the right to health.²⁴⁹

²⁴⁴ HR/ICESCR/NONE/20001/2.

²⁴⁵ Syrian Penal Code, article 598.

²⁴⁶ E/C.12/2001/SR.35, para.10.

²⁴⁷ Ibid., para. 27.

²⁴⁸ Ibid., para. 38.

²⁴⁹ Ibid., paras. 39 and 43.

5.5 Conclusions on the ICESCR and disability

5.5.1 Conclusions

Despite many excellent examples to the contrary, it emerges from the sample survey of reports shows that the coverage of people with disabilities in State party reports tends on the whole to be piecemeal.

In the first set of case studies, fewer than half of the reports analysed mention either a policy or a specific measure aimed at inclusion and participation in the context of disability.²⁵⁰ Three reports mention either a policy or law²⁵¹ or a measure or recognition of the need²⁵² to eliminate social barriers in the form of inaccessible buildings. One report explicitly mentions equality of opportunity as a goal in the context of persons with disabilities²⁵³ and another mentions the need for elimination of prejudice.²⁵⁴ Most of the reports surveyed mention persons with disabilities together with other groups of persons perceived as “innocent, vulnerable or dependent”²⁵⁵ such as “orphans, helpless women, the aged, the disabled and incapacitated persons”.²⁵⁶

The word “right” is seldom used in descriptions of measures to meet the needs of persons with disabilities. In most cases, the terms disability and handicap are used interchangeably²⁵⁷ and terminology²⁵⁸ such as “mentally retarded”²⁵⁹ is commonplace.

In the reports analysed, no reference is made to the United Nations Standard Rules or to General Comment No. 5. There is only one reference to the International Year of

²⁵⁰ Algeria, initial report; Germany, third and fourth periodic reports; Panama, second periodic report; Sweden, third periodic report; Ukraine, third periodic report; United Kingdom, second periodic report (Isle of Man); Yugoslavia, second periodic report; Zimbabwe, initial report.

²⁵¹ Republic of Korea, initial report.

²⁵² United Kingdom, fourth periodic report (Falkland Islands); Yugoslavia, second periodic report.

²⁵³ Germany, third periodic report.

²⁵⁴ Republic of Korea, initial report.

²⁵⁵ Nigeria, initial report.

²⁵⁶ Nepal, initial report.

²⁵⁷ But see Guatemala, initial report; Republic of Korea, initial report; Sweden, fourth periodic report, correcting the use of the term “handicap” in the previous report; Ukraine, third periodic report; United Kingdom, second periodic report (Isle of Man, Turks and Caicos Islands), fourth periodic report (Gibraltar, St Helena); Yugoslavia, second periodic report.

²⁵⁸ Algeria, second periodic report (disabled and maladjusted persons); Iraq, second periodic report (totally disabled/totally handicapped); Nepal, initial report (disabled and incapacitated persons); Ukraine, third periodic report (children with defects in their physical development); Zimbabwe, initial report (natural deformity).

²⁵⁹ Iraq, second periodic report (mentally, psychologically and physically retarded); Panama, second periodic report; Sweden, third periodic report; Ukraine, third periodic report; United Kingdom, second periodic report (Gibraltar, retarded), Isle of Man Zimbabwe, initial report.

the Disabled²⁶⁰ and one to the World Programme of Action.²⁶¹ One report mentions the creation of national institutions to further the rights of persons with disabilities.²⁶²

None of the reports refers to the UNESCO Declaration on Education for All - Meeting Basic Learning Needs, which states that all children and adults (including those with disabilities) have a “fundamental human right” to a basic education.

With regard to the second set of case studies, it should be recalled that the Committee’s reporting guidelines specifically request information on disability under articles 6, 9, 10 and 13. Two States parties address disability under all these articles in their reports. The lists of issues tend not to address disability comprehensively under the articles concerned. Four reports refer to the issue of disability in respect of only one ICESCR article. In one case a charitable rather than a rights-based approach to disability services is discernible.

No system is ever perfect. More could be done to realize the potential of the ICESCR in the context of disability. States parties should be actively encouraged to apply the letter and spirit of General Comment No. 5 when compiling their periodic reports. The ICESCR Committee might lay more emphasis on the disability issue when compiling its list of issues, although other pressing issues obviously compete for its attention and time. The dialogue between the Committee and the States parties should be used to a greater extent to explore important aspects of ICESCR in the context of disability, covering at least the four rights indicated in the revised reporting guidelines. The dialogue should be informed at all times by the need to use all ICESCR rights to enable people with disabilities to lead active lives and to ensure adequate protection for vulnerable persons with disabilities, including those residing in institutions. The Committee’s concluding observations might be used not merely to highlight deficiencies but also to draw attention to the many positive achievements of States parties in order to showcase what can be done.

The ICESCR has tremendous potential in the context of disability. General Comment No. 5 remains a landmark document within the United Nations human rights treaty system. The change is not normative; the challenge has to do with application. The consistent application of General Comment No. 5 can make a great difference to the way in which disability issues are framed and handled both by States parties and by the Committee. The emphasis placed by the Committee on the link between ICESCR rights and participation in the context of disability is highly positive and augurs well for the future.

²⁶⁰ Republic of Korea, initial report.

²⁶¹ Algeria, initial report.

²⁶² Guatemala, initial report (Office for the Rights of the Disabled, National Commission for the Disabled).

Chapter 6

The integrity of the person: the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and disability

Christina Burke, Gerard Quinn

The United Nations, after the Second World War, undertook the protection of the rights of the disabled within the framework for the promotion and protection of human rights, in order to efface from memory the atrocities committed by the Nazis against an unspecified number of disabled persons throughout Europe.¹

Emilio Columbo, former Minister for Foreign Affairs of Italy, 1981

6.1 An overview of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

6.1.1 Introduction

Torture conjures up for most people an image of some of the most cruel forms of physical and psychological suffering such as the extraction of fingernails, the administration of electric shocks and mock executions. Such images arouse in all of us feelings of deep distress. Torture has been universally condemned and this moral revulsion is reinforced by many human rights instruments since the adoption of the Universal Declaration of Human Rights in 1948.² Article 5 of the Universal Declaration is couched in admirably categorical terms:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

This categorical prohibition is amplified in article 7 of the International Covenant on Civil and Political Rights (ICCPR):

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

¹ Maria Rita Saulle, *The Disabled Persons and International Organizations* (Rome, 1981), preface.

² General Assembly resolution 271 A (III) of 10 December 1948.

Torture is therefore a profound concern for the world community. People with disabilities – and especially those who live in institutionalized settings – are particularly vulnerable to torture or other forms of cruel, inhuman or degrading treatment. In such settings (places that are generally cut off from the world and in which the world takes little interest), there is often a massive imbalance of power. Indeed, the inherent imbalance of power between an inmate and those in authority is magnified many times over in institutional settings for persons with disabilities. Regulatory agencies and law enforcement personnel are often indifferent to the plight of such persons. Torture or other forms of cruel, inhuman or degrading treatment of such persons affect their physical and emotional well-being, are an affront to their dignity and severely restrict their autonomy. Legal protections against torture are therefore of profound importance in protecting people with disabilities and ensuring that they retain their physical and psychic integrity no matter where they reside.

The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (hereinafter the Convention) was adopted on 10 December 1984 by the United Nations General Assembly to enhance the general protection provided under the Universal Declaration and the ICCPR and to provide clearer standards for the effective prohibition of torture and inhuman or degrading treatment.³ The impetus for this move had come many years earlier when the General Assembly adopted a Declaration on the Protection of All Persons from Being Subjected to Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (resolution 3452 (XXX) of 9 December 1975).

The Convention entered into force on 27 June 1984 following the deposit of 20 instruments of ratification as required under article 27(1). As of 8 February 2002, 128 States had ratified the Convention. A Committee against Torture (CAT) was set up to oversee its implementation (article 17). One of the main obligations of States parties to the Convention is, according to article 2(1),

[to] take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction.

The categorical tone of the Universal Declaration is maintained in the Convention, article 2.(2) of which states:

No exceptional circumstance whatsoever, whether a state of war or a threat of war, internal political instability or any other public emergency, may be invoked as a justification of torture.

Importantly, article 2(3) of the Convention denies the existence of any defence of “superior orders” – a defence invoked by former Nazi war criminals and now discredited under international law.

It is undeniable that torture, and the less severe but equally abominable phenomena of cruel, inhuman or degrading treatment or punishment, have lurked quietly behind the closed doors of mental and physical disability institutions – whether public or private.

Article 1 of the Convention defines torture broadly as follows:

³ The text of the Convention may be accessed at the following address on the OHCHR web site: http://www.unhchr.ch/html/menu3/b/h_cat39.htm

For the purposes of this Convention, the term “torture” means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.

In other words, torture involves the deliberate infliction of pain or suffering for particular purposes and is carried out by public officials or by private persons acting on the authority or with the consent of public officials. The high threshold established by this definition may not be reached in many cases involving the abuse of persons with disabilities in institutions. It should also be noted that torture can often be the cause of severe physical or mental disability.

The fact that the Convention only covers torture committed by or on the authority of public officials may be thought to limit further its significance in the context of disability, especially with the growing privatization of many services for people with disabilities throughout the world. However, the occurrence of torture, cruel inhuman or degrading treatment within private institutions may still engage State responsibility under the Convention if the State fails to regulate such institutions or to enforce its own regulations.⁴

States parties are under an obligation to prevent torture (article 2). They also have a clear duty to prevent cruel, inhuman or degrading treatment or punishment (article 16). Unlike torture, however, these terms are not clearly defined under the Convention.

A violation of the Convention may occur owing to the failure to initiate affirmative action such as the provision of medical treatment or services. For example, a high proportion of children in detention suffer from mental illness or intellectual disability. Many end up in detention because of behavioural problems resulting directly from their mental illness. Some become mentally ill as a result of abusive conditions of incarceration. Indeed in many cases the condition is exacerbated by substance abuse or addiction. These children are particularly vulnerable and need the protection of the Convention to address their high-risk situation. Looked at more broadly, the absence of such treatment and of care and forethought may constitute cruel, inhuman or degrading treatment.

It is sometimes said that torture or cruel, inhuman or degrading treatment of the disabled is invisible. Yet this invisibility does not mean that no abuses occur. Pioneering NGOs such as Mental Disability Rights International (MDRI) help to bring such abuses to light and ensure that they are seen for what they are: violations of international law.⁵

⁴ See the summary record of the 488th meeting of CAT (fourth periodic report of Ukraine, CAT/C/SR.488), para 43; the summary record of the 494th meeting (initial report of Zambia, CAT/C/SR.494), para 43; and the Committee’s conclusions and recommendations on the initial report of Zambia (CAT/C/XXVII/Concl.4), para. 8(h), and on the fourth periodic report of Ukraine (CAT/C/XXVII/Concl.2), para. 5(m).

⁵ www.mdri.org

Persons with disabilities who are institutionalized rarely have recourse to adequate means of protection or redress. They are unlikely to be confident enough to articulate allegations against offenders and they are often forced to direct their complaints to wardens or caretakers who may be the very individuals perpetrating the abuse. They may not be aware of their rights and even if they are, they may be less likely to have access to a lawyer or responsible third party who might be willing to make the matter public or refer it to the Committee against Torture.

Concrete action is therefore needed to prevent and halt violations of the Convention in the case of persons with disabilities. The advantage of a binding Convention is that international mechanisms exist to monitor violations by States parties.

6.1.2 An overview of Convention enforcement mechanisms

The implementation of the Convention is supervised by the Committee against Torture, which was established pursuant to article 17 in 1984. After its first meeting in Geneva, the members of the Committee adopted rules of procedure and defined the Committee's working methods in conformity with the provisions of the Convention.⁶

The general objectives of the Committee are to ensure that States parties respect their various obligations under the Convention and that they prevent and punish torture in conformity with Convention norms, rights and obligations. It should be borne in mind, however, that the Committee against Torture is not a court but a classic monitoring mechanism with only declaratory powers.

The Committee normally holds two regular sessions each year⁷ in April/May and November. Pursuant to rule 6 of the rules of procedures, the provisional agenda is prepared by the Secretary-General in consultation with the Chairman of the Committee and consists of items decided upon by the Committee at a previous session, items proposed by the Chairman of the Committee, items proposed by a State party to the Convention, items proposed by a member of the Committee, and items proposed by the Secretary-General relating to his functions under the Convention.⁸ The disability issue has not, so far, featured strongly under any of the above agenda items.

More specifically, the functions of the Committee are fourfold

- (a) To consider State party reports and to prepare conclusions and recommendations thereon (article 19);
- (b) To consider inter-State complaints provided that its competence to do so is recognized by the relevant State party (article 21);
- (c) To consider individual complaints provided that its competence to do so is recognized by the relevant State party (article 22); and
- (d) To initiate inquiries where it deems that well-founded allegations of systematic torture exist with respect to a State party (article 20).

⁶ See *Human Rights Fact Sheet No 17: The Committee against Torture*, which may be consulted on the OHCHR web site: <http://www.unhchr.ch/html/menu6/2/fs17.htm>

⁷ Rule 2.1 of the rules of procedure of the Committee (CAT/C/3/Rev.3).

⁸ *Ibid.*, rule 6.

These functions will be considered in turn.

(a) *Monitoring of implementation: the examination of State party reports (article 19)*

The States parties submit reports to the Committee through the United Nations Secretary-General on “the measures they have taken to give effect to their undertakings” under the Convention to prohibit, punish and prevent torture (article 19). Based on its analysis of the report in question, the Committee adopts “conclusions and recommendations” on the State party’s compliance with its obligations. It includes this information in its annual report to the Secretary-General.

If the reporting procedure is followed correctly, the Committee should be in a position to obtain a clear picture of the extent to which States parties are respecting their obligations. The procedure should prompt the States parties to engage in a self-evaluation exercise in a public and international setting. Indeed, if used properly, the reporting process provides an opportunity for domestic evaluation and for remedying any shortcomings that are identified. As such it is an aid to rational law reform.

The first or initial report by a State party must be submitted within one year after the entry into force of the Convention for that party. Thereafter reports should be submitted every four years, illustrating the extent to which Convention rights have been realized and the measures that are being taken to that effect.⁹ The initial report in particular is an opportunity for a State party to undertake a comprehensive review of all existing national legislation, administrative rules, procedures and practices in order to ensure the fullest conformity with the Convention.

In reporting on legislative developments,

Reports must strike a balance between the situation in theory and that in practice. This means that a detailed and soundly based review of current developments is required. Isolated example, or anecdotal evidence, will not suffice. Thus, a precondition for effective reporting is the existence of an adequate system for monitoring the situation with respect to each of the rights on a regular basis. It cannot safely be asserted that torture never occurs in prisons unless regular monitoring of the situation occurs.¹⁰

Action to combat torture or other cruel, inhuman or degrading treatment of the disabled may often require the formulation of long-term policies embodying the human rights dimension of disability. The reporting process has the potential to engage the policy-making apparatus of States parties on the question of the status and rights of persons with disabilities in institutional settings – issues that might otherwise remain unaddressed.

The preparation of a State party report should also be seen as an opportunity for appropriate consultation with civil society. There is a considerable body of sound practice in this regard. The United States obtained significant input from its disability

⁹ The reporting record of individual States parties may be consulted on the OHCHR web site: <http://www.unhchr.ch>

¹⁰ Philip Alston, “The purposes of reporting”, *Manual on Human Rights Reporting*, United Nations document HR/PUB/91/1 (Rev.1), 1997, p. 19.

NGO sector, notably in the context of treatment of the mentally ill in “super-maximum” security prisons. The involvement of NGOs can take the form of comments on draft State party reports.

Reading and reviewing a series of reports from the same State party over time enables the Committee to piece together a comprehensive picture and helps it to measure a State’s progress in complying with its obligations under the Convention. Often, the public admission by a State party that a problem exists is the first and most important step towards finding a possible remedy.

State party reports are reviewed in the presence of representatives of the Government concerned. Before the consideration of a report, the State party is informed of the date of its delegation’s meeting with the Committee. When a State party has failed to fulfil its reporting obligations, the Committee invites it to submit the missing report promptly. As no working group exists to read the report in advance, no written requests for additional information and no “list of issues” is sent out by the Committee to the State party in question.

The consideration of a report is spread over two meetings. In the light of the discussion, the Committee draws conclusions as to the performance of the relevant State party under the Convention and publishes them as its conclusions and recommendations. Among other things, the conclusions and recommendations represent guidelines for the further implementation of the Convention by the State party concerned.

The system of State reporting under the Convention has run into difficulties. Plainly, the system is overburdened. There are many profound problems relating to torture around the world and these problems naturally consume much of the Committee’s attention. One commentator, Roland Bank, drew attention in a paper written in 2000 to what had earlier been perceived to be the Committee’s shortcomings when examining State party reports: lack of depth in oral inquiries (in particular, failure to address structural problems underpinning a problematic observation); repetition of questions by different Committee members; lack of cohesion (no visible concept of interpretation of the Convention and contradictory remarks by different members); premature praising of Governments’ efforts; vague questions inviting evasive answers; and failure to insist on exhaustive answers in cases of wrong, incomplete or unsatisfactory answers. Bank goes on to say that:

[s]ome of these faults have been remedied to a certain extent in recent years. In particular, it is now much less likely that the Committee will rely solely on its own resources to examine acute problems of state parties under consideration. It makes considerably greater use of NGO information, including explicit reference to NGO reports during discussions.¹¹

The Committee established general guidelines in 1991 regarding the form and contents of initial reports to be submitted by States parties under article 19. The guidelines are as follows:

¹¹ Roland Bank, “Country-oriented procedures under the Convention against Torture: towards a new dynamism”, *The Future of UN Human Rights Treaty Monitoring*, Philip Alston and James Crawford (eds.) (Cambridge University Press, 2000), p. 150.

Part I: Information of a general nature

This part should:

- (a) Describe briefly the general legal framework within which torture as defined in article 1, paragraph 1, of the Convention as well as other cruel, inhuman or degrading treatment or punishment are prohibited and eliminated in the reporting State;
- (b) Indicate whether the reporting State is a party to an international instrument or has national legislation which does or may contain provisions of wider application than those provided for under the Convention;
- (c) Indicate what judicial, administrative or other competent authorities have jurisdiction over matters dealt with in the Convention and provide information on cases actually dealt with by those authorities during the reporting period;
- (d) Describe briefly the actual situation as regards the practical implementation of the Convention in the reporting State and indicate any factors and difficulties affecting the degree of fulfillment of the obligations of the reporting State under the Convention.

Part II: Information in relation to each of the articles in part I of the Convention

This part should provide specific information relating to the implementation by the reporting State of articles 2 to 16 of the Convention, in accordance with the sequence of those articles and their respective provisions. It should include in relation to the provisions of each article:

- (a) The legislative, judicial, administrative or other measures in force which give effect to those provisions;
- (b) Any factors or difficulties affecting the practical implementation of those provisions;
- (c) Any information on concrete cases and situations where measures giving effect to those provisions have been enforced including any relevant statistical data.

The report should be accompanied by sufficient copies in one of the working languages (English, French, Russian or Spanish) of the principal legislative and other texts referred to in the report. These will be made available to members of the Committee. It should be noted, however, that they will not be reproduced for general distribution with the report. It is desirable therefore that, when a text is not actually quoted in or annexed to the report itself, the report should contain sufficient information to be understood without reference to it. The text of national legislative provisions relevant to the implementation of the Convention should be quoted in the report.

General guidelines regarding the form and contents of periodic reports submitted subsequent to the initial report were also drawn up by the Committee in 1991 and revised in 1998. They read as follows:

1. Under article 19, paragraph 1, of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, "the States parties shall submit to the Committee against Torture, through the Secretary-General of the United Nations, reports on the measures they have taken to give effect to their undertakings under the Convention, within one year after the entry into force of the Convention for the State party concerned. Thereafter the States parties shall submit supplementary reports every four years on any new measures taken and such other reports as the Committee may request".
2. The general guidelines for the submission of periodic reports appearing below would assist the Committee to fulfil the tasks entrusted to it pursuant to article 19 of the Convention.
3. Periodic reports by States parties should be presented in three parts, as follows:

Part I: Information on new measures and new developments relating to the implementation of the Convention following the order of articles 1 to 16, as appropriate

(a) This part should describe in detail:

(i) Any new measures taken by the State party to implement the Convention during the period extending from the date of submission of its previous report to the date of submission of the periodic report to be considered by the Committee;

(ii) Any new developments which have occurred during the same period and are relevant to implementation of the Convention;

(b) The State party should provide, in particular, information concerning:

(i) Any change in the legislation and in institutions that affect the implementation of the Convention on any territory under its jurisdiction, in particular on places of detention and on training given to law enforcement and medical personnel;

(ii) Any new case law of relevance for the implementation of the Convention;

(iii) Complaints, inquiries, indictments, proceedings, sentences, reparation and compensation for acts of torture and other cruel, inhuman or degrading treatment or punishment;

(iv) Any difficulty which would prevent the State party from fully discharging the obligations it has assumed under the Convention.

Part II: Additional information requested by the Committee

This part should contain any information requested by the Committee and not provided by the State party, during the Committee's consideration of the State party preceding report. If the information has been provided by the State party, either in a subsequent communication or in an additional report submitted in accordance with rule 67, paragraph 2, of the Committee's rules of procedure, the State party does not need to repeat it.

Part III: Compliance with the Committee's conclusions and recommendations

This part should provide information on measures taken by the State party to comply with the conclusions and recommendations addressed to it by the Committee at the end of its consideration of the State party's initial and periodic reports.

Disability is sometimes included in State party reports on the insistence of NGOs. When the Committee sees a reference to disability in a report, its members ask questions relating to States' obligations in that context under the Convention. When disability is not mentioned, the Committee may ignore it on account of the weight of competing issues and also in the absence of the incentive that would be provided by a "general comment" on disability.

The United States initial report, published in 1999, was an example of good practice. Disability NGOs had taken a particularly active stance on the issue of the treatment of the mentally ill in "super-maximum" security prisons.¹² This engagement with the United States Government led to the mention of disability in several parts of the initial report. For example, there is a reference to the conditions of detention of sick and disabled inmates¹³ and to the provision of medical, dental and psychiatric care to inmates. Persons with disabilities are referred to in connection with the State party's obligations under article 14 of the Convention (the right to redress) and in connection

¹² The McArthur Justice Center response to the initial report of the United States concerning the housing of the mentally ill in "super-maximum" prisons.

¹³ Initial report of the United States to the Committee against Torture (CAT/C/28/Add.5), para. 139.

with medical and psychiatric treatment and rehabilitation.¹⁴ Under the heading “Abuse of the institutionalized”, mention is made of the fact that, under the Civil Rights of Institutionalized Persons Act, the United States Department of Justice is competent to investigate public facilities such as jails, prisons, nursing homes and institutions for the mentally retarded or the mentally ill.¹⁵ These investigations focus on the use of restraints and of psychotropic medication on the mentally ill. Reference is also made to inmates with disabilities in connection with the operation of the Rehabilitation Act and the Americans with Disabilities Act.

The United States example shows how well-resourced NGOs can make a major difference where it counts most, promoting honesty and openness by States parties. Disability NGOs should combine their resources to ensure that better use is made of the Convention machinery.

(b) Enforcement: inter-State complaints (article 21)

A State party may at any time declare under article 21 of the Convention that it recognizes the competence of the Committee to consider complaints (called communications) lodged by one State party against another under the Convention.

If a State party to the Convention considers that another State party is not giving effect to the provisions of the Convention, it may, by written communication, bring the matter to the attention of that State party. Within three months after the receipt of the communication, the receiving State is required to provide the initiating State with an explanation or any other statement in writing clarifying the matter, which should include, to the extent possible and pertinent, references to domestic procedures and remedies taken, pending or available in the matter.

If the matter is not adjusted to the satisfaction of both States parties concerned within six months after the receipt by the receiving State of the initial communication, either State has the right to refer the matter to the Committee. The Committee can deal with it once it has ascertained that all domestic remedies have been exhausted. Non-exhaustion is permitted “where the application of the remedies is unreasonably prolonged or is unlikely to bring effective relief to the person who is the victim of the violation” of the Convention.

The purpose of the inter-State mechanism is to assist States in reaching a friendly settlement of the issues raised. The use of article 21 would appear limited in the context of disability and it has in fact never been invoked in any circumstances.

(c) Enforcement: individual complaints (article 22)

Article 22 enables persons who claim to have been victims of torture or other forms of cruel, inhuman or degrading treatment to lodge complaints with the Committee. Such complaints can be considered only if the relevant State party has made a declaration recognizing the competence of the Committee under article 22. Only a limited number of States have done so. Importantly, complaints may also be submitted against States

¹⁴ Ibid., para. 267.

¹⁵ Ibid., para. 327.

parties “on behalf of individuals”, which creates some scope for NGOs to support or even submit complaints.

The procedure adopted in such instances is formal. The Committee is not intended to serve as a forum of original jurisdiction and can only accept complaints when all available domestic remedies have been exhausted (article 22(5)(b)). Non-exhaustion of such remedies is permitted only where “the application of the remedies is unreasonably prolonged or is unlikely to bring effective relief to the person who is the victim of the violation” of the Convention.

Complaints may relate to a specific alleged act of torture or cruel, inhuman or degrading treatment but they may also relate to cases in which the State party has allegedly omitted to act. There may be many circumstances in institutions where such omissions occur. Of course, a “victim” must still be found to file a complaint.

A State may fail to establish effective legal, political, administrative or other preventive structures, to take concrete steps to prevent torture from occurring within its boundaries or to initiate investigations or prosecute where there has been a violation.

An individual complaint can create publicity, thus shedding light on what goes on behind the closed doors of institutions for the disabled. The substance of a complaint should be submitted in writing and contain the following information:

1. The name of the author of the communication and of the State party concerned;
2. The exact provisions of the Convention that the State party is alleged to have infringed;
3. A detailed description of the facts and circumstances that surround the alleged violation;
4. An account of how the State is responsible for the violation through its action or inaction;
5. Details of the manner in which domestic remedies have been exhausted;
6. Details of domestic decisions that have been taken pertaining to the case;
7. Statements from the victim, witness statements and medical reports, including any photographs;
8. If relevant, general information on the country situation from, for example, the media and NGOs.

The conditions of admissibility of complaints are specified both under article 22(5) of the Convention and in rule 107 of the Committee’s rules of procedure (CAT/C/3/Rev.3). Rule 107 reads as follows:

Conditions for admissibility of communications

Rule 107

1. With a view to reaching a decision on the admissibility of a communication, the Committee or its Working Group shall ascertain:
 - (a) That the communication is not anonymous and that it emanates from an individual subject to the jurisdiction of a State party recognizing the competence of the Committee under article 22 of the Convention;

- (b) That the individual claims to be a victim of a violation by the State party concerned of the provisions of the Convention. The communication should be submitted by the individual himself or by his relatives or designated representatives or by others on behalf of an alleged victim when it appears that the victim is unable to submit the communication himself, and the author of the communication justifies his acting on the victim's behalf;
- (c) That the communication is not an abuse of the right to submit a communication under article 22 of the Convention;
- (d) That the communication is not incompatible with the provisions of the Convention;
- (e) That the same matter has not been and is not being examined under another procedure of international investigation or settlement;
- (f) That the individual has exhausted all available domestic remedies. However, this shall not be the rule where the application of the remedies is unreasonably prolonged or is unlikely to bring effective relief to the person who is the victim of the violation of this Convention.

2. The Committee shall consider a communication, which is otherwise admissible, whenever the conditions laid down in article 22, paragraph 5, are met.

Once a communication has successfully passed the admissibility threshold, the Committee transmits its decision to the author of the communication or his or her representative, as the case may be. The relevant State party is also informed of the decision on admissibility. The Government is then given six months within which to reply with comments on the merits of the communication. These may take the form of explanations or statements clarifying the case and may also include information on any measures it may have subsequently taken to remedy the situation.

The Government's comments are then sent to the author of the communication who may, within a further six weeks, submit his or her observations or additional information to the Committee. The author or his or her representative may be present at the closed meetings of the Committee if the Committee feels that clarifications are needed on the merits. The representatives of the State party concerned may also be invited to attend.

At any time during the proceedings, the Committee may request the State party to take steps to maintain the status quo, for instance to take steps to avoid any irreparable damage to the alleged victim.

The Committee then decides on the basis of all the information before it whether or not there has been a violation of the Convention. Any member of the Committee may express an individual opinion.

No individual complaint dealing with disability has passed the initial test of admissibility. The grounds for rejection were usually failure to exhaust domestic remedies.

(d) *Enforcement: confidential inquiry into allegations of systematic torture (article 20)*

Under article 20 of the Convention, the Committee may carry out a confidential inquiry into allegations of the existence of systematic torture in a State party. It may do so when it receives "reliable information which appears to it to contain well-

founded indications that torture is being systematically practised” in the relevant State party (article 20(1)). The information submitted to the Committee must contain strong factual evidence supporting the view that torture is habitual, widespread and deliberate in at least a considerable part of the territory of the relevant State. The information need not come from another State but can be provided by persons (including persons with disabilities) or NGOs acting on their behalf.

The article 20 inquiry procedure is confined to torture as defined under article 1 of the Convention. This may limit its use in the context of the treatment of disabled persons in institutions, since they are more likely to suffer from other forms of cruel, inhuman or degrading treatment. Unfortunately, article 28 allows States parties to opt out of the article 20 inquiry procedure. So far seven States have done so.

The facts submitted in support of an application for an article 20 inquiry should include details of the acts of torture practised by the State party concerned. Information may also be included on the absence of legislation to prevent torture effectively, the failure of the State party to monitor the implementation of the Convention in places such as prisons and psychiatric institutions, or any gaps in the law that allow the perpetrators to evade justice. Individuals with disabilities are often at a disadvantage in that they may not be in a position to initiate an inquiry. Doing so on their behalf could therefore be an effective way of shining light into the dark corners of institutions.

After considering the facts submitted, the Committee may undertake a fact-finding mission to the State party in which systematic torture is allegedly being practised. It must first, however, obtain the agreement of the State party, since it is required under article 20(1) to “invite the State party to cooperate in the examination” of the information.

The Committee may follow up any recommendations it makes as a result of an inquiry under article 20 by requesting the relevant State party for further information under the article 19 reporting mechanism.

While the inquiry procedure may exert pressure on States parties, the scope for its implementation in the context of disability may be limited. The Committee’s definition of systematic torture as torture that is habitual, widespread and deliberate probably rules out many forms of torture practised against people with disabilities, since such adverse treatment is often isolated and significantly under-reported. Nevertheless, if disability NGOs sense that systematic abuse is taking place, article 20 could potentially be very useful.

6.1.3 Normative clarity: general comments under the Convention

The Committee has issued only one general comment, which it adopted in 1997.¹⁶ It deals with the implementation of article 3 of the Convention (prohibition of the expulsion, return or extradition of persons to States where there are substantial

¹⁶ General Comment No. 1, Implementation of article 3 of the Convention in the context of article 22 (1997) (HRI/GEN/1Rev.5).

grounds for believing that they would be in danger of being subjected to torture) in the context of article 22 (individual complaints procedure).

General Comment No. 1 deals with the rights of individuals who risk being expelled, returned or extradited to a State in which they risk being subjected to torture. This risk is enhanced where there is evidence of “a consistent pattern or gross, flagrant or mass violations of human rights”. The onus is on the individual to establish convincingly, by means of medical and other evidence, that he or she has been tortured in the past.

A general comment is perhaps needed on torture and cruel, inhuman or degrading treatment or punishment in the context of disability, especially with respect to institutionalized settings.

6.1.4 The United Nations Special Rapporteur on torture and his/her relationship with the Convention

The office of Special Rapporteur on torture was created by resolution 1985/33 of the United Nations Commission on Human Rights. The Special Rapporteur’s findings and recommendations are treated with great respect by the Committee. It is important, therefore, to be aware of his or her potential role in bringing torture to light or exposing widespread inhumane practices in the context of disability.

The Special Rapporteur’s activities are reported on the web site of the Office of the High Commission for Human Rights (OHCHR). The present Special Rapporteur is Theo van Boven. His primary function is to respond to allegations of torture in any part of the world, irrespective of whether they concern States parties to the Convention, to engage in fact-finding missions on the ground and to help prevent torture from occurring.

The Special Rapporteur reports to the Commission on Human Rights, providing it with as accurate a picture as possible of the practice of torture throughout the world. He also reports annually to the General Assembly. In discharging his mandate, the Special Rapporteur relies on information from a number of sources, including NGOs, individuals and Governments. In the light of this information, he may engage in a dialogue with Governments about allegations of torture and may carry out fact-finding visits.

The Special Rapporteur can initiate a dialogue with a State party in two ways. If he believes that an allegation is credible, he can transmit an urgent appeal to the Government in question. An allegation may also be transmitted to the State party in a standard communication. The urgent appeal procedure is designed to ensure a rapid response to credible allegations, thus preventing possible incidents of torture. It is therefore used only on receipt of very recent information. It is a non-accusatory procedure in that it may entail requesting a Government to take steps to ensure that a person is not tortured without adopting any position on whether the person’s fear of torture is justified.

Standard communications are transmitted to Governments by the Special Rapporteur on a periodic basis and contain allegations concerning both individual cases and general trends, patterns and special factors contributing to the possible practice of torture in a country. The Governments concerned generally respond. If they do so in a

manner deemed inappropriate by the Special Rapporteur, he may initiate further inquiries. All the Special Rapporteur's activities are later published in an annual report.

The Special Rapporteur may visit a State party in respect of which allegations of torture have been made on obtaining the consent of the State concerned. During such visits, the Special Rapporteur may confer with a wide range of individuals ranging from Government officials and NGOs (including disability NGOs) to individual victims. He may also visit places of detention and State institutions where persons with disabilities may reside. By conducting investigations of this nature, the Special Rapporteur obtains a well-rounded picture of the domestic situation and the range of issues involved in an allegation of torture.

It should be borne in mind, however, that his powers are limited in terms of the adoption of legally binding decisions. Yet the potential for publicity is significant, particularly in the context of disability. The following information should be included in any submission to the Special Rapporteur regarding an alleged case of torture: the name of the victim, including details of the incident, with a description of the alleged perpetrators of the torture or ill-treatment; a detailed description of the form of the torture or ill-treatment; details of the organization submitting the report; a detailed description of the injuries sustained, including whether medical assistance was requested or obtained at the time of the incident or afterwards; and details of any domestic remedies sought by the victim or his or her family, with particular reference to the applicability of these remedies in the context of disability.

6.1.5 The United Nations Voluntary Fund for Victims of Torture

The United Nations Voluntary Fund for Victims of Torture was established pursuant to General Assembly resolution 36/151 of 16 December 1981. It receives voluntary contributions from Governments, NGOs and individuals for distribution to victims of torture and members of their families. Donors are asked to make their voluntary contributions to the Fund before 31 March each year.

A brief description of the mandate and administration of the Fund is contained in a report by the Secretary-General.¹⁷ The Secretary-General administers the Fund through the Office of the High Commissioner for Human Rights with the assistance of a Board of Trustees. The Board is authorized to hold meetings with a variety of organizations and to present the Fund's activities to interested Permanent Missions to the United Nations Office in Geneva. Only NGOs, including, of course, disability NGOs, can apply for grants from the Fund.

The number of requests for grants increases each year. The purpose of projects for which a grant is requested should be to provide medical, psychological, social, economic, legal, humanitarian and other forms of assistance to victims of torture and members of their families. Applications by organizations in respect of projects involving legal assistance to defend the right to restitution, compensation and rehabilitation of victims of torture are considered favourably by the Board.

¹⁷ United Nations document A/52/387, paras. 7-11.

It is important to note, in the disability context, that applications are also welcome for: projects concerning the social or economic reintegration of torture victims into society, including vocational training; projects to organize training courses, seminars or conferences for health or other professionals providing assistance to victims; projects to carry out investigations or studies or to publish newsletters. The grant may cover a period of up to twelve months. Applications for grants should be submitted by 31 December each year. Applications received after this deadline are deemed inadmissible as are incomplete applications that do not comply with the relevant guidelines.

Narrative and financial reports accompanying applications should be submitted by 31 December each year. They should state the number of victims to be assisted and provide information on their history, the context and perpetrators of the torture, its physical and psychological after-effects, the type of assistance provided by the organization, the results expected or already obtained, and any future assistance to be given to victims.

The list of organizations financed by the Fund in 2000 was quite long and included a wide range of organizations dealing with various aspects of torture.¹⁸ They included: Advocates for Survivors of Trauma and Torture (United States), Boston Medical Center (United States), Centre for Treatment and Rehabilitation of Victims of Torture (Malawi), Centre for the Treatment of Torture Victims (Germany), Medical Rehabilitation Centre for Torture Victims and their Families (Latvia), Rehabilitation Centre (Philippines), Voice against Torture (Pakistan) and World Organization against Torture (Switzerland). There is nothing to prevent disability NGOs from making applications to the Fund. Indeed, the Fund seems like an ideal platform for highlighting the disability dimension of torture.

6.1.6 Access points to the Convention system for civil society

The present Chairperson of the Committee against Torture, Mr. Peter Burns, is quoted as saying that

The Committee could not function properly without input from NGOs. We rely heavily on NGOs to provide us with commentaries on the State parties reports, to point out the areas that states have overlooked and any misrepresentation that may have occurred.¹⁹

The participation of NGOs is vital for the effective implementation of all human rights instruments. They can ensure that relevant issues are taken into account by the Committee and they provide a reality check on the content of State party reports. They also have a vital role to play at the domestic level in ensuring that the promises that States parties make to the Committee in Geneva are actually implemented at home.

(a) NGO participation in the monitoring of State party reports

¹⁸ United Nations document A/55/178, table 4.

¹⁹ Speech by Rita Maran at the Human Rights Conference, University of Chicago Human Rights Program, 4-7 March 1999:
<http://humanrights.uchicago.edu/documents/Torture%20Conference/Maran.htm>.

As soon as a State has ratified the Convention, any national NGO working in the field of torture is encouraged to contact the Committee secretariat and establish relations. When the State party submits its initial report, NGOs have an opportunity to submit information on how the Convention is being implemented in the country in question.

NGOs can also submit “parallel reports” in two forms. On the one hand, they may prepare thematic reports focusing on specific human rights violations in the period under consideration. On the other, they may submit comprehensive reports providing parallel information on the implementation of each substantive provision of the Convention. Such “parallel reports” may be submitted in any of the Committee’s working languages: English, French, Spanish and Russian. The Association for the Prevention of Torture has produced an excellent set of guidelines on parallel reporting by NGOs.²⁰

If a “parallel report” is submitted in the correct format by an NGO in the context of the State party reporting procedure, it can help the treaty body to make accurate and informed findings about a particular domestic situation. Such a report also helps the Committee to put more probing and precise questions to the State party and to make more pertinent recommendations.

Disability NGOs should become more aware of the possibility and usefulness of “parallel reporting” under the Convention.

(b) NGO participation in the individual complaints procedure

NGOs may support individual petitions directly or provide general information to the Committee of relevance to the complaint. NGOs wishing to submit information in the context of individual complaints must ensure that they include the following: the name of the victim, the date and place of the incident, the alleged perpetrators and details of treatment.

Individual complaints could prove very significant for persons with disabilities, who may often be unaware of their rights or without access to advocates who can articulate them. A properly structured individual complaint should describe the political, legal and social context. NGOs often have the resources to do this – or at least more resources than the individual. This is equally true of disability NGOs, which should be encouraged to provide more support for individual complaints.

6.2 The general relevance of Convention norms in the context of disability

The prohibition of torture and other cruel, inhuman or degrading treatment or punishment obviously lies at the core of the Convention, but States parties also have a

²⁰ The “APT guidelines for national NGOs on alternative reporting to United Nations bodies, including the Committee against Torture” (2000) may be accessed at the following address on the APT web site: <http://www.ap.t.ch/cat/guidelines.htm>.

number of ancillary obligations whose relevance in the context of disability is discussed in this section.

(a) *The obligation to prevent torture (article 2)*

Article 2 of the Convention reads as follows:

1. Each State Party shall take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction.
2. No exceptional circumstances whatsoever, whether a state of war or a threat of war, internal political instability or any other public emergency, may be invoked as a justification of torture.
3. An order from a superior officer or a public authority may not be invoked as a justification of torture.

The provisions of article 2 are relevant in the context of disability. The following questions arise and should be addressed in State party reports. What type of legislation prohibits torture? Does it clearly cover persons with disabilities? Are there any factors that inhibit persons with disabilities from using the law? What specific measures have States parties taken to prevent the use of torture and other forms of cruel, inhuman or degrading treatment in the case of persons with disabilities?

(b) *The obligation to prevent cruel, inhuman or degrading treatment or punishment (article 16)*

Article 16(1) reads as follows:

Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article 1, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. In particular, the obligations contained in articles 10, 11, 12 and 13 shall apply with the substitution of references to torture of references to other forms of cruel, inhuman or degrading treatment or punishment.

While article 2 prohibits torture, article 16 prohibits all forms of treatment falling short of torture. Moreover, article 16(1) renders the provisions of articles 11 (systematic review of interrogation rules, instructions, methods and practices), 12 (prompt and impartial investigation) and 13 (right to complain) applicable in the context of cruel, inhuman or degrading treatment or punishment.

(c) *The obligation to make torture a criminal offence (article 4)*

Article 4 of the Convention requires each State party to ensure that all acts of torture are criminal offences under its criminal law. Reports should therefore provide detailed information on criminal laws that prohibit torture. Emphasis should be placed on their applicability to persons with disabilities.

(d) *The obligation to apprehend those suspected of committing acts of torture (article 6)*

Article 6 of the Convention states that “[u]pon being satisfied, after an examination of information available to it, that the circumstances so warrant, any State party in whose territory a person alleged to have committed any offence referred to in article 4 is present shall take him into custody or take other legal measures to ensure his presence.” Article 6, paragraph 2, requires such States to make a preliminary inquiry immediately into the facts.

(e) *The obligation to keep interrogation rules and custody arrangements under systematic review (article 11)*

Article 11 of the Convention reads as follows:

Each state party shall keep under systematic review interrogation rules, instructions, methods and practices as well as arrangements for the custody and treatment of persons subjected to any form of arrest, detention or imprisonment in any territory under its jurisdiction, with a view to preventing any cases of torture.

This article is essentially concerned with the human rights of persons subjected to any form of detention. Persons with disabilities, especially mentally ill persons, are particularly vulnerable in places of detention.

A shortcoming of article 11 of the Convention, and indeed of the Convention as a whole, is that no specific provision addresses the needs of persons with disabilities in detention. Perhaps the only detailed guidelines in this regard are those set forth in United Nations General Assembly resolution 46/119 of 17 December 1991: Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care.

(f) *The obligation not to extradite or deport where to do so could expose a person to torture (article 3)*

Article 3 of the Convention reads as follows:

1. No State Party shall expel, return (“*refouler*”) or extradite a person to another State where there are substantial grounds for believing that he would be in danger of being subjected to torture.
2. For the purpose of determining whether there are such grounds, the competent authorities shall take into account all relevant considerations including, where applicable, the existence in the State concerned of a consistent pattern of gross, flagrant or mass violations of human rights.

The provisions of this article also apply in the context of persons with disabilities. They may be relevant in the context of disabled asylum-seekers who fear that if returned to their own country they may be placed in institutions where torture may be practised.

(g) *The obligation to provide torture awareness education and training to public officials (article 10)*

Article 10 requires each State party to ensure that education and information regarding the prohibition of torture are fully included in the training of both civil and military law enforcement personnel, medical personnel, public officials and other

persons who may be involved in the custody, interrogation or treatment of any individual subjected to any form of arrest, detention or imprisonment. This article is of great relevance to persons with disabilities. It is vitally important for the police to be sensitive to disability during interrogation. The training of medical personnel is also vital to ensure that standards of care conform to the Convention.

(h) *The obligation to investigate allegations of torture promptly (article 12)*

Whenever allegations of torture are made, the State party concerned is under an obligation to investigate. Article 12 stipulates that:

Each State Party shall ensure that its competent authorities proceed to a prompt and impartial investigation, wherever there is reasonable ground to believe that an act of torture has been committed in any territory under its jurisdiction.

This provision applies in the context of mental and other institutions.

(i) *The obligation to provide for a remedy (article 13)*

Article 13 of the Convention reads as follows:

Each State Party shall ensure that any individual who alleges he has been subjected to torture in any territory under its jurisdiction has the right to complain to , and to have his case promptly and impartially examined by, its competent authorities. Steps shall be taken to ensure that the complainant and witnesses are protected against all ill treatment or intimidation as a consequence of his complaint or any evidence given.

This article is also applicable to victims of cruel, inhuman or degrading treatment. State party reports under the Convention should contain information on relevant laws and administrative practices. Domestic remedies should be accessible to persons with disabilities. Impediments to the enjoyment of this right experienced by persons with disabilities may not reside in the law but they may nevertheless be real.

(j) *The obligation to provide redress and compensation (article 14)*

Article 14 of the Convention requires each State party to ensure in its legal system that the victim of an act of torture can obtain redress and has an enforceable right to fair and adequate compensation, including the means for rehabilitation. In the event of the death of the victim as a result of an act of torture, his or her dependents should be entitled to compensation. Nothing in the article should affect any right of the victim or other persons to other forms of compensation that may exist under national law. Article 14 is of obvious relevance in the context of disability. State party reports should contain information on programmes of rehabilitation for victims of torture who become disabled.

6.3 Case studies on the operation of the Convention in the context of disability

This section reviews the operation of the Convention in the context of disability. It looks first at a number of recent State party reports to ascertain whether the disability

dimension is mentioned and, if so, how it was handled by the Committee. It then examines the individual complaints mechanism, focusing on the single complaint to date relating to disability, which failed to clear the admissibility stage.

6.3.1 An examination of recent State party reports in the light of disability

(a) Iceland – initial report (1997)

The State party report

Iceland's initial report to the Committee was published in 1997.²¹ The report describes Icelandic legislation prohibiting torture and inhuman and degrading treatment. It presents an overview of the Icelandic constitutional order.

Paragraph 17 of the report states that the Constitutional Act No 97/1995 introduced many amendments and additions to the human rights provisions of the Constitution. These measures were considered necessary because the provisions in effect until then had remained practically unchanged since 1874. In spite of the general consensus that Icelanders enjoyed fundamental rights in fact, since ordinary legislation and the unwritten principles of the Constitution secured them, this was no longer considered adequate. The amendments to the Constitution were intended to remedy the situation. They added various new rights to those already provided for and added more detail to some of the older provisions. The rights added to the Human Rights chapter of the Constitution included a prohibition of torture and inhuman or degrading treatment or punishment (article 68, para. 2). Paragraph 20 of the report states that other rights provided for in the Constitution are the right to assistance in case of sickness or invalidity (article 76, para. 3).

The report states that the Prisons and Imprisonment Act No. 48/1988 contains general provisions on the treatment to be afforded to convicted prisoners. It specifies the rights they are to enjoy in prison and the extent to which their special needs should be taken into account if they suffer from physical ailments or mental deficiencies (para. 32). The Act also contains clear provisions on disciplinary measures and the conditions under which a prisoner may be subjected to solitary confinement.

The report further states that Icelandic law provides for the protection from torture of persons other than those deprived of liberty on account of suspicion of criminal conduct or serving a prison sentence (para 35). A risk of torture is also deemed to exist where an individual is placed in the personal charge of another individual, or where a person is dependent on another person by reason of his or her sensitive position. Situations that may be examined in this context include the treatment of children in homes or schools and of patients in hospitals.

Section 63 of the Act on Protection of Children and Adolescent Persons No. 58/1992 is applicable to persons who have a child or an adolescent in their care. It makes it a punishable offence to inflict ill-treatment on the child, to violate his/her mental or physical integrity or to endanger his/her life or health by negligence. Under Section 64 it is a criminal offence to punish, threaten or intimidate a child so as to endanger

²¹ CAT/C/37/Add.2.

his/her emotional or physical well-being. Section 52, paragraph 2, of the Act concerning the supervision of homes and institutions for children and adolescent persons also prohibits physical and mental punishment.

Patients are stated in the report to enjoy special protection against cruel, inhuman or degrading treatment under the Act on the Rights of Patients No. 74/1997, which provides, among other things, for the right of patients to decline medical treatment (Section 7). Under Section 10, the written approval of a patient is required for his or her participation in scientific experimentation concerning, for example, clinical trials.

Summary records

The Committee thanked Iceland for its generous donations in recent years to the United Nations Voluntary Fund For Victims of Torture.

In the summary record of a meeting held on 12 November 1998,²² the Committee members asked the four-member delegation from Iceland several questions relating to mental illness. The Committee wished to know more about the procedure applicable in the case of persons committed to hospital by order. The delegation replied that the law on legal capacity provided for hospitalization only for a limited duration and subject to strict conditions in the case of persons suffering from serious psychological illness or acute forms of alcoholism or drug addiction. According to the procedure applicable, the commitment order had to be backed by a medical opinion prescribing such a measure to protect the health of the person suffering from a severe mental illness or disorder. The stay in hospital could not exceed 48 hours, except by decision of the Ministry of Justice, which could extend it for up to 21 days on the advice of a psychiatrist. Only the courts could decide to extend the hospitalization beyond that limit. What was more, the Constitution guaranteed the right of any person deprived of freedom to ask a court to decide on the legality of the measure applied to him or her.

Fuller information was requested by the Committee about the concerns expressed by the European Committee for the Prevention of Torture and Inhuman and Degrading Treatment after its visit to Iceland. The European Committee had taken the view that the medical care provided for prisoners, particularly psychiatric services, was less than ideal and that the directives issued by the Ministry of Health were insufficient or vague. The Icelandic delegation replied that since the beginning of 1998 it was the Ministry of Health and no longer the Ministry of Justice that dealt with the health of prisoners. Since then the Icelandic authorities had improved the situation in most of the areas concerned, taking into account the European Committee's comments about the organization of shifts for doctors and nurses and the assignment of psychiatrists. More emphasis would be laid on preventive work, the promotion of healthy lifestyles and the treatment of prisoners with drug and alcohol problems.

A member of the Committee, asked whether there were any regulations in Iceland governing the use of physical restraint for controlling mentally ill persons. He requested particulars of cases of suicide that had occurred in the main prison. A member of the Icelandic delegation replied that he was unable for the moment to provide further information about the treatment of mentally ill persons. He added that

²² CAT/C/SR. 351.

there had been three suicides, not two, at Iceland's main prison but that the third had occurred after the visit of the European Committee for the Prevention of Torture.

The Chairmen suggested that the Icelandic delegation should send the Committee a note at a later date on any regulations governing the use of physical restraint for controlling mentally ill persons.

*The Committee's conclusions and recommendations*²³

The Committee thanked the Government of Iceland for its frank cooperation and its representatives for the constructive dialogue. It considered that the initial report of the State party fully conformed with the Committee's general guidelines for the preparation of reports and provided detailed information on the implementation of each provision of the Convention. The Committee commended the Icelandic authorities on the enactment of legislation and rules on the rights of arrested persons, on interrogations by the police and on the protection of persons committed to psychiatric hospitals against their will. It expressed concern at the fact that torture was not considered a specific crime in the penal legislation of Iceland.

The concluding observations and recommendations make no reference to disability.

(b) *Mexico – third periodic report (1996)*²⁴

The State party report

Mexico's third periodic report to the Committee was published in 1996.

It contains little direct reference to disability save in connection with article 14 of the Convention, which relates to the legal and other measures for obtaining fair and adequate compensation for victims of torture. Paragraph 155 of the report states that such measures are enumerated in article 10 of the Federal Act to Prevent and Punish Torture. Paragraph 158 states that there are physical and mental rehabilitation programmes for taking care of victims of offences.

Summary records

The summary record of the meeting on the Mexican report held on 30 of April 1997 makes no reference to disability.²⁵

*The Committee's conclusions and recommendations*²⁶

The conclusions and recommendations make no direct reference to disability.

(c) *Russian Federation - second periodic report (1996)*

The State party report

²³ CAT/C/SR.357.

²⁴ CAT/C/34/ADD.2.

²⁵ CAT/C/SR.285.

²⁶ CAT/C/SR.289.

The second periodic report of the Russian Federation to the Committee was published in 1996.²⁷

Disability is mentioned in the report in relation to article 1 of the Convention. Paragraph 10 states that the regulatory instruments adopted between 1990 and 1995 contain a number of important provisions aimed at the further implementation of the norms of the Convention and also include legislation on psychiatric care and safeguards for citizens during such care.

Disability is also mentioned in relation to article 4 of the Convention. Paragraph 23 states that the criminal law of the Russian Federation contains no norms directly providing for liability for torture. However, the Criminal Code of the Russian Federation does contemplate punishment for the unlawful placement of a person in a psychiatric hospital.

A further reference is made to disability under article 16 of the Convention. Paragraph 101 of the report states that an Act of the Russian Federation on psychiatric care and safeguards of citizens' rights during such care came into force on 1 January 1993. The preamble to the Act states that one of its aims is to prevent the use of psychiatry for non-medical purposes which might be detrimental to the health, human dignity and rights of citizens. Under article 5 of the Act, persons "suffering from psychic disorders" are guaranteed the right to respectful and humane treatment precluding any injury to their human dignity.

Summary records

The summary records make no reference to disability.

The Committee's conclusions and recommendations

The conclusions and recommendations make no reference to disability.

(d) United Kingdom – third periodic report (1998)

The State party report

The third periodic report of the United Kingdom to the Committee was published in 1998.²⁸ It consists of an examination of existing laws in the United Kingdom that prohibit torture and their application in practice.

The British Government, recognizing that many NGOs and other independent bodies such as the Standing Advisory Committee on Human Rights in Northern Ireland had a significant role to play in developing ways of preventing torture and other forms of ill treatment, sought their assistance in preparing its report.

The focus of NGO concerns in this instance was the alleged ill-treatment of prisoners in Northern Ireland. Amnesty International had stated that it would inform the Committee about reported abuses of prisoners there. This stimulated considerable

²⁷ CAT/C/17/ADD.15.

²⁸ CAT/C/44/Add.1.

media attention from the British Broadcasting Corporation (BBC) and *The Guardian* newspaper. The presence of the media stimulated the Committee members to ask probing and difficult questions. It also heightened the sense of occasion. Reports appeared in *The Independent*, *The Guardian*, *The Irish Times* and *Irish News* and the meetings were covered by the BBC and Channel Four television.²⁹

The State party report covers the United Kingdom and dependent territories. Disability is mentioned in the context of article 11 (right to have a claim heard promptly and impartially).

Paragraph 66 of the report states that procedures are in place in all parts of the United Kingdom for ensuring that any individual who is considered to be at medical or psychiatric risk in police custody receives attention by a police surgeon and in urgent cases is sent to hospital. A study on self-harm and suicide by detained persons, illustrating possible preventive measures, had recently been circulated to all police forces in England and Wales. The report states in paragraph 106 that all asylum-seekers are seen by port medical inspectors on arrival. Any individuals detained are also offered a medical assessment within 24 hours of arrival at a detention centre. Port medical inspectors and immigration staff are trained to be alert to signs of stress and suicide risk.

The section of the report concerning the Crown dependency of Guernsey provides statistics relating to suicides of persons in custody, complaints against police officers and mental health staff and details of extraditions and deportations. One suicide occurred in 1995 and one in 1997 among persons detained in mental health hospitals.

Since the United Kingdom's initial report, two deaths by suicide had occurred in La Moye prison in the Crown dependency of Jersey. Following the deaths, steps were taken by the prison authorities to improve provision for assessment of prisoners potentially at risk of self-harm, to provide extra training for prison staff on the prevention of suicide, to modify cells at the prison where "at risk" prisoners were kept and to install closed circuit television monitoring in some cells.

A summary of the recommendations of Dr V Foot, health-care advisor to Her Majesty's Prison Service in the North of England, is presented. She recommended, for example, that shared accommodation with or without continuous observation should be the normal approach to the management of suicidal prisoners until there was a psychiatric assessment and consideration of transfer under the Mental Health Act and that alternatives to the Segregation Unit should be urgently explored for mentally disturbed prisoners.

Summary records

Three meetings in all were held on the United Kingdom's third periodic report. No reference is made in the summary records to disability. A member of the State party's delegation reported that the United Kingdom had increased its contribution to the United Nations Voluntary Fund for Victims of Torture.³⁰

²⁹ Andrew Clapham, "Human rights reporting procedures: an NGO perspective", *The Future of UN Human Rights Treaty Monitoring*, Alston and Crawford (eds.) p. 183.

³⁰ CAT/C/SR.355.

*The Committee's conclusions and recommendations*³¹

The conclusions and recommendations make no reference to disability.

*(e) Initial report of the United States (1999)**The State party report*

The initial report of the United States to the Committee was published in October 1999.³² It contains a detailed review of United States laws that effectively proscribe torture. The constitutional prohibition of cruel and inhuman punishment also operates in the individual states.³³ The report acknowledges problems concerning inhuman treatment at the hands of state authorities.

Disability is mentioned in several places: under articles 1 and 2, article 10 (the training and education of law enforcement personnel, civil or military, medical personnel, public officials and other persons who may be involved in the custody, interrogation or treatment of any individual subjected to any form of arrest, detention or imprisonment) and article 16 (prevention of cruel, inhuman or degrading treatment or punishment).

On ratification of the Convention, the United States made a declaration to the effect that in order to constitute torture, an act must be specifically intended to inflict severe physical or mental suffering and that mental pain or suffering refers to prolonged mental harm caused by or resulting from, inter alia, the administration or application or threatened administration or application of mind-altering substances or other procedures calculated to disrupt profoundly the senses or the personality.

According to the report, the Eighth Amendment has been interpreted to apply, inter alia, to inadequate conditions of confinement resulting from an official's deliberate indifference to identifiable human needs (such as continuous deprivation of food, warmth and exercise) (*Wilson v. Seiter*, 501 US 294, 1991) and to inadequate provision of medical, dental and psychiatric care, including an official's deliberate indifference to an inmate's serious medical needs which exceeds simple medical malpractice (*Estelle v. Gamble*, 429 US 97, 1976).

Paragraph 139 of the report, referring to conditions of detention, states that prisoners must be provided with nutritionally adequate food, prepared and served under conditions which do not present an immediate danger to the health and the well-being of the inmates who consume it. Prisoners must be provided with medical care, although an inadvertent failure to provide medical care does not rise to the level of a constitutional violation. Rather, it is the prison official's "deliberate indifference" to a prisoner's serious illness or injury that may constitute "cruel and unusual" punishment.

³¹ CAT/C/SR.360.

³² CAT/C/28/Add.5

³³ Stefanie Grant, "The United States and the international human rights treaty system", *The Future of UN Human Rights Treaty Monitoring*, Alston and Crawford (eds.), p. 325.

Paragraph 146 of the report, referring to conditions in so-called “super-maximum” security facilities, states that in January 1995 a United States district court found that the conditions prevailing at the Security Housing Unit in the California State Department of Corrections’ Pelican Bay facility were in violation of the United States Constitution. The court held specifically that: (1) there was unnecessary and wanton infliction of pain and the use of excessive force; (2) that prison officials did not provide inmates with constitutionally adequate medical and mental health care; and (3) that the conditions of confinement in the security housing unit, which included extreme isolation and environmental deprivation, did not inflict cruel and unusual punishment on all inmates, but did impose cruel and unusual punishment on mentally ill prisoners.

According to the report (para. 155), the involuntary administration of anti-psychotic medication generally deprives an inmate of a constitutionally protected liberty interest and may also infringe the inmate’s rights under state law. If, however, the inmate has a serious mental illness or poses a threat to himself or others and such treatment is determined to be in his medical interest, such drugs can be lawfully administered.

Paragraph 218 concerning article 10 of the Convention (the education, training and information of law enforcement personnel) states that, in the military context, all personnel involved in custody, interrogation or the treatment of individuals subjected to any form of arrest, detention or imprisonment receive appropriate training regarding the prohibition of torture and related maltreatment. This training is given to military police, interrogators, inspectors-general and psychiatric hospital staff.

Paragraph 225 states that the Torture Victims Relief Act, 1998 authorizes the President to provide assistance for the rehabilitation of victims of torture in the form of grants to treatment centres and programmes in foreign and domestic treatment centres.

Paragraph 267 states that a person subjected to torture in the United States has a legal right to redress and an enforceable legal right to fair and adequate compensation from the alleged offender. A victim may pursue several possible avenues of redress, depending on the specific circumstances. Medical and psychiatric treatment and rehabilitation are also available to victims of torture.

Under article 16 of the Convention which requires State parties to prevent acts of cruel, inhuman or degrading treatment or punishment, the report refers to the Civil Rights of Institutionalized Persons Act (CRIPA), which was originally enacted in the early 1980s. Under the Act, the United States Department of Justice is authorized to investigate public facilities (such as prisons, jails, nursing homes and institutions for the mentally retarded or mentally ill) in which it is believed that confined individuals are being deprived of their constitutional rights. This responsibility is being carried out through the Department’s Civil Rights Division, which by 1 June 1999 had initiated CRIPA actions against approximately 340 facilities, resulting in nearly 100 consent decrees governing conditions in about 200 facilities. According to paragraph 328, these investigations and consent decrees typically focus on protection from abuse and harm, provision of adequate medical and mental health services and proper sanitary and fire safety conditions. For example, in 1997 the Civil Rights Division entered into consent decrees with institutions in Wisconsin and Tennessee regarding the provision of proper medical treatment, use of restraints and use of psychotropic

medications on the mentally ill. In the same year the Civil Rights Division settled a lawsuit against a Montana State prison with an agreement ensuring that vulnerable inmates were protected from predatory inmates.

Paragraph 329 states that protection is also afforded by other statutes. In the *Coleman v Wilson* case, for example, a federal magistrate found that policies and practices of mental health care at most institutions within the California Department of Corrections were so inadequate as to violate the federal Rehabilitation Act and the Eighth Amendment.

According to the report, informed consent is the touchstone of the United States Government's approach to medical and scientific testing. Reference is made to a study by the United States National Bioethics Advisory Commission of the effectiveness of protections for human subjects participating in medical and scientific tests and of other relevant topics such as research involving individuals with diminished capacity. Informed consent by a legally authorized representative allowing minors and individuals who are mentally incapacitated to participate in research on mental illness and paediatric disease has been a particular focus of the debate in medical and scientific communities in the United States. In December 1996 a New York State appellate court invalidated State regulations allowing surrogates to consent to certain experiments on behalf of minor children and those incapable of giving consent at state mental health facilities.

Summary records

At a meeting on the United States initial report on 10 May 2000³⁴, a member of the State party's delegation described his country's achievements, through its laws and policies, in the fight against torture and inhuman and degrading treatment. Ending the practice of torture was not enough, however. Assistance should also be given to the victims. Two laws had been enacted to assist torture victims who had sought refuge in the United States and the United States was the largest donor to the United Nations Voluntary Fund for Victims of Torture. The fight against torture was not simply a governmental fight but one in which NGOs, the media and individuals could serve as valuable allies.

The speaker, from the Civil Rights Division of the United States Department of Justice, addressing the issues of disability and mental health, stated that the Division took an active interest in the running of places of detention and had investigated over 300 facilities in different states and territories since the enactment of the Civil Rights of Institutionalized Persons Act in 1980. Thanks to its efforts, tens of thousands of institutionalized persons who had been living in dire conditions now received adequate physical and mental health services and proper sanitary and fire safety protections. In 1997, for example, the Civil Rights Division had entered into consent decrees with certain institutions regarding the provision of medical treatment, the use of restraints and the administration of psychotropic medication to the mentally retarded. In recent years, the Division's work had focused on abuse and neglect in nursing homes.

³⁴ CAT/C/SR.424.

One member of the Committee thanked the United States delegation for its informative introduction and for a very comprehensive and clearly structured report, which showed that the United State had developed a whole range of legal protections that were reflected in the federal and state constitutions and at common law. He asked for an explanation of the five-year delay in submitting the report.

Another member, while noting that the United States was the principal donor to the United Nations Voluntary Fund for Victims of Torture, raised a number of questions regarding physical and sexual violence against prisoners by prison staff and other inmates. He expressed concern at the fact that male prison wardens had unsupervised access to women prisoners and at the treatment of mentally ill prisoners. Long-term solitary confinement was another matter of concern. He noted that over 20,000 prisoners, including many who were mentally ill, were held in so called super-maximum facilities. A large number of them spent many years, or even served their entire life sentence, in such facilities. Such practices were clearly in breach of the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment adopted by General Assembly resolution 43/173 of 9 December 1988 and had previously been denounced by the United Nations Special Rapporteur on torture.

At a meeting on 11 May 2000,³⁵ a member of the State party delegation stated that medical attention was routinely given to any person in need of it at the time of arrest, including access to a physician if warranted. The Department of Justice had sought stringent limitations on the use of electro-shock weapons in law enforcement agencies and correctional facilities as well as increased training for officers. The United States Government acknowledged reports that restraint chairs, improperly used, had caused deaths in health care facilities and acknowledged that they might also cause deaths in prisons. It was energetically seeking information on such incidents. In 1999 a Senate Subcommittee had held hearings on the subject and efforts were under way to improve the use of restraints in federally funded health-care facilities. Super-maximum facilities were a necessity in United States law enforcement and their use was strictly controlled. Prisoners in such facilities were screened and monitored.

*Committee's conclusions and recommendations*³⁶

In its conclusions and recommendations, the Committee welcomed the extensive legal protection in the United States against torture and other cruel inhuman and degrading treatment or punishment and the authorities' efforts to achieve transparency in institutions and practices. It also welcomed the United States contributions to the United Nations Voluntary Fund for Victims of Torture. The Committee recommended that the Government should abolish electro-shock stun belts and restraint chairs as methods of restraining those in custody. However, it made no direct reference to disability.

³⁵ CAT/C/SR.427.

³⁶ CAT/C/SR.431.

6.3.2 Case study on the individual complaints mechanism: communication No. 67/1997 (*Akhidenor et al. v. Canada*)³⁷

Only one individual complaint concerning disability has been heard so far. It failed, however, to get beyond the admissibility hurdle.

The authors of the communication were the surviving relatives and dependants of the deceased Mr Akhimien. The complaint concerned the circumstances surrounding his death and the adequacy of the subsequent investigation into the causes of his death. The authors of the communication contended that Canada had acted in violation of articles 2, 10, 11, 12, 13, 14 and 16 of the Convention.

Mr Akhimien was an asylum-seeker of Nigerian origin in Canada. He was arrested on 28 October 1995 and transferred to the Canadian Immigration Holding Centre (Celebrity Inn) on 30 October 1995, where he remained until his death on 17 December 1995. He died of pneumonia and/or untreated diabetes.

Mr Akhimien was a known diabetic and his medical symptoms clearly indicated his condition. While in detention he complained that he was experiencing health problems, including blurred vision, and requested to see a medical doctor. On 7 December a doctor ruled out diabetes as the cause of his failing health. No laboratory tests were performed. On 13 December he complained again of dizziness, loss of appetite, lack of strength, a bitter taste in his mouth, lack of saliva and nausea. He was put in solitary confinement and characterized as a troublemaker because of his constant complaints. He had also argued with a guard who had refused him water from the kitchen.

A nurse who noticed Mr. Akhimien's condition advised him to consult a doctor. On 14 December a medical doctor was known to be at Celebrity Inn but he did not examine Mr Akhimien, who again requested medical assistance the following day but was ignored by the guards who assumed that he was faking his condition. On 17 December the guards called the security supervisor of Celebrity Inn and a nurse to the room in which Mr Akhimien was held. His symptoms were consistent with untreated diabetes. He was thereafter monitored every 30 minutes for several hours before an ambulance was eventually called. Sadly, Mr Akhimien was pronounced dead on arrival at the hospital. The autopsy revealed that the cause of death was either pneumonia or diabetic ketacidosis arising from untreated diabetes. The coroner's inquest found that the cause of death was diabetic ketacidosis. An application was filed by the Nigerian Canadian Association for judicial review of the coroner's inquest.

Counsel for the family submitted that the treatment of Mr Akhimien amounted to cruel, inhuman and degrading treatment in violation of article 16 of the Convention.

It was submitted that the conditions and rules prevailing in Canadian immigration centres did not comply with the standards established by the Convention, especially under article 10, according to which education and information regarding the prohibition of torture must constitute an integral part of the training of civil and military personnel in charge of law enforcement, and of medical personnel and other public officials involved in the custody, interrogation or treatment of detained persons.

³⁷ CAT/C/21/D/67/1997.

Pursuant to article 16 the same provisions apply to cruel, inhuman or degrading treatment.

It was also contended that Canada acted in violation of article 11 of the Convention, which requires systematic surveillance of interrogation methods and of provisions governing the custody and treatment of arrested, detained or imprisoned persons. This article is of wide application, encompassing the conduct of police, prison personnel and the armed forces. Pursuant to article 16, its provisions also apply to cruel, inhuman or degrading treatment or punishment.

Counsel for the authors claimed that the failure of the State party to ensure a prompt and impartial investigation of torture in connection with the death of Mr Akiminen as well as its failure to ensure that the family of the deceased received adequate compensation, constituted violations of articles 12, 13 and 14 of the Convention. Article 14 states that the victim of an act of torture has the right to redress, including the means for as full rehabilitation as possible, and that, in the case of a victim's death, his or her dependents are entitled to compensation.

The State party cited rule 107 of the Committee's rules of procedure,³⁸ according to which the author of a communication must justify acting on the victim's behalf. It maintained that it was unclear from the submissions made whether counsel had a mandate from Mr. Akhimien's family and dependents. Canada submitted that the Committee could not examine the communication until counsel produced a document clearly indicating the persons who had mandated him to act on their behalf.

Canada further submitted that the communication should be considered inadmissible on the basis that the authors had not exhausted all available domestic remedies as prescribed by article 22(5)(b) of the Convention. The State party suggested that if a complaint existed against the conduct of the coroner's inquest, an effective domestic remedy was available in the form of a judicial review. At the time of the State party's submission, the application for judicial review was still pending.

In response to the allegation that the available domestic remedies did not comply with the Convention requirement that a prompt and impartial investigation should be undertaken, the State party pointed out that the coroner's inquest had been held within five months of Mr. Alkhimien's death. It further argued that there was adequate provision in the Criminal Code to allow charges to be brought against the individuals who had allegedly inflicted an act of torture on Mr. Alkhimien.

The Canadian Government insisted that negligence did not constitute in itself torture, cruel, inhuman or degrading treatment or punishment within the meaning of the Convention and that the Convention was not intended to apply in such circumstances.

In response to the State party, counsel for the family submitted that domestic remedies should not only be theoretically available but there should be a realistic chance that the redress would be effective. Subsection 31 of the Coroner's Act explicitly prohibited the inquest jury from making "any finding of legal responsibility" or from reaching "any conclusion of law" regarding the circumstances that were the subject of the inquest.

³⁸ CAT/C/3/Rev.3.

Counsel further submitted that the authors of the communication had not been parties to the application for judicial review, which had been made by the Nigerian-Canadian Association to the Ontario Divisional Court. The family and dependants of the deceased lacked the necessary resources to pursue and bring to a timely conclusion an application for judicial review.

The main issue before the Committee was whether the requirement of exhaustion of domestic remedies had been met. No charges had been filed under the Canadian Criminal Code and an application for compensation was currently pending before the Ontario Divisional Court.

In response to the argument that the application of domestic remedies was or would be unreasonably prolonged or unlikely to bring effective relief, the Committee concluded that this was not the case for the time being. It therefore decided that the requirement for the exhaustion of domestic remedies under Art 22(5)(b) had not been met and that the communication was therefore inadmissible.

The Committee's decision in the case described above might be expected to deter the disability community from submitting petitions. Yet, with better education on what constitutes an effective domestic remedy, it should be possible to bring such cases before the Committee and clear the admissibility hurdle.

6.4 Conclusions on CAT and disability

6.4.1 Conclusions

People with disabilities are at their most vulnerable in institutional settings. Lax law enforcement and the relative absence of champions beyond the walls of existing institutions compounds their vulnerability. The Convention procedures have a great deal to offer. The reporting requirement alerts States parties to the potential for abuse in such institutions. The potential of the complaints mechanism has not yet been properly exploited by the disability community.

In instances where disability NGOs have been involved, be it in the drafting of State party reports or in providing the Committee with information, they have clearly had an impact. Their involvement prompts States parties to explore in greater depth the human rights problems experienced by persons with disabilities in institutions. The Committee is thereby enabled to pose more probing questions. On the other hand, the problems of disabled inmates of institutions (including prisons) have seldom been referred to in the Committee's conclusions and recommendations. This is undoubtedly due to the range of issues and the weight of competing priorities that confront the Committee against Torture.

The drafting of a general comment on the application of the Convention to persons with disabilities in institutions, including day-care facilities and sheltered workshops, would be most welcome. It would clarify for States parties what their obligations are with respect to the inmates of such institutions, which are slowly but surely coming under the spotlight of world attention. The Convention can play a tremendously important role in helping to support the process of reform throughout the world.

The Convention aims at ensuring that the conditions within such institutions meet acceptable international standards. A process of de-institutionalization is now under way worldwide. Other human rights treaties provide a bedrock of rights for people with disabilities for whom institutionalization was never acceptable as well as for those who have recently been de-institutionalized. In other words, the potential of the Convention should be analysed as part of a web of human rights treaties and not in isolation.

Chapter 7

Gender and disability: the Convention on the Elimination of all Forms of Discrimination against Women

Anna Bruce, Shivaun Quinlivan, Theresia Degener

Purpose and outline of this chapter

The adoption of a thematic treaty on the human rights of women was felt necessary in order to tailor the more general rights protected by the ICCPR and the ICESCR to the circumstances of women. The provisions of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) do not explicitly mention women with disabilities, but since CEDAW rights belong to all women, women with disabilities are implicitly covered.

This chapter evaluates the current use of CEDAW to further the rights of women with disabilities. In the light of this analysis, it suggests ways of developing the Convention's full potential in the context of disability. The chapter is divided into four sections. The first introduces CEDAW and its monitoring mechanisms. The second addresses the general applicability of the Convention in the context of disability. The third analyses five recent State party reports under CEDAW from the standpoint of disability. And the fourth contains our conclusions and suggestions.

7.1 Introduction to CEDAW

7.1.1 Background

The United Nations General Assembly adopted CEDAW in 1979 after five years of work by the United Nations Commission on the Status of Women and, in the final stages, by a special General Assembly working group. The Convention entered into force in 1981 following its ratification by 20 States. By 8 February 2002, the number of States parties had risen to 168. On ratification they entered a large number of reservations to important articles, but many were later withdrawn.¹

¹ States may exempt themselves from one or more of the provisions of the instrument by formally submitting a reservation; reservations incompatible with the object and purpose of CEDAW are not permitted (article 28 (2)). Article 29 gives two or more States parties the right to refer a dispute about the interpretation of CEDAW for arbitration and, if it remains unresolved, to the International Court of Justice. To date this provision has not been acted on. See General Recommendations No. 4 and No. 20 on reservations to the Convention adopted by the Committee on the Elimination of Discrimination against Women (United Nations document HRI/GEN/1/Rev.5).

An Optional Protocol to CEDAW was adopted in 1999 which introduced two new enforcement mechanisms: (1) the consideration of individual complaints and (2) the conduct of inquiries. The Optional Protocol entered into force on 22 December 2000.²

CEDAW deals exclusively with the human rights of women and girls. Its adoption greatly increased the visibility of women in the human rights system. This in turn created an awareness of both the obstacles to the enjoyment of human rights for women and the specific measures needed to remove them.

The overarching goal of CEDAW is the achievement of de facto equality for women with men. The Convention recognizes that targeting only the outward manifestations of inequality (discriminatory practices) is not enough. The achievement of de facto equality also necessitates the identification and elimination of the causes of discrimination. Accordingly, article 5 requires States parties to modify any social and cultural practices that are based on suppositions about the superiority of either of the sexes or on stereotyped roles of men and women.

CEDAW is also applicable in the private sphere. This is important since a great deal of discrimination against women, including women with disabilities, occurs in the private sector. The State bears ultimate responsibility for the regulatory environment in which private discrimination takes place. The Convention requires States parties:

To take all appropriate measures to eliminate discrimination against women by any person, organization or enterprise.³

The non-discrimination rights in CEDAW cover the whole spectrum of human rights, be they civil, political, economic, social or cultural.

The first six articles of the Convention are overarching in the sense that they create general obligations. Beginning with a definition of discrimination against women in article 1, they set forth States parties' general obligations to end discrimination against women (article 2), require them to guarantee full enjoyment of all human rights for women on the basis of equality with men (article 3), give permission to introduce temporary special measures on behalf of women (article 4), impose an obligation to tackle stereotypes and prejudice and to bring about a proper understanding of maternity (article 5), and require States parties to suppress egregious abuses such as trafficking in women and the exploitation of prostitution (article 6).

Many of the remaining articles deal with general human rights but tailor them to the circumstances of discrimination against women. They set forth States parties' obligations with respect to women's education (article 10), employment (article 11) and health care (article 12), the participation of women in public and political life (article 7) and their participation at the international level (article 8). Article 13 requires States parties to eradicate discrimination against women in other areas of economic and social life. Article 14 focuses on rural women.

Another category of provision deals with the legal situation of women and their status within the family. Article 9 requires States parties to grant women equal rights to

² General Assembly resolution 54/4 of 6 October 1999, annex.

³ Article 2(e).

acquire, change or retain their nationality. Article 15 requires them to guarantee women equality with men before the law, equal protection of the law, and freedom of movement and residence. Article 16 requires them to eliminate discrimination against women in all matters relating to marriage and family relations.

As acknowledged in General Comment No. 5 adopted by the Committee on Economic, Social and Cultural Rights, women with disabilities may be vulnerable on account of both disability and gender. A woman with a disability is more likely to suffer from discrimination than an able-bodied woman. This is illustrated by the double jeopardy a woman with a disability faces when seeking to establish an independent, self-determined life. The cumulative effect of attitudes based on the interaction of gender and disability is that women with disabilities often have less independence, less access to education and less access to employment than both men with disabilities and able-bodied women.

7.1.2 Monitoring – the role of the CEDAW Committee

The Committee on the Elimination of Discrimination against Women monitors the implementation of the Convention. In accordance with article 17, the Committee is composed of twenty-three independent experts, elected for a renewable term of four years. The members are nominated by States parties and elected by State party representatives. They serve on the Committee in their personal capacity.

The Committee meets for two three-week sessions annually. Two working groups meet intersessionally, a pre-sessional working group and a Working Group on the Optional Protocol. Article 20 of CEDAW limits the Committee's normal meeting time to two weeks annually but in 1995 the State parties adopted an amendment to article 20 introducing a procedure that allows for more flexible time allocation.⁴ So far, this amendment has not received the number of acceptances required for its entry into force. Since the early 1990s, and pending the entry into force of the amendment, the General Assembly has authorized the Committee to meet for two three-week sessions annually.⁵ An extraordinary session will be held in August 2002 to deal with the backlog of reports.

In contrast to the other United Nations human rights treaty bodies, which are based in Geneva, the Committee performs its task of monitoring the implementation of CEDAW in New York. At the time of the adoption of the Convention, it was decided that the Committee should be geographically connected to the Commission on the Status of Women⁶ and the Division for the Advancement of Women (DAW).⁷ The Committee can be contacted through:

⁴ General Recommendation No. 22 (HRI/GEN/1/Rev.5).

⁵ General Assembly resolution 51/68 of 12 December 1996. See also the Committee's report on its fifteenth session, decision 15/I (A/51/38), p. 1.

⁶ The Commission on the Status of Women (CSW) is an intergovernmental body established by the Economic and Social Council in 1946 and based in New York.

⁷ The Division for the Advancement of Women (DAW) provides technical servicing to both the Commission on the Status of Women and the CEDAW Committee.

The Women's Rights Unit
Division for the Advancement of Women (DAW),
United Nations
DC2-1228, 2 United Nations Plaza
NY, NY 10017
Phone: 212 963 3162
Fax: 212 963 3463

7.1.3 Monitoring through State party reporting

Article 18 requires each State party to submit a report to the Committee within one year after the entry into force of CEDAW and every four years thereafter. The report should illustrate the legislative, judicial, administrative and other measures the State party has taken to give effect to the provisions of CEDAW.

At the end of the session preceding the session when a second or subsequent periodic report is being considered by the Committee, a working group examines the report and sends a written request for additional information (called a “list of issues”) to the State party. The State party submits a written reply (called “responses to the list of issues”) answering the questions raised by the working group. This practice is not used for initial reports, which are not considered by a working group before the relevant session. For each State party report, one member of the Committee is assigned the role of Country Rapporteur and serves as the main actor in both compiling the “list of issues” and reviewing the report.

The report is then discussed at a meeting between representatives of the Government of the State party and the Committee. A synthesis of the discussion is presented in the press releases.⁸ After deliberation, the Committee draws its conclusions about the performance of the State party and publishes them as its concluding comments, which offer guidance for the further implementation of the Convention by the State party.

The time lag between submission of a report and its consideration is roughly two years. As the Committee seeks to establish a geographical balance among the reports considered at each session, the waiting time varies. As many reports are overdue, the Committee has adopted a procedure whereby States parties are allowed to combine reports.⁹

7.1.4 Enforcement through individual complaints under the Optional Protocol to the Convention

State party reporting is not the only enforcement mechanism under CEDAW. The Convention has an Optional Protocol which provides for a right of complaint – something that was suggested in the Vienna Declaration and Programme of Action

⁸ Owing to the requirement that summary records of Committee meetings should be distributed simultaneously in all six official languages of the United Nations, no summary records have been published since 1997.

⁹ See rule 49, paragraph 3, of the Committee’s rules of procedure (A/56/38, annex I).

adopted in 1993.¹⁰ It entered into force on 22 July 2001 after the requisite number of ratifications had been deposited. Under the Optional Protocol, individual women and groups of women, under the jurisdiction of a State party, can submit complaints to the Committee alleging violations of the Convention provided that the State party in question has ratified the Protocol. A person other than the victim can also submit a complaint on her behalf.¹¹

Article 10 of the Optional Protocol gives States parties the right not to recognize the competence of the Committee to conduct inquiries. Other than that, no reservations to the Optional Protocol are permitted.¹²

When a communication is declared admissible, the Committee initiates a procedure of communication with the State party involved, which concludes with the transmission of its views on the issue to the State party. Within six months of receiving the views, the State party must inform the Committee of the action it has taken in the light of the Committee's views and recommendations. The Committee may also invite the State party to submit further information on measures taken in subsequent periodic reports.¹³

The Committee also has the authority, before deciding on the merits of a case, to request the State party to take such interim measures as may be necessary to avoid possible irreparable damage to the victim or victims.¹⁴

Complaints under the Optional Protocol are to be sent to the Division for the Advancement of Women. As of October 2001, no registrable complaints under the Optional Protocol had been received. At its twenty-sixth session in January/February 2002, the Committee finalized guidelines for the submission of communications that had been drafted by the Working Group on the Optional Protocol. They will be published in the Committee's next annual report to the General Assembly.

Articles 3 and 4 of the Optional Protocol set out the conditions for admissibility of complaints as follows:

Article 3

Communications shall be in writing and shall not be anonymous. No communication shall be received by the Committee if it concerns a State Party to the Convention that is not a party to the present Protocol.

Article 4

1. The Committee shall not consider a communication unless it has ascertained that all available domestic remedies have been exhausted unless the application of such remedies is unreasonably prolonged or unlikely to bring effective relief.
2. The Committee shall declare a communication inadmissible where:
 - (a) The same matter has already been examined by the Committee or has been or is being examined under another procedure of international investigation or settlement;

¹⁰ Vienna Declaration and Programme of Action (A/CONF.157/24, Part I).

¹¹ Optional Protocol, article 2.

¹² Optional Protocol, article 17.

¹³ Optional Protocol, articles 6 and 7.

¹⁴ Optional Protocol, article 5.

- (b) It is incompatible with the provisions of the Convention;
- (c) It is manifestly ill-founded or not sufficiently substantiated;
- (d) It is an abuse of the right to submit a communication;
- (e) The facts that are the subject of the communication occurred prior to the entry into force of the present Protocol for the State Party concerned unless those facts continued after that date.

Rule 58 (1) of the Committee's rules of procedure gives a further indication of the required form and content of complaints. It reads as follows:

Rule 58

1. The Secretary-General may request clarification from the author of a communication, including:
 - (a) The name, address, date of birth and occupation of the victim and verification of the victim's identity;
 - (b) The name of the State party against which the communication is directed;
 - (c) The objective of the communication;
 - (d) The facts of the claim;
 - (e) Steps taken by the author and/or victim to exhaust domestic remedies;
 - (f) The extent to which the same matter is being or has been examined under another procedure of international investigation or settlement;
 - (g) The provision or provisions of the Convention alleged to have been violated.

7.1.5 Enforcement through "inquiries" under the Optional Protocol

Another novel enforcement procedure under the Optional Protocol is the provision which allows the Committee to conduct an inquiry into allegations of "grave or systematic violations" of CEDAW rights by a State party. This could be useful in challenging practices against women with disabilities or practices that could lead to disabilities in women.

When the Committee receives information of such alleged violations, it invites the State party concerned to cooperate in the examination of the information and to submit relevant observations to the Committee. On the basis of its observations, and any other reliable information, the Committee can designate one or more of its members to conduct an inquiry and report back to the Committee. If the State party gives its consent, the inquiry may include a visit to its territory. Inquiries are confidential and the cooperation of the State party concerned is to be sought at all stages of the proceedings.

The Committee transmits its findings to the State party together with any comments and recommendations. Within six months of receiving the findings, comments and recommendations, the State party is required to submit its observations to the Committee.¹⁵ At the end of the six-month period, the Committee may, if necessary, invite the State party to inform it of the measures taken in response to the inquiry. It

¹⁵ Optional Protocol, article 8.

may also invite the State party to submit such information in subsequent periodic reports.¹⁶

To trigger an inquiry procedure under the Optional Protocol, information on alleged violations of the Convention should be sent to the Division for the Advancement of Women. Aside from article 8(1) of the Optional Protocol and rule 82(2) of the Committee's rules of procedure, no documentation has been issued to date on the required form and content of information submitted under this procedure. Article 8(1) and rule 82(2) read as follows:

Article 8

1. If the Committee receives reliable information indicating grave or systematic violations by a State Party of rights set forth in the Convention, the Committee shall invite that State Party to cooperate in the examination of the information and to this end to submit observations with regard to the information concerned.

Rule 82

2. The Committee shall determine whether the information received contains reliable information indicating grave or systematic violations of rights set forth in the Convention by the State party concerned.

Although not very detailed, the above provisions give some indication of the required form and content of information to be submitted under the inquiry procedure. The information should indicate that the alleged violations are grave or systematic. This can be done by indicating the dates and frequency of occurrence of violations, the number of women affected and the impact of the violations. The information must be reliable. It should therefore be supported by evidence or corroborated by a large number of sources. The information must indicate the State party against which it is directed.

7.1.6 Towards normative clarity: the practice of issuing general recommendations

To assist States parties in fulfilling their obligations under CEDAW, the Committee issues general recommendations interpreting and elaborating on different aspects of their rights and obligations. While general recommendations are not legally binding as such, they represent the most authoritative interpretation of the Convention available. Since 1997, the Committee has followed a three-stage procedure for the elaboration of general recommendations. First, it solicits information about the topic under discussion from NGOs and other actors. Second, a member of the Committee prepares a draft for discussion by a working group of the Committee at the next session. Third, a revised draft is adopted at the subsequent session.

To date, the Committee has adopted 24 general recommendations and is currently elaborating General Recommendation No. 25 on the reconciliation of temporary special measures (article 4) with the general norm against discrimination (article 2).

Two general recommendations specifically mention disability.¹⁷

¹⁶ Optional Protocol, article 9.

General Recommendation No. 18 on “disabled women” focuses explicitly on women with disabilities and urges States parties to provide information on their situation in their periodic reports.

Among the general recommendations dealing with non-discrimination rights (as distinct from different categories of women), General Recommendation No. 24 on article 12 (women and health) contains a reference to women with disabilities. The content of the two general recommendations will be further analysed below.

7.2 The general application of CEDAW norms in the context of disability

The main purpose of this section is to provide a clear account of the benchmarks that States can be expected to meet with respect to the realization of CEDAW rights for women with disabilities. It discusses general parameters for the application of the Convention in the context of disability, including General Recommendation No. 18, the definition of discrimination in the Convention, general State party obligations and the obligation to submit periodic reports.

Article 1 of CEDAW defines discrimination as follows:

For the purposes of the present Convention, the term "discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

As the CEDAW protections cover all women, they apply equally to women with disabilities and able-bodied women. When a woman with a disability is exposed to discrimination, it is not always clear whether the discriminatory practice is attributable to her gender or her disability.

Discrimination against disabled women takes various forms and the standard of comparison differs accordingly. Disabled women may experience discrimination vis-à-vis non-disabled women. They may share the discrimination experienced by other women vis-à-vis men. And they may experience discrimination vis-à-vis disabled men.

Disabled women are sometimes confronted with eugenic practices such as compulsory sterilization or prohibition of marriage. Compared to disabled men, they may not experience direct discrimination in this regard since eugenic population policies tend to target both men and women with disabilities. In practice, however, disabled women are usually affected to a greater extent. Moreover, if non-disabled men (and women) are taken as the standard of comparison, discrimination is more readily discernible.¹⁸ Disabled women often tend to receive fewer or poorer quality

¹⁷ Recommendation No. 18 and Recommendation No. 24 (HRI/GEN/1/Rev.5).

¹⁸ See generally Theresia Degener, “Disabled women and international human rights”, *Women and International Human Rights Law*, Kelly D. Askin and Dorian M. Koenig (eds.) (Ardsley, N.Y.: Transnational, 2001), vol. III, pp. 262-282.

vocational rehabilitation services than disabled men.¹⁹ Article 11 of the Convention requires States parties to eliminate discrimination against women in employment. The standard of comparison is relevant in this context. It makes little sense to compare disabled women with non-disabled men (or women) since members of these groups usually do not need vocational rehabilitation. The relevant comparator is thus disabled men.

7.2.1 Applying CEDAW in the context of disability: the relevance of General Recommendations Nos. 18 and 24

As the wording of the provisions of the Convention is of a general nature, the role of the general recommendations is to elaborate and apply CEDAW rights in specific contexts. General recommendations are an important means of making explicit the inclusion of women with disabilities in the protection against discrimination enjoyed by all women under the Convention.

General Recommendation No. 18 mentions the need to take measures (including special measures) in the areas of employment (article 11), education (article 10), health services (article 12) and social security (article 13). It urges States parties to provide information on the situation of women with disabilities in their reports. It recommends:

that States parties provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life.

The emphasis on participation in the above excerpt is noteworthy.

General Recommendation No. 24 on article 12 (women and health) analyses the right to health and specifically refers to women with disabilities.²⁰ In paragraph 6, it urges that:

special attention should be given to the health needs and rights of women belonging to vulnerable and disadvantaged groups such as ... women with physical or mental disabilities.

It acknowledges that certain cultural or traditional practices such as female genital mutilation carry a high risk of causing disabilities in women (para. 12(b)). Moreover, the Committee recommends (in General Recommendation No. 14) that States parties “take appropriate and effective measures with a view to eradicating the practice of female circumcision”. General Recommendation No. 24 also expresses a concern for the health status of older women who live longer than men and who are susceptible to disabling conditions (para. 24).

General Recommendation No. 12 on “violence against women” requests States parties to include in their periodic reports information concerning the incidence of violence against women. Although it does not specifically mention women with disabilities, it can logically be interpreted to include them, perhaps especially in the context of

¹⁹ Ibid.

²⁰ Paras. 5, 6, 12 (b), 24, 25 and 27.

institutional environments. General Recommendation No 23, an important recommendation on “political and public life”, fails to mention women with disabilities and their difficulties in the political arena. Again, however, logic indicates that women with disabilities are implicitly included.

In addition to its general recommendations, the Committee has indicated that other sources can be used in the interpretation of CEDAW rights as they relate to women with disabilities. General Recommendation No. 18 refers to the World Programme of Action concerning Disabled Persons²¹ and the Nairobi Forward-Looking Strategies for the Advancement of Women.²² In addition, the guidelines for preparation of reports by States parties under CEDAW²³ request States to provide information on measures taken to implement the Beijing Declaration and Platform for Action.²⁴ The specific situation of women with disabilities is mentioned in all of these instruments.

The 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities²⁵ are not referred to in General Recommendation No. 18 (adopted in 1991). Nevertheless, there is nothing to impede the use of the Standard Rules as a guide for interpretation of CEDAW rights in the context of women with disabilities.

7.2.2 General State obligations in the context of women with disabilities (article 2)

Article 2 of CEDAW sets out the following general obligations of States parties:

States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women and, to this end, undertake:

- (a) To embody the principle of the equality of men and women in their national constitutions or other appropriate legislation if not yet incorporated therein and to ensure, through law and other appropriate means, the practical realization of this principle;
- (b) To adopt appropriate legislative and other measures, including sanctions where appropriate, prohibiting all discrimination against women;
- (c) To establish legal protection of the rights of women on an equal basis with men and to ensure through competent national tribunals and other public institutions the effective protection of women against any act of discrimination;
- (d) To refrain from engaging in any act or practice of discrimination against women and to ensure that public authorities and institutions shall act in conformity with this obligation;
- (e) To take all appropriate measures to eliminate discrimination against women by any person, organization or enterprise;
- (f) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women;
- (g) To repeal all national penal provisions which constitute discrimination against women.

²¹ General Assembly resolution 37/52 of 3 December 1982.

²² See <http://www.un.org/esa/gopher-data/conf/fwcw/nfls/nfls.en>.

²³ CEDAW/C/7/Rev. 3, paras. 8, 13 (f).

²⁴ Beijing Declaration and Platform for Action, Fourth World Conference on Women (A/CONF.177/20).

²⁵ General Assembly resolution 48/96 of 20 December 1993.

Two features are noticeable about State obligations under CEDAW. First, the declared goal of CEDAW is complete equality in practice between men and women. Second, States parties are responsible not only for their own acts of discrimination but also for discriminatory acts committed by private actors. Article 2 (a) to (g) sets out some of the measures that States parties are required to take in pursuit of their policy of eliminating discrimination against women, including women with disabilities.

Under article 2, States parties are required to incorporate the principle of equality between men and women with disabilities in their national constitution and other legislation and to ensure the practical realization of this principle. They should prohibit all discrimination against women, including those with disabilities, by adopting legislative and other measures, including sanctions. They should ensure that women, including those with disabilities, enjoy legal protection of their rights equal to that enjoyed by men and that protection against discrimination is ensured through competent national tribunals and other public institutions. States parties should refrain from any act that discriminates against women, including those with disabilities, and ensure that all public authorities do likewise. They are required to modify or abolish existing laws, regulations, customs and practices that discriminate against women with disabilities by taking all appropriate measures, including legislation. Lastly, they are required to repeal all national penal provisions that constitute discrimination against women, including those with disabilities.

General Recommendation No. 6 on "effective national machinery and publicity" recommends that States parties:

1. Establish and/or strengthen effective national machinery, institutions and procedures, at a high level of Government, and with adequate resources, commitment and authority to:
 - (a) Advise on the impact on women of all government policies;
 - (b) Monitor the situation of women comprehensively;
 - (c) Help formulate new policies and effectively carry out strategies and measures to eliminate discrimination.²⁶

States parties are thus required to establish effective national machinery to advise on the impact of all government policies on women, including those with disabilities.

7.2.3 The permissibility of temporary special measures in the context of women with disabilities (article 4)

Article 4 of CEDAW allows for (but does not require) temporary special measures in favour of women. It reads as follows:

1. Adoption by States Parties of temporary special measures aimed at accelerating de facto equality between men and women shall not be considered discrimination as defined in the present Convention, but shall in no way entail as a consequence the maintenance of unequal or separate standards; these measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved.

²⁶ HRI/GEN/1/Rev. 5.

2. Adoption by States Parties of special measures, including those measures contained in the present Convention, aimed at protecting maternity shall not be considered discriminatory.

According to article 4 (1), advantages in the form of "quotas" or different forms of priority access in areas such as education or employment that are used to accelerate the achievement of equality between women with disabilities and men do not constitute discrimination.²⁷ Such measures should be discontinued, however, when equality of opportunity and treatment has been achieved.

Article 4 (1) is based on the belief that one day equality of opportunity and treatment between men and women will be achieved so that special measures will no longer be necessary. By contrast, article 4 (2), which deals with special standards protecting maternity, has no time limit because, however much society changes, women will still get pregnant and give birth. In fact, women with disabilities face greater difficulties than able-bodied women in respect of maternity.

Most of the lack of equality of opportunity and treatment with respect to disability is based on societal prejudice and can be challenged and changed by the use of temporary special measures. For example, if enough women with disabilities obtain the support they need to break down existing barriers created by prejudice and misunderstanding and to enter mainstream employment, their place there and the presence of "difference" will soon be recognized and accepted as normal. Future generations of women with disabilities will no longer face the same social barriers and hence no longer need "quotas" or different forms of priority access to employment. Still, as in the case of maternity, there may be aspects and forms of disability that will always necessitate special measures in order to achieve equal opportunity and treatment.

It will be recalled that the Committee recommends in General Recommendation No. 18 that States parties submit information on "special measures" in their reports. It thus views the application of special measures as central to the enjoyment of CEDAW rights by women with disabilities.

7.2.4 The State party reporting process: the required content of reports in respect of women with disabilities (article 18)

Article 18 reads as follows:

1. States Parties undertake to submit to the Secretary-General of the United Nations, for consideration by the Committee, a report on the legislative, judicial, administrative or other measures which they have adopted to give effect to the provisions of the present Convention and on the progress made in this respect:
 - (a) Within one year after the entry into force for the State concerned;
 - (b) Thereafter at least every four years and further whenever the Committee so requests.
2. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

²⁷ Ibid.: General Recommendation No. 5 on "temporary special measures" encourages States parties to "make more use of temporary special measures such as positive action, preferential treatment or quota systems to advance women's integration into education, the economy, politics and employment".

According to article 18, State party reports should describe the "legislative, judicial, administrative and other measures" that they have taken to fulfil their obligations under CEDAW. Reports should also provide an account of progress made and indicate factors and difficulties experienced.

A more detailed account of States parties' reporting obligations is contained in the "Guidelines for preparation of reports by States parties". The Committee adopted the first version of the guidelines in 1983 and the latest revision in 1996.²⁸ According to the guidelines, initial State party reports should be divided into two parts.

Part I should be prepared in accordance with the consolidated guidelines for the initial part of State party reports submitted under all other human rights treaties.²⁹ Part II of initial reports should provide specific information regarding each article of the Convention, including relevant constitutional, legislative and administrative provisions in force. The Committee requests States parties to submit copies of the legal and administrative texts referred to in their reports. If the original text is not submitted, the report should be comprehensive enough to be understood without it.³⁰ In addition to information on the legal status of women, Part II of initial reports should contain information on the de facto status of women and their level of enjoyment of each of the CEDAW rights. States should endeavour to provide data disaggregated by sex in all areas covered by the Convention and the general recommendations.³¹ States parties should also provide additional information on progress made in the realization of each right since the entry into force of the Convention, including information on the establishment of programmes and institutions.³² Initial reports should include information on obstacles³³ to the equal participation of women in political, social, economic and cultural life.³⁴ The report should also indicate any restrictions or limitations imposed by law, practice or tradition or in any other manner on the enjoyment of each right under the Convention.³⁵ It should contain information about NGOs and other women's associations, including their participation in the elaboration and implementation of plans and programmes by public authorities.³⁶ All initial reports and supporting documentation should be submitted in as concise a form as possible and in one of the working languages of the Committee.³⁷

States parties should further report on any reservations made to the Convention. In the case of substantive reservations, they should indicate why they are considered necessary, whether the State party has made comparable reservations to rights and obligations in other treaties that are consistent with the reservations to CEDAW, what

²⁸ CEDAW/C/7/Rev. 3.

²⁹ Consolidated guidelines for the initial part of reports of States parties, (HRI/CORE/1, annex).

³⁰ CEDAW/C/7/Rev. 3, paras. 4 (a), 6.

³¹ *Ibid.*, paras. 4 (d), 5. See also General Recommendation No. 9 on statistical data concerning the situation of women (HRI/GEN/1/Rev. 5).

³² CEDAW/C/7/Rev.3, para. 4 (b) and (c).

³³ General Recommendation No. 1 on reporting by States parties (HRI/GEN/1/Rev. 5).

³⁴ CEDAW/C/7/Rev. 3, para. 7.

³⁵ *Ibid.*, para. 4 (e).

³⁶ *Ibid.*, para. 4 (f).

³⁷ *Ibid.*, para. 10.

the precise effects of the reservations are in terms of national law and policy, and whether there are any plans to limit the effects of reservations or to withdraw them (including a timetable).³⁸ If a State party has made general reservations that do not refer to specific articles of the Convention, or if it has made reservations to articles 2 and 3, it should make a particular effort to provide information on the effect and interpretation of such reservations.³⁹

The guidelines for second and subsequent reports are similar to those for initial reports. They should cover matters that were not included in the initial report and concentrate on the period of time since the consideration of the last report by the Committee.⁴⁰ They should furthermore have regard to the deliberations of the Committee concerning the preceding report, include legal and other measures adopted to implement the Convention since the last report and describe progress made in eliminating discrimination against women.⁴¹

In the context of disability, General Recommendation No. 18 observes that State party reports contain scanty information on disabled women. Referring to article 3 (basic human rights and fundamental freedoms), it expresses concern about women with disabilities, "who suffer from a double discrimination linked to their special living conditions".⁴²

Although General Recommendation No. 18 identifies priority areas for reporting in respect of women with disabilities (human rights and fundamental freedoms and special measures in education, employment, health services and social security), it clearly does not imply that States parties are thereby relieved from reporting on women with disabilities under the other provisions of the Convention.

7.3 Case studies on the current use of CEDAW in the context of disability

This section examines the current use of CEDAW in the context of disability. It examines five recent periodic reports by Azerbaijan, Bulgaria, Finland, Indonesia and Ireland. These States parties were chosen on the basis of availability of documentation and to ensure a reasonable geographic spread. They give an indication of how the CEDAW system is working in the context of disability.

It will be recalled that General Recommendation No. 18 specifically requests States parties to include information on women with disabilities in their reports under articles 10 (education), 11 (employment), 12 (health) and 13 (social security).

³⁸ Ibid., para. 9 (a) and (b). See also General Recommendation No. 4 and General Recommendation No. 20 on reservations to the Convention (HRI/GEN/1/Rev.5).

³⁹ CEDAW/C/7/Rev. 3, para. 9 (c).

⁴⁰ Ibid., para. 11.

⁴¹ Ibid..

⁴² General Recommendation No. 18 on disabled women (HRI/GEN/1/Rev.5).

(a) *Azerbaijan's initial report (1996)*

Azerbaijan's initial report was published in September 1996.⁴³ Azerbaijan is a relatively new State party, having achieved independence from the former Union of Soviet Socialist Republics in 1995.

The report did not address the situation of women with disabilities.

Article 25 of the Constitution guarantees equality on a number of grounds, which do not include disability. Article 19 of the Constitutional Act of State Independence of the Republic of Azerbaijan sets out the State party's equality provisions, which make no direct reference to disability:

All citizens of the Republic of Azerbaijan enjoy equal rights and obligations according to the law. The Republic of Azerbaijan, subscribing to the Universal Declaration of Human Rights, the Final Act of the Helsinki Conference, and other generally recognized international legal documents, ensures the enjoyment and free exercise of all the rights and freedoms provided therein, irrespective of sex, racial or ethnic affiliation, religion, social origin, political convictions and other circumstances.

While disability is not specifically mentioned, it could conceivably be covered by "other circumstances".

The educational system is reported to provide for "special schools, classes, groups and home study for physically immature and mentally retarded children".⁴⁴

Paragraph 111 of the report deals with protection for pregnant women. Provision is made under the Labour Code for flexible working arrangements for women who care for a sick relative. Provision is also made for unpaid leave to care for chronically ill children.⁴⁵

The Employment Act states that persons "who particularly need social protection include ... women raising preschool or disabled children". The State party provides assistance to this group in finding work, organizes training courses on their behalf and affords them tax concessions.

According to paragraph 117:

The right of citizens to social security are laid down in article 38 of the Constitution of the Azerbaijani Republic. Everyone is entitled to social security on attaining the age established by law or on grounds of sickness, invalidity, loss of the breadwinner or incapacity to work.

This provision suggests that allowances exist under the Social Security Code that are of relevance to women with disabilities. Mothers are entitled to State pensions in certain situations. Mothers of disabled children who have cared for children up to the

⁴³ CEDAW/C/AZE/1.

⁴⁴ Ibid., para. 104.

⁴⁵ Ibid., para. 113.

age of eight are entitled to an old-age pension on attaining the age of 50 with at least 15 years' service.⁴⁶

Summary records

Disability was not mentioned in the summary record.

Concluding comments

Disability was not mentioned in the concluding comments.⁴⁷

(b) Bulgaria's second and third periodic reports (1994)

The State party report

Bulgaria's combined second and third periodic reports under the Convention were published in November 1994.⁴⁸

The combined report does not deal explicitly with women with disabilities.

The report reflects on the political upheaval of the recent past, which resulted in a new Constitution for Bulgaria. The Constitution contains a non-discrimination clause which does not refer to disability as a prohibited ground of discrimination.

At the time of writing its report, Bulgaria had not yet adopted a charter on human rights. However, there were plans to introduce such a charter to ensure that Bulgaria was in compliance with its international legal obligations.⁴⁹ No direct reference was made to women with disabilities in these plans.

Women with disabilities were not specifically referred to in the context of violence against women, in institutions or elsewhere. The Bulgarian Penal Code contains an offence of sexual abuse of any person in a "helpless condition". The punishment for such an offence is imprisonment for up to five years.

The statistics contained in the report do not refer to women with disabilities.

An indirect reference to people with disabilities occurs in the context of employment. Article 48 of the Bulgarian Constitution states that:

- (1) Citizens shall have the right to work. The State party shall take care to provide conditions for the exercising of this right.
- (2) The State party shall create conditions conducive to the exercise of the right to work by the physically or mentally handicapped.

Article 51, paragraph 3, of the Constitution states that:

⁴⁶ Ibid., para. 118.

⁴⁷ A/53/38, paras. 69-79.

⁴⁸ CEDAW/C/BGR/2-3.

⁴⁹ Ibid., para. 35.

- (3) The aged without relatives and unable to support themselves, as well as the physically and mentally handicapped, shall enjoy the special protection of the State party and society.

The report mentions that the social care system in Bulgaria provides for "institutions for the handicapped".⁵⁰ The institutionalization of people with disabilities is mentioned in a positive light as helping to alleviate women's work in the family. Reference is made to the fact that there are not enough of these services available.

Another indirect reference to disability is made under article 18 of the Family Code concerning marriage and the family. The requirements for equality between spouses include mutual care, especially in the case of illness, disability and exceptional workload. Failure to provide such care on the part of the healthy spouse is considered to be a breach of that spouse's marital obligations.⁵¹

In its conclusions, the report acknowledges that pensioners and the handicapped have proven to be the most vulnerable groups during the period of social transition because of Bulgaria's financial difficulties and the policy of structural and economic reform.⁵²

List of issues

The list was not available at the time of writing.

Responses to the list of issues

The responses were not available at the time of writing.

Summary records

The issue of women with disabilities was not referred to.

*Concluding comments*⁵³

No reference was made to women with disabilities in the concluding comments.

(c) Finland's fourth periodic report (1999)

The State party report

Finland's fourth periodic report under the Convention was published in 1999.⁵⁴

Disability is mentioned in the context of articles 5 (prejudice and stereotypes) and 11 (discrimination in employment). Under article 5,⁵⁵ Finland reports that the social position of "disabled women" has been the subject of public debate for years and that there has been a strong increase in awareness of their rights during the 1990s.

⁵⁰ Ibid., para. 110

⁵¹ Ibid., para. 147

⁵² Ibid., para. 165

⁵³ A/53/38, paras. 208 - 261.

⁵⁴ CEDAW/C/FIN/4.

⁵⁵ Ibid., para. 3.

Rehabilitation and participation in society is emphasized in “social policy for the disabled”. Services and aid are said to be central to such policy and the services to which “the severely disabled” have a “so-called subjective right” are said to have increased in the 1990s. They include medical rehabilitation and services based on an Act concerning services for the disabled, including transport, interpretation, housing, home improvement and provision of household tools and equipment.

According to the report, “special services for the mentally handicapped” are used by 21,000 persons. One of the main purposes of a three-year project introduced in 1997 (Networking Special Services) by the Ministry for Social Affairs and Health is reported to be the provision of “special services for the mentally handicapped”.

The Finnish report notes that the delivery of such “special services” is being moved from districts to municipalities. However, district care will still support municipal care with institutional care and expertise. Institutionalization is reported to be decreasing and is being replaced by housing in the community and auxiliary services. The report notes that it is especially challenging to meet the service needs of “ageing mentally handicapped persons living with their parents” who will need public housing services in the near future.

In the context of article 11,⁵⁶ the report notes under the heading “Supporting the professional training and employment of the disabled” that improvements in the employability of “disabled people” enhance their full integration into society. In accordance with the European Union guidelines for employment, and with the help of employment methods created by the European Social Fund, the goal of Finnish employment policy is to raise the employment rate of the entire population. The aim is to improve quality control over subsidized employment and to improve the training of job counsellors and the organization of job counselling services in order to cover the whole country by the end of the year 2000.

As part of the Finnish employment plan under the European Union guidelines, the legislation on rehabilitation allowances, disability allowances and national pensions is reported to have been amended in 1999. The amendments guarantee the right of 16/17-year-old “disabled persons” to professional training and an increased rehabilitation allowance. According to the report, “seriously disabled young persons” who retired at 16 without an evaluation of their working capacity and without rehabilitation will not be granted an “invalidity pension” unless “occupational rehabilitation has been found to be impossible”. Persons who are entitled to an “invalidity pension” can interrupt their pension for 6 months to 2 years. In order to make working more profitable than being on a pension, a “special disability allowance” is paid during this interruption.

The terminology used in the report with reference to women (and others) with disabilities includes: “disabled women”, “severely disabled”, “mentally handicapped”, “ageing mentally handicapped persons”, “the disabled”, “disabled people”, “disabled persons”, “seriously disabled young persons” and “invalidity pension”.

⁵⁶ Ibid., para. 5.

List of issues

The Committee's "list of issues" regarding Finland's fourth periodic report was submitted to the Finnish Government in July 2000.⁵⁷ As the Committee considered Finland's third and fourth reports together, the questions in the list refer to both reports.

The "list of issues" mentions disability in the context of articles 5, 11 and 12.

In the context of article 5,⁵⁸ the working group wished to receive more information on the Networking Special Services project mentioned in the fourth periodic report. It noted that 21,000 persons had used the "special services for the mentally handicapped". Other questions raised by the working group were:

- Are there sex-disaggregated data on disabled persons, including the mentally handicapped?
 - Are there any measures in place to protect disabled women from abuse?
 - Do disabled women have access to the full range of health care for their particular needs?
 - What provisions are there for continuing their education and training?
 - To what extent is public transportation made available and designed for accessibility, safety and the convenience of disabled women?
 - Describe cases of disabled women who have been physically and sexually abused while in the care of their families or in the community and the measures taken to address such abuse;
 - Provide statistics on violence against disabled women.

The working group also wished to know more about the shift in responsibility for caring for "the elderly and the disabled" from women to men as described in the third and fourth periodic reports. It noted that such care was supported only through home-care allowances for children and relatives.

Some of the questions put by the working group to Finland under article 5 were intended to clarify information on women with disabilities contained in the report and others concerned issues such as education, public transport and abuse of women with disabilities that had not been mentioned.

In the context of article 11, the working group requested more information on the implementation of the Finnish "Employment Plan" relating to "disability". It wished to know how many "disabled women" received benefits from the plan compared with "disabled men". In the context of article 12, the working group noted that, according to a study referred to in Finland's third report, 60 per cent of the population had suffered from some form of mental illness and these illnesses were more common among women than among men. It wished to know what the main causes were, what

⁵⁷ CEDAW/PSWG/2001/I/CRP.1/Add. 3.

⁵⁸ Ibid., paras. 20-21.

measures the Government had taken to address the issue and whether the Government had undertaken a gender analysis of mental health care services.

The terminology used by the working group with regard to women (or other persons) with disabilities included “mentally handicapped”, “disabled persons”, “disabled women”, “the disabled”, “mental illnesses”, “disability” and “disabled men”.

Responses to the list of issues

The Finnish Government's responses to the list of issues were received by the Committee in September 2000. They mentioned disability in the context of articles 5, 11 and 12.

In relation to article 5, the Finnish Government noted that disability was one of the prohibited grounds of discrimination in its revised Constitution. In addition, under the Act on Basic Education, sign language could be selected as the language of instruction and could, if the guardian so wished, be taught as a person's mother tongue.

The Government provided information on the Networking Special Services project. The first part of the project, which had been carried out in 1998-1999, was designed to ensure that all 460 municipalities had access to experts in “special services (e.g. special services for the mentally handicapped)”. In addition to State party actors, research and educational institutions and NGOs were reported to have participated in the project.

In response to the Committee's question about sex-disaggregated data on “disabled persons”, the Finnish Government said that no such data was available. In response to the question on abuse of “disabled women”, it stated that awareness of the sexual abuse of “disabled women” had increased and that it had been a subject of public debate. On the question of legal protection, the Government stated that the Finnish Penal Code had been amended in 1998 and that sexual abuse of “the disabled” was a criminal act. The Penal Code was also reported to contain separate provisions protecting persons placed in institutional care. With regard to coercive measures in social welfare and health care, the Ministry of Social Affairs and Health was stated to be preparing provisions that would protect “the disabled” from “sexual harassment”.

Persons with severe disabilities were entitled to a personal assistant by virtue of the Service and Assistance for the Disabled Act. While the primary purpose of this Act was to “ensure the independent life of a disabled person and reduce his or her dependence on other people”, a personal assistant would also help to protect against sexual abuse. In general, the problem had reportedly been addressed in many “institutions meant for the disabled” by training the personnel in identifying sexual abuse. There were no statistics on offences committed against “disabled women”.

On the issue of access for “disabled women” to health care, the Government stated that although the special needs of “the disabled” were generally taken into account in the health care system, not all health care centres or municipalities could provide “the disabled” with the necessary services in a way that took their “special needs” into account. In such cases, they were referred to another establishment. The networking of municipal services was one way of tackling the problem.

In response to the working group's question on the education and training of women with disabilities, the Finnish authorities stated that both men and women with disabilities had "in principle good possibilities to study". They acknowledged that, while there were no legislative obstacles to the education of women with disabilities, practical problems such as lack of "services supporting...studies" and physical access to buildings hampered access to educational establishments in some towns.

In response to the working group's question about the convenience, accessibility and safety of public transport, the State party noted that the convenience of public transport was being constantly improved. In the Helsinki district all new vehicles for public transport had to be accessible. However, the accessibility of long-distance coaches had not been improved to the same extent as that of town coaches. The State party also acknowledged that, while new trains were designed for accessibility, older trains were "problematic for the disabled".

In the context of article 11,⁵⁹ the Finnish response noted that 58 per cent of some 80,000 persons with disabilities registered as job seekers during 1999 were women. Among all "disabled clients" seeking vocational counselling, about 60 per cent were women. In 1999, 9,000 "persons with disabilities" had begun labour market training, 32,237 had found a placement in the open labour market and over 12,000 placements had been arranged by means of support measures implemented by the labour administration.

Four tables were included in the reply, showing the number of "disabled women" in sheltered workshops, in daytime activity units, and seeking vocational rehabilitation in employment offices and under a rehabilitation scheme run by the social insurance institutions. In addition to measures taken under the Finnish Employment Plan, new measures supported by the European Social Fund had been taken to improve the educational and employment possibilities of "persons with disabilities". These measures included "job hunting counselling based on peer support, development of supported employment, rehabilitation club houses for persons with mental problems, social enterprises and cooperatives as well as individual paths to employment". The measures were reported to assist women with disabilities in integrating into working life.

A quality system was being developed for supported employment and specialists in the field were being trained. Steps had been taken to expand a European Social Fund project called the Fountain House Model, which assisted "persons with mental problems" who were undergoing rehabilitation in finding employment. Reform was reportedly under way in the area of sheltered work. Finland also noted that the requirements for "disability allowance" were different for Finnish citizens and foreign citizens.

In the context of article 12,⁶⁰ the State party explained that the figure of 60 per cent mentioned in the fourth periodic report as the number of persons with "mental illness" was an unfortunate misinterpretation. The figure referred to a study in which a representative sample of the population had been asked about their "everyday mental problems (such as experiencing overstrain, melancholy, nervousness or tension,

⁵⁹ CEDAW/PSWG/2001/I/CRP.1/Add. 3, questions 35 and 37.

⁶⁰ Ibid., question 40.

powerlessness or tiredness)". Approximately every sixth person experienced "actual mental disorders" that required treatment.

The summary records

The records were not available at the time of writing.

Concluding comments

The concluding comments on Finland's fourth periodic report make no mention of disability.⁶¹

(d) *Indonesia's second and third periodic reports (1997)*

The State party report

The Indonesian Government's combined second and third periodic reports under CEDAW were published in February 1997.⁶²

Disability is mentioned in the context of article 5.

Under article 5,⁶³ the report states that a new approach to family education attempts to encourage men to share the responsibility for aspects of family life including "care of the elderly, the sick and the disabled". The report does not provide information on the specific rights of women with disabilities

List of issues

The list of issues regarding Indonesia's second and third periodic reports does not mention disability.⁶⁴

Responses to the list of issues

The responses were of no relevance to women with disabilities because no pertinent issues had been raised in the "list of issues".

Summary records

The summary record of the review of Indonesia's second and third periodic reports makes no mention of disability.⁶⁵

Concluding comments

The concluding comments on Indonesia's second and third reports do not mention disability.⁶⁶

⁶¹ A/56/38, paras. 279 - 311.

⁶² CEDAW/C/IDN/2-3.

⁶³ Ibid., p. 25.

⁶⁴ CEDAW/C/1998/1/CRP.1/Add. 3.

⁶⁵ CEDAW/C/SR.377.

(e) *Ireland's second and third periodic reports*

Ireland's second and third periodic reports were combined and published in August 1997.⁶⁷

Women and other persons with disabilities are specifically referred to under articles 2, 3, 10, 11, 12 and 13.

Under article 2, the report refers to the 1996 Social Welfare Act and, more particularly, to the "disabled person's maintenance allowance" (to be renamed the "disability allowance"). This provision is intended to benefit both men and women with disabilities.

Women with disabilities are specifically mentioned in the report under article 3. A reference is made to the activities and final report of a high-level Commission on the Status of People with Disabilities. The report estimates that 5 per cent of the population are women with disabilities who can suffer a "double disadvantage". Reference is made to various housing acts and to the requirement for public housing authorities to identify the disabled/handicapped as a separate category in their assessment of needs. The report acknowledges the need for non-discrimination legislation in respect of women with disabilities. Plans are reported to be advanced for the enactment of such legislation.

Reference is also made to special needs education, inter alia for children with mental and other disabilities.⁶⁸ The report highlights the allocation of additional teaching posts, the establishment of a comprehensive school psychological service and the need to provide a system that is flexible enough to accommodate the particular needs and abilities of disabled students.

Under article 11, reference is made to the provision of social security allowances such as sickness, invalidity and other benefits in respect of incapacity to work. Under article 13, statistics are given for men and women in receipt of disability benefit. In 1990 about 3,000 more men than women were in receipt of disability allowances. By 1996 about 5,000 more women than men were receiving such allowances. The figure for women had remained broadly unchanged, while that for men had decreased each year. The statistics were interpreted as indicating the existence of a difficulty in the area of employment for women with disabilities.⁶⁹

With regard to women's health, the report stated under article 12 that the Department of Health was set to introduce a patients' charter to cover groups such as the mentally ill and people with a mental or physical disability. The report also addressed the issue of mental health, indicating that psychiatric services were shifting from an institution-based to a community-based approach.

⁶⁶ A/53/38, paras. 262-311.

⁶⁷ CEDAW/C/IRL/2-3.

⁶⁸ Ibid., page 80.

⁶⁹ Ibid., table 13.2.

List of issues

In its list of issues the Committee requested the following information about women with disabilities:

Describe mechanisms to monitor measures to protect groups of vulnerable women such as ... women with disabilities.⁷⁰

Response to the list of issues

In response to the above question, the State party referred to the non-discrimination protections provided under the Employment Equality Act for people with disabilities. It also referred to the forthcoming Equal Status Bill, which would provide additional non-discrimination protection for people with disabilities in spheres other than employment. Moreover, funding would be provided for a new representative Council of People with Disabilities, and a statutory National Disability Authority was to be established.

The State party indicated its recognition that double discrimination could occur for women with disabilities.⁷¹

Summary records

The summary records had not yet been issued at the time of writing.

Concluding comments

There is no reference to disability in the concluding comments.⁷²

7.4 Conclusions and future perspectives on CEDAW

7.4.1 Conclusions

The five reports examined above only provide a snapshot of recent reports submitted under CEDAW. However, although the sample is small, several tentative conclusions may be drawn.

The Convention has tremendous potential for women with disabilities who experience double discrimination and the Committee clearly views its provisions as important tools for enhancing levels of participation by women with disabilities.

The reports surveyed differ markedly in terms of coverage of women with disabilities and the approach adopted. Although the information provided on women with disabilities is more extensive in some reports, none can be said to have reached the benchmarks for reporting on women with disabilities set under General Recommendation No. 18 on disabled women and in the reporting guidelines. Ideally, reports should contain information on the situation of women with disabilities under

⁷⁰ CEDAW/C/1999/II/CRP.1/ADD.1, question 10.

⁷¹ CEDAW/PSWG/1999/II/CRP.1/Add.3

⁷² A/54/38, paras. 161 - 201

each right, including their current *de facto* and *de jure* situation, measures taken to enhance their status, progress made and difficulties and obstacles encountered.

It would appear from the sample that the Committee tends to ask for additional information on women with disabilities in its list of issues when information is volunteered on disability in the State party report. Conversely, if disability is not mentioned, it tends to be omitted also at a later stage.

States parties' responses to the list of issues tend to focus fairly narrowly on the issues raised in the list. Even when the question of disability arises in the dialogue between the Committee and the State party delegation, it usually fails to find its way into the concluding comments. This is important since concluding comments also provide an opportunity for drawing attention to good practice.

General Recommendation No. 18 requests States parties to report on the enjoyment of certain rights by women with disabilities. It does not, however, examine how States parties' obligations in respect of those rights relate to the circumstances of the women concerned. Fuller treatment of the non-discrimination rights of women with disabilities is therefore necessary and could be done either in a revised General Recommendation No. 18 or in a new general recommendation. Any such text should contain an assessment of the impact of disability on the enjoyment of each right under the Convention.

Chapter 8

Disability and children: the Convention on the Rights of the Child (CRC)

Dr Ursula Kilkelly

8.1. Background to the Convention

The United Nations Convention on the Rights of the Child (CRC) was adopted unanimously by the General Assembly on 20 November 1989. It was opened for signature on 26 January 1990 and came into force in record time on 2 September 1990. To date, it has been ratified by 191 States. With the exception of Somalia which has neither signed nor ratified and the United States which has signed but not yet ratified, it has been universally adopted.¹

The Convention on the Rights of the Child is the first binding instrument in international law to deal with the rights of children, although declarations on the rights of the child were adopted by the League of Nations in 1924 and the United Nations in 1959. The CRC contains 42 detailed provisions enshrining the rights of children in all areas of their lives and includes provisions on economic, social and cultural rights and on civil and political rights. In the former category, the Convention details the child's rights with respect to health care, education, social security and protection from violence and exploitation. Rights in the latter category include the child's right to have his/her opinion taken into account, the right to freedom of speech and association, the right of access to appropriate information and the right to identity. The Convention contains one provision (article 23) that deals specifically with the rights of children with disabilities but article 2, importantly, prohibits any discrimination in respect of the enjoyment of Convention rights on the ground of disability. It is therefore a vital source of rights for children with disabilities.

The Convention has been supplemented by two Optional Protocols.² The Optional Protocol on the involvement of children in armed conflict, which raises the minimum age for involvement in armed conflict to 18, entered into force on 12 February 2002. The Optional Protocol on the sale of children, child prostitution and child pornography strengthens the Convention's protection in these areas and entered into force on 18 January 2002.

¹ For a list of States that have signed, ratified or acceded to the Convention, as well as the dates of their signature, ratification or accession, see United Nations document A/52/348 or the web site of the Office of the High Commissioner for Human Rights: <http://www.unhchr.ch/pdf/report.pdf>.

² Both Protocols were adopted and opened for signature, ratification and accession by General Assembly resolution 54/263 of 25 May 2000.

8.2 The relevance of the CRC norms in the context of disability

8.2.1 Article 23: a dedicated provision on children with disabilities

Article 23 of the Convention on the Rights of the Child directly concerns children with disabilities and is, as such, an unusual provision among human rights treaties. It reads as follows:

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development
4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

In article 23, paragraph 1, States parties recognize that children with disabilities *should* enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. However, the relevant provision does not recognize or seek to guarantee this for children with disabilities as a matter of right and places no obligation on State parties to take measures to that end.

In article 23, paragraph 2, States parties recognize the right of children with disabilities to special care but the article stops short of specifying how this right is to be secured. It therefore contrasts with other Convention provisions such as article 19 on protection from abuse and article 22 on refugee children, which require States parties to take all appropriate measures to ensure that children receive the care and protection they need. A lower standard thus seems to be afforded under the Convention to children with disabilities, although this may be corrected by article 4 which sets forth the basic obligations of States parties under the entire Convention.

Children with disabilities have no absolute right to assistance under article 23. In paragraph 2, States parties are required to ensure assistance to children with disabilities who are eligible and who apply for such services and to encourage the

provision of such assistance subject to the conditions set forth in the paragraph. Thus, access to services is not set out as a matter of right or as a general entitlement based on need.

The article is also riddled with qualifications and limitations with regard to resources. Thus, paragraph 2 encourages the extension to children with disabilities of assistance but makes it "subject to available resources" and paragraph 3 repeats the resource qualification by stipulating that assistance extended under paragraph 2 shall be provided free of charge "wherever possible" and "taking into account the financial resources of the parents or others caring for the child".

Positive elements are discernible, however, in the second half of paragraph 3, which stipulates that assistance provided under paragraph 2 (i.e. limited to eligible children who apply for it and subject to available resources) shall be designed to ensure effective access to and receipt of education, training, health care and rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to achieving the fullest possible social integration and individual development. Again, however, there is no clear need-based entitlement or right to have access to or to benefit from such services.

The last paragraph of article 23 requires States parties to promote the exchange of appropriate information on preventive health care and treatment and on education and vocational services for children with disabilities. The stated aim of this cooperation is to enable States to widen their experience and improve their capabilities in the areas concerned. It is recognized that developing countries have special needs in this regard.

8.2.2 Mainstreaming disability: the relevance of all CRC norms to children with disabilities

For the reasons highlighted above, the other provisions of the Convention hold out more promise of vindication of the rights of children with disabilities. In contrast to other human rights treaties, the application of general rights provisions to children with disabilities is expressly provided for in the article 2 prohibition of discrimination in respect of the enjoyment of Convention rights on the ground of disability. Children with disabilities are thus expressly entitled under the Convention to enjoy all the protection it offers. This provision is vital as it dramatically expands protection of the rights of children with disabilities in a whole range of areas.

8.2.3 General CRC principles and their application for the benefit of children with disabilities

The Committee on the Rights of the Child has identified four general principles that should guide the implementation of all Convention rights.

(a) Non-discrimination

Article 2 prohibits discrimination in respect of the enjoyment of Convention rights: this provision is hugely significant inasmuch as it reinforces the right of children with disabilities to enjoy the benefits of the Convention equally with other children. In this regard, the Committee on the Rights of the Child has noted that the fact that article 23

is dedicated to children with disabilities does not mean that the rights of these children are confined to that article.³ Their right to enjoy all rights and freedoms equally has also been emphasized frequently by the Commission on Human Rights, most recently in April 2001.⁴

(b) *Best interests of the child*

Article 3 stipulates that the best interests of the child shall be a primary consideration in all actions taken concerning children: this provision requires the best interests of children with disabilities to be a core consideration in decision-making concerning them.

(c) *Right to life, survival and development*

Article 6 recognizes the right of every child to life, survival and development, a vital provision for all children but one of particular importance for children with disabilities, whose mortality rate is consistently higher and whose quality of life is deemed by many to be diminished by disability. Indeed in some countries 90 per cent of disabled children do not survive beyond the age of 20.⁵ Other threats to the life of children with disabilities occur before birth, since in some countries expectant mothers who risk giving birth to a disabled child are encouraged to consider abortion. The right to survival and development is also of enormous significance for children with disabilities, since neglect of such children can cause death or institutionalization resulting in an extremely poor quality of life. For example, babies or young children with disabilities may not receive the medical or other treatment accorded to a child without disabilities and attempts may be made to withhold care and food from severely disabled children, whose right to life is not considered to be equal to that of non-disabled children. In such cases, children with severe disabilities may have their right to die given priority over their right to life, which constitutes a gross violation of human rights.⁶

(d) *Right to be heard and to participate*

Given that children with disabilities are even more marginalized and silent than children in general, the recognition of their equal right to be heard and to participate is hugely significant. Many barriers impede the participation of children with disabilities in society and at school. Physical barriers prevent them from participating in activities and sharing experience with their peers at school, and leisure centres and other venues are often inaccessible. Failure to provide children with a means of expression, such as sign language interpreters, also excludes them from general activities and makes it very difficult for them to use hospitals, libraries and other public places. The behaviour of other children, who subject disabled children to bullying and name-calling, creates further invisible obstacles to their full participation. Perceptions of the disabled as inferior, less capable or less worthy individuals also create a glass barrier

³ CRC/C/SR.418 (summary record of meeting held on 6 October 1997), para. 4.

⁴ E/CN.4/RES/2001/75, para. 22, and also E/CN.4/RES/2000/85, para. 29.

⁵ CRC/C/SR.418, para. 2.

⁶ See further Gerison Lansdown, *It's Our World Too! A Report on the Lives of Disabled Children*, Disability Awareness in Action, 2001, pp 24-26.

to their involvement, which is compounded by the failure of society to secure their participation and to listen to their views.

Article 12 enshrines children's right to be heard in all matters affecting them and to be represented in all relevant proceedings. The Committee on the Rights of the Child considers the self-representation and full participation of children with disabilities as central to the fulfilment of their rights under the Convention. Article 12 may thus be viewed as the Convention's backbone. It encourages States parties to give a face to the invisible and a voice to the unheard, thereby enabling children with disabilities to enjoy a full and decent life in accordance with article 23. Furthermore, the Committee has expressed its determination to do all it can to encourage Governments to prioritize the rights of children with disabilities and, in line with article 12, to ensure that disabled children participate in devising solutions to their problems.⁷

8.2.4 The application of general Convention provisions in the context of disability

Although all Convention provisions are as relevant to children with disabilities as to other children, the following provisions are particularly relevant to them:

(a) The right not to be separated from one's family

The Convention lays strong emphasis throughout on the importance of the family in promoting the healthy development of children. At the same time, it lays a clear obligation on State parties to support parents and other carers in that role. The Preamble to the Convention recognizes the family's position as a fundamental group in society and a number of provisions specify the child's rights in relation to his/her family. These provisions are hugely significant for children with disabilities, who are still systematically removed from their parents and placed in institutional care, a practice that denies them their right to a family and also frequently subjects them to life in an institution, where they are isolated and segregated from all aspects of cultural and social life, and deprived of educational and other opportunities for human contact and personal development. As article 23 indicates, the denial of these rights is best addressed by a policy of inclusion and participation of children with disabilities in society. Their right to life with their families is central to any such approach and to the vindication of the rights of disabled children.

Article 7 recognizes the right of every child to know and be cared for by his or her parents and article 9 requires States parties to ensure that children are not separated from their parents unless a competent authority subject to judicial review determines it to be necessary for the child's best interests. During its day of general discussion on the rights of children with disabilities in 1997, the Committee on the Rights of the Child recognized the importance of the child's family and the child's rightful place in it.⁸

Provisions concerning the State's obligation to support the family and parents in the rearing of their children are clearly important to children with disabilities, whose

⁷ CRC/C/SR.418, paras. 2 and 6.

⁸ Ibid., para. 3.

families must also have the right to benefit from such support. In this regard, article 18, which requires States parties to render appropriate assistance to parents in the performance of their child-rearing responsibilities and ensure the development of institutions, facilities and services for the care of children, is extremely important. It is reinforced by article 20, which stipulates that a child deprived of his/her family shall be entitled to special protection and assistance provided by the State.

(b) *The right to protection from abuse*

While violence remains a problem for many children, children with disabilities are particularly vulnerable to abuse and neglect. Indeed, there is evidence that abuse is even more prevalent in the case of disabled children, particularly those with speech, intellectual or behavioural disorders.⁹

As children with disabilities are more likely to be in institutional care or in a residential setting than their non-disabled peers, their right to physical integrity is violated more frequently. Widespread institutional abuse of children with disabilities has been documented and it is therefore crucial for the Convention to address the rights of children in that area.

All children are entitled to benefit from the protection afforded by article 19 of the Convention, under which States parties are required to take all appropriate measures to protect children from neglect, abuse, maltreatment, violence or exploitation. Such protective measures should include programmes that provide support for the child as well as mechanisms designed to prevent, identify, report, refer, investigate, treat and follow up instances of child maltreatment. It is important that article 19 has been interpreted as an obligation to protect children from all forms of violence and abuse, including domestic violence, child abuse, mental and sexual violence, abuse by the police and other law enforcement authorities or by employees in juvenile detention centres, orphanages, child care institutions and other establishments, as well as violence in the street and in schools.¹⁰ It is apparent that this provision has the scope to provide special protection for children with disabilities who are represented among children in all these circumstances. Article 19 thus aims to protect children with disabilities regardless of whether the abuse or violence they suffer occurs in the home, at school, in a residential setting or in custody.

(c) *Right to an adequate standard of living*

In addition to the fact that poverty may give rise to malnutrition and thus disability, families with disabled children are disproportionately represented among the poorest in most societies. Moreover, the failure of developing countries to ensure the right of access to education for children with disabilities condemns them to a life in which they lack the knowledge and skills to rise out of poverty.¹¹

Given the specific relevance of poverty to children with disabilities, it is important that the Convention makes provision for the child's right to social assistance. Article

⁹ See Lansdown, *It's Our World Too!*, p 28.

¹⁰ E/CN.4/RES/2001/75, paras. 17-19.

¹¹ Lansdown, *It's Our World Too!*, p 27.

27 recognizes the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development. Although article 27, paragraph 2, places responsibility for the fulfilment of this right firmly on the shoulders of parents and others responsible for the child, paragraph 3 requires States to take appropriate measures to assist parents and others in its implementation. Notwithstanding the resource limitation, this provision thus goes further than article 23 - the dedicated provision on children with disabilities - by requiring specific State action to implement the right. Given their special needs, it is vital that children with disabilities receive the higher standard of rights protection afforded by article 27 and that States parties are not permitted to invoke article 23 as a reason for applying a lower standard to this category of children.

Article 27, paragraph 3, also requires States parties to provide "material assistance and support programmes" for children, particularly with regard to "nutrition, clothing and housing". The fact that children with disabilities are equally entitled under article 27 to fulfilment of their needs in these areas as a matter of right is vital.

The right of children to benefit from social security, including social insurance, is recognized clearly by article 26, paragraph 1, which also requires the State to take all necessary measures to achieve the full realization of that right. The special relevance of this provision to children with disabilities is highlighted in article 26, paragraph 2, which stipulates that the benefits should be granted, taking into account any "consideration relevant to an application for benefits made by or on behalf of the child". This permits the special circumstances and needs of children with disabilities to be taken into account by those calculating an entitlement to social security.

(d) The right to health care

Access to adequate and comprehensive health care facilities is important for all children, but children with disabilities are frequently denied access to the kind of care that is deemed vital for their physical, mental and emotional well-being. Children with disabilities need to be able to access health care services on an equal basis with their peers. Yet there can also be physical and other invisible barriers to their use of the health care system. Thus, poor, inaccessible or expensive transport may make physical access to health care facilities a problem. Moreover, while States may establish a basic health care system, access to rehabilitation services such as speech therapy and physiotherapy may be restricted by resources or other factors. Yet access to such services by children with disabilities at an early age is crucial for the development of a disabled child's potential and his/her active and independent involvement in society. Indeed, article 23 makes the link between accessing health services and achieving the fullest possible social integration and individual development.

Article 24 of the Convention recognizes the right of the child to enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. The applicability of the principle of non-discrimination in this context is expressly confirmed by the second sentence of article 24, paragraph 1, which stipulates that States parties "shall strive to ensure that no child is deprived of his or her right of access to such health care services". Article 24, paragraph 2, requires States parties to pursue full implementation of this right and take appropriate measures:

- (a) To diminish infant and child mortality;
- (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
- (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
- (d) To ensure appropriate pre-natal and post-natal health care for mothers;
- (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
- (f) To develop preventive health care, guidance for parents and family planning education and services.

(e) *The right to education*

The right to education is both the most important right for children with disabilities and the right most frequently denied. Moreover, the scale of violation is compounded by a number of factors. First, severely disabled children may be considered ineducable and denied any education, specialist or otherwise, on that ground. Second, only 2 per cent of disabled children in developing countries have access to an education system.¹² Third, while many disabled children receive no education, many more children fail to receive an effective education or one from which they can draw any benefit. Fourth, children with disabilities continue to endure an approach that favours their segregation and marginalization from the mainstream education system on the ground that they are receiving "special education". But students in so called "special schools" frequently fail to enjoy the same range of academic and leisure activities as children in mainstream schools, and the needs of individual pupils are not met in a comprehensive or dedicated manner.

The Convention contains two provisions on education, article 28 and article 29. They read as follows:

Article 28

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:
 - (a) Make primary education compulsory and available free to all;
 - (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;
 - (c) Make higher education accessible to all on the basis of capacity by every appropriate means;
 - (d) Make educational and vocational information and guidance available and accessible to all children;

¹² See CRC/C/SR.418, para. 2.

(e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.

3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

Article 29

1. States Parties agree that the education of the child shall be directed to:

(a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;

(b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations;

(c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own;

(d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin;

(e) The development of respect for the natural environment.

2. No part of the present article or article 28 shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principle set forth in paragraph 1 of the present article and to the requirements that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

Neither article makes express reference to children with disabilities although the Committee's General Comment No. 1 on the aims of education¹³ has helped to identify their relevance and significance for children with disabilities. In particular, it emphasizes the interrelationship between article 29 and the Convention's other provisions, particularly article 23 on the rights of disabled children and the general principles set forth in articles 2, 3, 6 and 12, as noted above. It recognizes that discrimination in education can undermine or even destroy the child's capacity to benefit from educational opportunities and makes it clear that discriminatory practices directly contradicts the requirement in article 29(1)(a) that education be directed to the development of the child's personality, talents and mental and physical abilities to their fullest potential.

General Comment No. 1 also makes it clear that respect for the child's right to education is a prerequisite for ensuring respect for all the child's rights under the Convention as a whole. Thus, an education system that is discriminatory in that it restricts access in physical terms or by virtue of the content of the curriculum taught fails to take into account the best interest of the child in disciplinary or other matters, or fails to facilitate the child's participation is per se contrary to the Convention

¹³ General Comment No. 1, 17 April 2001 (HRI/GEN/1/Rev.5).

inasmuch as it fails to reflect the values that education is trying to pass on to the child. The values of non-discrimination and equal treatment, respect for the human rights of others and the environment, development of respect for cultural and national values and preparation of the child for responsible life in a free society are as important to disabled children as to their non-disabled peers, if not more so.

General Comment No. 1 is disappointing, however, in its failure to address in any way the right of children with disabilities to education. In particular, it fails to make explicit the fact that articles 28 and 29 encompass a right to either effective or inclusive education for disabled children and it is a wasted opportunity in this regard. However, the importance of the right to inclusive education was one of three key aspects of article 23 emphasized during the day of general discussion on the rights of children with disabilities in 1997.¹⁴ A range of non-governmental organizations and specialized agencies highlighted the importance of an inclusive and holistic approach to the right to education for disabled children and identified the need for educating and awareness-building in society and the population in general about the right of all children to an inclusive education. Moreover, the issue of cost must continually be challenged, particularly in the light of the cost of exclusion, which deprives society of everything that the disabled child has to offer.

8.3 Implementation of the Convention

8.3.1 The State party reporting process

The task of monitoring the implementation of the Convention is entrusted to the Committee on the Rights of the Child, which was established under article 43 for the purpose of examining the progress made by States parties in fulfilling their obligations under the Convention. The Committee consists of 10 experts of high moral standing and recognized competence in the field covered by the Convention. Although they are nominated by States parties, the experts serve in their personal capacity. Provision for reporting is made in articles 44 and 45. Pursuant to article 44, paragraph 1:

States parties . . . undertake to submit . . . reports on the measures they have adopted which give effect to the rights recognized [in the Convention] and on the progress made in the enjoyment of those rights.

Reports are to be submitted within two years of the Convention's entry into force for the State party and thereafter every five years. Article 44, paragraph 2, states that reports submitted:

shall indicate factors and difficulties, if any, affecting the degree of fulfilment of the obligations under the present Convention. Reports shall also contain sufficient information to provide the Committee with a comprehensive understanding of the implementation of the Convention in the country concerned.

In addition, the Committee is authorized under article 44, paragraph 4, to request from reporting States further information relevant to the implementation of the Convention.

¹⁴ The other issues were the right to life, survival and development and the right to self-representation and full participation. See CRC/C/SR.418 and CRC/C/SR.419.

Under article 45 (a), specialized agencies, the United Nations Children's Fund (UNICEF) and other United Nations bodies may be represented when the Committee considers State party reports. Under article 45(b), the Committee may invite these agencies and other "competent bodies" - widely understood to include non-governmental organizations (NGOs) - to provide expert advice on implementation of the Convention. These bodies may also be asked to submit reports on implementation of the Convention in areas falling within the scope of their activities. Strong emphasis is thus placed on identifying means of ensuring effective implementation of the Convention and the role of United Nations agencies and national and international NGOs is a formal one. In addition, the Committee has the authority to forward to these bodies any State party report that contains a request or identifies a need for technical assistance. It can make suggestions and general recommendations on reports under article 45(d) but has no power to impose sanctions in the event of non-compliance. It is not competent either to receive individual complaints and the Convention makes no provision for addressing gross violations or for taking emergency action. The only provision relating to activities outside the reporting mechanism is contained in article 45 (c), which authorizes the Committee to request the Secretary-General to undertake studies on its behalf on specific issues relating to the rights of the child.

8.3.2 Guidelines for the preparation of initial reports

Despite the limited nature of the Committee's role under the Convention, article 43, paragraph 8, which authorizes the Committee to establish its own rules of procedure, provides the expert body with scope for developing activities both within and outside the framework of the reporting process. The Committee thus issued general guidelines to assist States parties in preparing their initial reports in order to minimize ineffective or inadequate reporting and to ensure uniformity in the form and content of reports.¹⁵ According to the guidelines, the initial report should contain:

Relevant information, including the principal legislative, judicial, administrative or other measures in force or foreseen, factors and difficulties encountered and progress achieved in implementing the provisions of the Convention.¹⁶

Details of implementation priorities and specific goals for the future should also be provided, together with detailed statistical information and indicators. This information serves to enhance the Committee's overall understanding of implementation and to clarify the *de facto* situation faced by children in the State party concerned.

The Committee has adopted a thematic approach, grouping rights under the following eight headings:

1. General measures of implementation
2. Definition of the child

¹⁵ General guidelines regarding the form and content of initial reports to be submitted by States parties under article 44, paragraph 1(a), of the Convention (CRC/C/5)

¹⁶ *Ibid.*

3. General principles
4. Civil rights and freedoms
5. Family environment and alternative care
6. Basic health and welfare
7. Education, leisure and cultural activities, and
8. Special protection measures

The aim of this categorization of Convention rights for reporting purposes is to encourage a coherent approach to implementation, to reinforce the indivisibility of Convention rights and to facilitate the participation of competent and specialized bodies in the reporting process.

The Committee considers that the process of preparing a report offers an important opportunity for conducting a comprehensive review of the various measures undertaken to harmonize national law and policy with the Convention and that the process should encourage and facilitate popular participation and public scrutiny of government policies. This approach is supported by the duty in article 44, paragraph 6, to make the State party report widely available to the public.

The reporting guidelines set out the various provisions of the Convention to be dealt with under each heading. It is a source of criticism that information on the rights of children with disabilities is required only under article 23 in section 6 on basic health and welfare.¹⁷ This encourages a narrow, minimalist approach to State party reporting on the rights of children with disabilities, as the only issues raised are those covered by the limited provisions of the article. Thus, States parties are not encouraged to report on the implementation of general Convention provisions on behalf of disabled children or the enforcement of rights such as those highlighted above, particularly protection from abuse, the right to education and the right to life, survival and development. As a result, Governments submit information only on the narrow field of health care and on needs relating to impairment instead of addressing the wider context of securing for children with disabilities the whole range of rights to which they are equally entitled under the Convention.

8.3.3 Guidelines for the preparation of periodic reports

In October 1996 the Committee on the Rights of the Child adopted its general guidelines regarding the form and contents of periodic reports to be submitted by States parties under article 44, paragraph 1(b), of the Convention¹⁸ to assist States parties in submitting their second and subsequent periodic reports under the Convention. In a clear attempt to encourage them to provide higher-quality and more appropriate and relevant information, the Committee describes in far greater detail what is required of States parties for the reporting process to be effective. Thus, although the guidelines maintain the Committee's thematic grouping of Convention provisions, they state far more explicitly exactly what kind of information is required

¹⁷ Lansdown, *It's Our World Too!*, p 19.

¹⁸ CRC/C/58.

under each heading. Under section 6 on basic health and welfare, for example, States parties are required to describe measures taken under article 23 to ensure, for children with disabilities:

- The child's enjoyment of a full and decent life, in conditions which ensure the child's dignity and self-reliance;
- The child's enjoyment of his or her rights without discrimination of any kind and the prevention and elimination of discriminatory attitudes against him or her;
- The promotion of the child's active participation in the community;
- The child's effective access to education, training, health care and rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development;
- The consideration given to the inclusion of disabled children together with children without disabilities in institutions, services and facilities, including within the education system;
- The child's right to special care and the steps taken to ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance appropriate to the child's condition and to the circumstances of the parents or others caring for the child;
- That, whenever possible, assistance is provided free of charge, taking into account the financial resources of the parents or others caring for the child;
- The measures taken to ensure an effective evaluation of the situation of disabled children, including the development of a system of identification and tracking of disabled children, the establishment of any appropriate monitoring mechanism, the assessment of progress and of difficulties encountered, as well as any targets set for the future;
- The measures taken to ensure adequate training, including specialized training, for those responsible for the care of disabled children, including at the family and community levels and within relevant institutions;
- The measures taken to promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of the medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services. An indication should be given of the measures taken with the aim of enabling States Parties to the Convention to improve their capabilities and skills and to widen their experience in these areas, and the consideration given to the particular needs of developing countries;
- The children concerned, including by type of disability, the coverage of the assistance provided, programmes and services made available, including in the fields of education, training, care, rehabilitation, employment and recreation, the financial and other resources allocated, and other relevant information, disaggregated inter alia by gender, age, rural/urban area, and social and ethnic origin.

These specific requests for information and statistical data make it far more difficult for States parties to avoid reporting on areas where little if any progress has been made in implementing the Convention with respect to disabled children. They should serve to enhance the quality of the State party's reporting and the subsequent dialogue with the Committee.

In addition to providing the above specific information to the Committee, States parties preparing periodic reports are also required to describe measures adopted in response to the Committee's concerns and recommendations regarding the previous report, as set forth in its concluding observations. Thus, States parties must indicate what consideration they have given to

- The areas of concern identified by the Committee, as well as difficulties which may have affected the realization of such suggestions and recommendations;
- The measures adopted as a follow-up to the suggestions and recommendations addressed by the Committee to the State party upon examination of its previous report. Steps taken to implement should be identified in relation to each suggestion and recommendation and all relevant action taken should be specified including in relation to legislation, policy, mechanisms, structures and allocation of resources;
- The difficulties which may have affected the realization of such suggestions and recommendations;
- The steps taken to widely disseminate the previous report, as well as the concluding observations adopted by the Committee.

In addition to requiring more detailed information from States parties in their periodic reports, the Committee thus also emphasizes in the guidelines the ongoing nature of States parties' commitment to implement and report on the implementation of their Convention obligations.

8.3.4 The role of specialized agencies and NGOs in the monitoring process

Both United Nations specialized agencies and NGOs with an interest or expertise in children's rights have been assigned a formal role in the reporting process under the Convention. Bodies such as the Office of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the International Labour Organization (ILO), the Office of the High Commissioner for Human Rights (OHCHR), the World Health Organization (WHO) and, in particular, UNICEF play a vital role in the reporting process, undertaking examinations of the implementation of the Convention in areas falling within their remit. They provide the Committee with statistical data on the country concerned and, where appropriate, evaluate the need for technical advice or assistance. UNICEF's history of working on children's issues means that it is a particularly important source of knowledge, statistics and expertise in this area and WHO also acts as an invaluable source of information on health care and related issues. Both are thus extremely important participants in the process from the standpoint of disability.

In view of the prominent role that non-governmental organizations played in the drafting of the Convention, the Committee encourages their active participation at all stages of the reporting process. In particular, the experts seek relevant and reliable information from NGOs on areas in which the government report fails to provide sufficient information or provides information that may be misleading or incorrect.¹⁹

¹⁹ See *A Guide for Non-Governmental Organizations Reporting to the Committee on the Rights of the Child* (NGO Group for the Convention on the Rights of the Child, 1994).

Many national NGOs submit parallel reports either alone or as members of an umbrella group representing several other bodies interested in children's rights. This is an enormously valuable source of information to the Committee and considerably enhances the quality and effectiveness of the reporting process.²⁰

8.3.5 The civil society perspective: the NGO Group for the Convention on the Rights of the Child

Following the adoption of the Convention by the General Assembly, the NGOs that had taken an active interest in the drafting process created a coalition to work together to facilitate its implementation. This coalition of over 50 international NGOs, all of which have a constituency in at least three countries, is called the NGO Group for the Convention on the Rights of the Child.

It has had an unprecedented impact on the effectiveness of the Convention's reporting mechanism at the international level and on the organization of children's rights coalitions at the national level.²¹ Its core body is the Liaison Unit which supports the participation of NGOs, particularly national coalitions, in the reporting process to the Committee on the Rights of the Child and generally aims to strengthen links between the NGO community and the Committee. The Unit also monitors the existence and work of national child right coalitions worldwide and encourages and helps to establish such coalitions. It provides them with technical support in effectively promoting and monitoring the implementation of the Convention. To these ends, the Liaison Unit:

- **Assists NGOs in participating in the meetings of the Committee's pre-sessional working group.** To this end, the NGO Group Liaison Unit revised its *Guide for Non-Governmental Organizations Reporting to the United Nations Committee on the Rights of the Child* in 1998. This publication now includes vital information on how to prepare a report that will meet the Committee's need to maximize the impact of the reporting process and how to approach the Committee's pre-sessional working group.²² The Group also endeavours to fill the gap when national NGOs are not in a position to participate in the reporting process, attempting to gather or submit information to the Committee on their behalf via its members.
- **Provides regular information to keep NGOs/coalitions in over 90 countries informed about and involved in key international events and developments related to children's rights.** For example, the NGO Group

²⁰ See Ursula Kilkelly, "The UN Committee on the Rights of the Child – an evaluation in the light of recent UK Experience", *Child and Family Law Quarterly* vol. 8:2 (1996), pp. 105-120, and Ursula Kilkelly, "In the best interests of the Child? An evaluation of Ireland's performance before the UN Committee on the Rights of the Child" *Irish Law Times*, vol. 19 (1998), pp. 293-299.

²¹ See Denise Allen, *Networking in the Child Rights Community: NGO Group for the Convention on the Rights of the Child*, www.crin.org.

²² *Guide for Non-Governmental Organizations Reporting* (revised edition, 1998).

prepared advice for national coalitions and NGOs seeking to contribute to the United Nations General Assembly Special Session on Children's Rights.²³

- **Creates tools and guides for NGOs/coalitions for advocacy and monitoring:** The NGO Group seeks to highlight examples of good practice in NGO action to facilitate implementation of the Convention. Examples include its recent survey of national child rights coalitions regarding implementation of the Committee's concluding observations at country level²⁴ and its review of national NGO coalitions' regional reports.²⁵
- **Provides training to NGO representatives in child rights advocacy and networking.**

The NGO Group can be contacted by e-mail (dc-ngo.group@pingnet.ch), telephone (+ 41 22 740 4730) or fax (+ 41 22 740 1145). Its address is: c/o Defence for Children International, P.O. Box 88, 1211 Geneva 20, Switzerland. Its web site is hosted by the Children's Rights International Network (www.crin.org) which is an invaluable source of information for NGOs interested in implementation of the United Nations Convention through the reporting process and otherwise. In particular, it contains links to numerous shadow or alternative reports submitted to the Committee, providing useful comparative and illustrative material and oral submissions to the Committee's pre-session hearing.

8.3.6 Civil society and disability: Rights for Disabled Children (RDC)

Rights for Disabled Children (RDC) is a working group consisting of international organizations such as Disabled People's International and the Save the Children Alliance, chaired by the United Nations Special Rapporteur on disability (in his personal capacity) and attended by a member of the Committee on the Rights of the Child. It is funded by the Swedish International Development Association.

One of the specific objectives of the group, which was set up after the Committee's day of general discussion on the rights of children with disabilities in 1997, is to work with the Committee on the Rights of the Child on issues relating to disabled children. To this end, RDC has been involved in producing written and oral evidence for the Committee's pre-session hearings. This work is now in its second year and suggests that the Committee is beginning to understand the implications for disabled children and to question States parties more appropriately on their measures to implement the Convention in that area.

²³ See NGO Group for the Convention on the Rights of the Child, *A Checklist for National Child Rights Coalitions*, 1 January 2001, and *National Coalitions and the Special Session*, 1 January 2001, both at www.crin.org/resources.

²⁴ NGO Group for the Convention on the Rights of the Child, *National Level Implementation of Treaty Body Recommendations*, www.crin.org/resources.

²⁵ NGO Group for the Convention on the Rights of the Child, *Report on the Review of National NGO Coalitions' Regional Reports*, 1 January 2000, www.crin.org/resources.

8.3.7 Process: the Committee's pre-sessional working group

One of the Committee's innovations was the introduction of a pre-sessional hearing at which a preliminary examination of the information available to the Committee on States parties' implementation of the Convention is conducted. As part of this process, the Committee permits NGOs and other interested individuals to present oral and written submissions on their concerns regarding implementation.

The pre-sessional working group thus affords NGOs the opportunity to meet directly with the Committee, to highlight specific concerns regarding children's situation and to draw attention to inadequacies or inaccuracies in the State party's report. This discussion forms the basis for the Committee's list of issues,²⁶ a list of requests for additional details, up-to-date information and clarifications from the State party on matters arising from its report or the material submitted by NGOs.²⁷ The list is forwarded to the Government in two sections: the first demands further statistical information to be submitted in writing prior to the formal hearing and the second provides a forewarning of the type of issues that the Committee is likely to address at the formal consideration of the State party's report. On a practical level, this written and preliminary part of the process is important because it allows all the parties to prepare for the formal consideration of the State party's report and it can form a useful basis for discussion at the public hearing.

8.3.8 Process: the formal hearing

The formal consideration of the State party's report takes place during two public meetings, at which the Committee and the delegation sent to Geneva by the relevant State party engage in dialogue.²⁸ However, unlike the Human Rights Committee, which allows the government delegation time to prepare its answers to issues raised, the Committee on the Rights of the Child requires the delegation to reply almost immediately to the questions it raises.

Following the conclusion of the debate, the Committee issues concluding observations in which it acknowledges positive aspects of implementation, draws attention to areas of concern and suggests appropriate action to enhance the enjoyment of children's rights as set out in the Convention.²⁹ It encourages the Government to publicize and publish this documentation and to make it the focus of both parliamentary and national debate following the conclusion of the process.

²⁶ For example, NGOs such as Rights for Disabled Children suggest to the Committee the form that questions might take.

²⁷ The authority for this is derived from article 44, paragraph 4, which states that the Committee may request from States parties further information relevant to the implementation of the Convention.

²⁸ For a review of Ireland's performance before the Human Rights Committee, see Michael O'Flaherty, "Implementation of the International Covenant on Civil and Political Rights - Ireland before the Human Rights Committee", *Irish Law Times*, October 1993, pp. 225- 233.

²⁹ The Committee derives this authority from article 45(d) of the Convention.

8.3.9 Process: the Committee's overall approach

Given the Committee's lack of authority to impose sanctions for failure to comply with the Convention, it is significant that its approach to monitoring compliance is non-adversarial. States parties are strongly encouraged to undertake a critical examination of their efforts and to identify their own failings in respect of implementation of the Convention. In addition, the Committee's working practices are characterized by recommendations and offers of advice and technical assistance, rather than damning indictments of law and practice. This is consistent with the aim of encouraging a holistic and comprehensive approach to implementation.³⁰ Understandably, this approach cannot be effective without the active and honest participation of the State party throughout the reporting process. Also indispensable is the role played by NGOs from the reporting State, which can act as a valuable source of independent and reliable information during the process.³¹ The following section contains an analysis, on a case-study basis, of the activities of these actors in the Convention's reporting process.

8.4 Case studies on the current operation of the CRC in the context of children with disabilities

8.4.1 Introduction to the case studies

The Committee on the Rights of the Child held its twenty-eighth session from 24 September to 12 October 2001. During the session it examined ten State party reports from Cameroon, Cape Verde, Mauritania, Gambia, Oman, Kenya, Qatar, Paraguay, Portugal and Uzbekistan.

This section analyses the reporting process in five of these cases in an attempt to indicate, by means of example, the kind of information and detail included in State party reports on the rights of children with disabilities. Attention is thus focused on the State party's report and the Committee's comments relating to non-discrimination under article 2 of the Convention and children with disabilities under article 23.

(a) Cameroon – initial report (2000)

Cameroon's initial report to the Committee, which had been due in 1995, was published in 2000. It stated in the section on non-discrimination that measures had been taken to ensure disabled children's access to educational, medical and social welfare assistance.³² It also reported a limited number of developments relating to the rights of children with disabilities, their participation in sport and their access to

³⁰ For criticism of this approach, see K. McSweeney, "The potential for enforcement of the United Nations Convention on the Rights of the Child: the need to improve the information base", *Boston College International and Comparative Law Review*, vol. 16 (1993), p. 467.

³¹ On the reporting process see Kilkelly, "The UN Committee on the Rights of the Child", *Child and Family Law Quarterly*.

³² CRC/C/28/Add.16, para. 27.

health care and other services provided by non-State bodies.³³ In conclusion, however, the report noted with honesty that:

these activities are constrained by scarce public resources, which make it difficult to address the manifold problems facing disabled children, and by the qualitative and quantitative inadequacies of specialized institutions and personnel.³⁴

The list of issues submitted to Cameroon contained a request for detailed statistics with regard to children with disabilities on:

- (a) The number and proportion of children with disabilities;
- (b) The number of children with disabilities either taken care of at home or living in institutions;
- (c) The number of children with disabilities being enrolled in regular education and how many benefit from the special education system. In addition, please indicate the number of schools and teachers involved in the inclusive policy with regard to children with disabilities.³⁵

The Committee also informed the State party that its delegation should come to the formal hearing prepared to discuss policies and programmes designed to ensure non-discrimination against children, especially children with disabilities.

During the discussion, the delegation from Cameroon told the Committee that, although no statistics were currently available on children with disabilities, the next general population census, which would take place in 2002, would include some disaggregated information about that group. However, the delegation went on to say that disabled children were entitled to the same rights as any other children, although in practice there were many problems. Moreover, the national education strategy had not taken into account the special educational needs of disabled children, although a document was being prepared for the Ministry of National Education to address the issue.³⁶

Following this discussion, the Committee expressed concern in its concluding observations about the impact of the country's social and economic conditions on the rights of children generally.³⁷ With regard to discrimination, it noted with concern the disparities in the enjoyment of rights experienced by children belonging to the most vulnerable groups, including children with disabilities, and recommended that greater efforts be made to ensure non-discrimination in respect of the enjoyment of the rights of all children. The Committee expressed concern at the lack of statistical data on children with disabilities in the State party, at the situation of children with physical and mental disabilities and, in particular, at the limited specialized health care, education and employment possibilities available for them. Moreover, it was concerned that poor health conditions and poverty were leading to an increase in the

³³ Ibid., paras. 127-133.

³⁴ Ibid., para. 133.

³⁵ CRC/C/Q/CAME/1.

³⁶ Summary record of the 738th meeting (CRC/C/SR.738), para. 17.

³⁷ CRC/C/15/Add. 164.

number of children with disabilities. In order to address these concerns, the Committee recommended that Cameroon:

- (a) Ensure the use of adequate and comprehensive data in the development of policies and programmes for children with disabilities;
- (b) Review the situation of these children in terms of their access to suitable health care, education services and employment opportunities;
- (c) Take note of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (General Assembly resolution 48/96) and the Committee's recommendations adopted at its day of general discussion on the rights of children with disabilities (see CRC/C/69);
- (d) Allocate adequate resources to strengthen services for children with disabilities, to support their families and for training of professionals in the field;
- (e) Strengthen policies and programmes of inclusion in regular education, train teachers and make schools accessible;
- (f) Carry out genetic and other studies to assess the causes of disabilities in the State party;
- (g) Sensitize the population to the human rights of children with disabilities;
- (h) Seek assistance from, inter alia, UNICEF and WHO.³⁸

(b) *Cape Verde - initial report (1999)*

The initial report of Cape Verde was due for submission in 1994 but was not received by the Committee until November 1999.³⁹ Its section on discrimination notes that the Constitution prohibits discrimination and then states confidently that no discrimination is practised in private or public institutions.⁴⁰ The information provided with regard to article 23 is equally brief and legalistic as it highlights only those provisions of the Constitution which offer special protection to children with disabilities and gives no details of other laws, policies or practices that affect implementation of the Convention in that area.⁴¹

The Committee's list of issues requested further information on the treatment of children with disabilities in terms of ensuring access to medical and health services (including access to public buildings) and inclusive education.⁴² During the formal hearing, the delegation reported that the Government was discussing with NGOs and international organizations the development of a specific plan of action for children with disabilities. The overwhelming majority of disabled children were in mainstream schools because resources were lacking for special educational facilities and it was acknowledged that more attention must be given to assisting such children. The delegation reported plans to set up a core of specialized teachers to provide education for the disabled at regular schools and admitted that some 500 disabled children did not attend school and were given educational services in the home or through community efforts. These services were partially subsidized by the Government.

³⁸ Ibid, para. 51.

³⁹ CRC/C/11/Add. 23).

⁴⁰ Ibid., paras. 67-68.

⁴¹ Ibid., paras. 133-135.

⁴² CRC/C/Q/CAP/1.

Overall, the delegation conceded that the national legislation needed to be brought into line with the provisions of the Convention, in particular by prohibiting discrimination against disabled children.⁴³

This was followed up by the Committee, which expressed concern in its concluding observations that the Constitution did not include provisions prohibiting discrimination against children with disabilities and recommended that the Constitution and other relevant legislation prohibit discrimination on all grounds covered by article 2 of the Convention, including, in particular, discrimination on the basis of disability. It expressed concern that the substantive rights of children with disabilities were not fully respected and that available specialized assistance, including economic assistance, was insufficient. In addition, it was concerned at the absence of public schools or trained teachers for children with disabilities in need of special facilities. In the light of these concerns, it recommended that Cape Verde:

- (a) Make urgent efforts to improve respect for the rights of children with disabilities, including the rights to non-discrimination, family life, an adequate standard of living, health care, education and leisure;
- (b) Continue to provide and encourage access to the regular education system for children with disabilities who are able to participate in this system;
- (c) Ensure that, where necessary, specialized educational and health assistance are made available to children with disabilities in need of such assistance;
- (d) Ensure the provision of specialized services for children with disabilities making a transition to the regular education system;
- (e) Provide additional assistance to families caring for children with disabilities;
- (f) Develop and implement information campaigns targeting, among others, parents, teachers, care givers and children, on the rights of children with disabilities, including the right to equal treatment;
- (g) Seek technical assistance from UNICEF and WHO.⁴⁴

(c) *The Gambia – initial report (1999)*

The initial report of the Gambia was due for submission to the Committee in 1992 but was not received until November 1999 and failed to follow the Committee's guidelines.⁴⁵ On article 2, the report highlights the constitutional provision on non-discrimination, which does not include discrimination on the ground of disability. It goes on to mention frankly the legislative exceptions to this principle which, according to the report, conflict with article 2 of the Convention. However, nothing is said about the failure to mention discrimination on the ground of disability.⁴⁶ The section on article 23 paints an overwhelmingly positive picture of the rights protection enjoyed by children with disabilities in the Gambia where their inalienable rights to a full life and other opportunities are enjoyed and the corresponding "infrastructure and legislative and administrative support are already in place".⁴⁷ While the report states

⁴³ Summary record of the 746th meeting (CRC/C/SR.746), paras. 6-7.

⁴⁴ CRC/C/15/Add. 168.

⁴⁵ CRC/C/3/Add. 61.

⁴⁶ Ibid, paras. 69-76.

⁴⁷ Ibid., para. 113.

that "cultural stigmas and inadequate institutional support for the disabled in the traditional social system relegated most disabled adults to the undesirable habit of begging", it notes in a more positive light that "growing social awareness of the abilities of and professional care for the disabled is rapidly transforming the opportunities for disabled children in the Gambia." Mention is made of UNICEF cooperation in the conduct of a national disability survey.⁴⁸

In its very brief list of issues, the Committee requested detailed information from the Gambia on the budgetary allocation for children with disabilities.⁴⁹ As little attention seems to have been given to issues of disability in the discussions between the Committee and the delegation,⁵⁰ the Committee's focused in its concluding observations on discrimination against children with disabilities, which it noted was not prohibited under the Constitution.⁵¹ It was also concerned about:

- The inadequate legal protection and the insufficient facilities and services for children with disabilities;
- The limited number of trained teachers available to work with children with disabilities;
- The insufficient efforts made to facilitate their inclusion in the educational system and generally within society;
- The inadequate resources allocated to special education programmes for children with disabilities.

In the light of its day of general discussion on the rights of children with disabilities and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the Committee recommended that the Gambia:

- (a) Take effective measures to collect adequate statistical data on children with disabilities and to ensure the use of such data in the development of policies and programmes for these children;
- (b) Reinforce its efforts to develop early detection programmes to prevent disabilities;
- (c) Implement alternatives to the institutionalization of children with disabilities;
- (d) Establish special education programmes for them and, where feasible, integrate them into mainstream schools and public life;
- (e) Undertake awareness-raising campaigns to sensitize the public about the rights and special needs of children with disabilities as well as children with mental health concerns;
- (f) Increase resources, both financial and human, allocated to special education and enhance the support given to families of children with disabilities; and
- (g) Seek technical cooperation for the training of professional staff, including teachers, working with and for children with disabilities from, among others, WHO and UNESCO.⁵²

⁴⁸ Ibid., paras. 117-118.

⁴⁹ CRC/C/Q/GAM/1.

⁵⁰ Summary record of the 740th meeting (CRC/C/SR.740).

⁵¹ CRC/C/15/Add. 165, paras. 25-26.

⁵² Ibid., paras. 50-51.

(e) *Portugal - second periodic report (1998)*

The second periodic report of Portugal was received by the Committee in October 1998.⁵³ Despite the specific reporting guidelines, the report does not highlight any problems in relation to discrimination against children with disabilities.⁵⁴ Its section on the rights of children with disabilities is lengthy and detailed, however, and provides considerable statistical data as well as information on recent legislative and other initiatives addressing the disabled child's access to inclusive education and other services.⁵⁵

This data notwithstanding, the Committee requested further statistics in its list of issues, particularly disaggregated data (by gender, age, if possible by minority groups, urban or rural areas) covering the period 1998-2000 on the:

- (a) Number of children with disabilities;
- (b) Number of children with disabilities living at home and in institutions;
- (c) Number of children with disabilities enrolled in regular education or special education systems;
- (d) Budget allocation in favour of children with disabilities.

Portugal was also asked to give further consideration in advance of the formal hearing to the policies designed to counter discrimination against children with disabilities.⁵⁶

At the formal hearing the Committee expressed concern regarding the discrepancies in the statistical data on children with disabilities and urged the delegation to look into them.⁵⁷ On a general level, the delegation expressed considerable confidence that access to education and health services was afforded without discrimination.

Nevertheless, the Committee's concluding observations make no reference to children with disabilities in the context of the principle of non-discrimination.⁵⁸ On the implementation of article 23, however, the Committee welcomes the State party's emphasis on the integration of children with disabilities into mainstream education but expresses concern that resources for the special education of children with disabilities are unevenly distributed across the country, with a particular concentration in Lisbon, limiting the access of some children to these facilities. Consequently, it recommends that Portugal:

- (a) Continue and strengthen its efforts to ensure the integration of children with disabilities into regular schools;

⁵³ CRC/C/65/Add. 11.

⁵⁴ Ibid., paras. 54-80.

⁵⁵ Ibid., paras. 217-268.

⁵⁶ CRC/C/Q/POR/2.

⁵⁷ Summary record of the 732nd meeting (CRC/C/SR.732), para. 51.

⁵⁸ CRC/C/ 5/Add.162.

(b) Review the distribution of resources for the special education of children with disabilities, with a view to ensuring that all children and their families in need of such services have easy access to them.⁵⁹

(d) *Qatar – initial report (1999)*

The initial report of Qatar was due in 1997 and received by the Committee in 1999.⁶⁰ On discrimination, the report states confidently that children enjoy the rights set out in the Convention without discrimination of any kind. Legislation does not permit such discrimination and there are no complaints on record alleging discrimination on any ground.⁶¹ Under article 23, the report states that children with disabilities receive appropriate care and assistance from a range of public and private organizations.⁶² An exclusively positive account of how these bodies meet the education, health and other needs of disabled children is given.

In its list of issues the Committee requested statistical data on children with disabilities, asking the Government, in particular, to specify the number of children with disabilities, disaggregated by sex and age:

- (a) Living with their families;
- (b) In institutions;
- (c) Attending regular schools; and
- (d) Attending special schools.

Qatar was also advised to come to the formal hearing prepared to discuss issues relevant to children with disabilities, such as adequate access to services, public awareness campaigns to combat negative attitudes, support for families and steps for inclusion in regular schools.⁶³

The efforts made to implement the rights of children with disabilities were discussed during the formal hearing and the delegation conceded, in response to questions from the Committee, that the level of care provided for disabled children could be improved. Both governmental and non-governmental organizations were working to improve the situation. With regard to education, the delegation stated that the Government was facing resistance from some parents, who refused to send their children to schools with disabled children. Support from United States and Belgian experts in that area was acknowledged.⁶⁴

Despite other extensive remarks concerning non-discrimination generally, the Committee's concluding observations disappointingly failed to highlight any inadequacies or make any recommendations regarding the right of children with disabilities to enjoy their rights without discrimination.⁶⁵ The Committee failed to

⁵⁹ Ibid., paras. 36-37.

⁶⁰ CRC/C/51/Add. 5.

⁶¹ Ibid., para. 22.

⁶² Ibid., para. 100.

⁶³ CRC/C/Q/QAT/1.

⁶⁴ Summary record of the 734th meeting (CRC/C/SR.734), para. 37.

⁶⁵ CRC/C/15/Add. 163 6, paras. 30-34.

note any specific area of concern relating to the implementation of article 23 but welcomed the establishment of the National Committee for Persons with Special Needs, the drafting of the Persons with Special Needs Bill and the State's efforts at awareness-raising and inclusion. However, it gave considerable attention to children with disabilities in the recommendations, urging the State party to:

- (a) Review existing policies and practice in relation to children with disabilities, including draft legislation, taking due regard of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (General Assembly resolution 48/96) and of the Committee's recommendations adopted at its day of general discussion on "Children with Disabilities" (see CRC/C/69);
- (b) Continue to involve children with disabilities and their families in the development of surveys and policy review;
- (c) Undertake greater efforts to make available the necessary professional and financial resources;
- (d) Undertake greater efforts to promote and expand community-based rehabilitation programmes, including parent support groups, and inclusive education of children with all forms of disability; and
- (e) Seek assistance from, among others, UNICEF and WHO.

8.4.2 Conclusions to be drawn from the case studies

It is apparent from this random selection of initial and periodic reports that, in general, States parties could take their obligations with respect to children with disabilities more seriously. There is a lack of specific statistical data on children with disabilities and inadequate detail on the extent to which these children enjoy their rights in practice. Not all States parties adhere strictly to either the letter or the spirit of the Committee's reporting guidelines, which require them to identify problems and barriers to implementation.

On the other hand, it is apparent from the Committee's consideration of these reports that States parties' failure to provide the experts with comprehensive and honest data does not preclude the reporting process from having a positive effect. In particular, it is clear that the Committee does not adopt a merely formulaic approach to reporting obligations but rather considers each report on its merits. Thus, although there is an inevitable arbitrariness as to whether the subject of disability is discussed owing to the severe time constraints at the formal hearings, the Committee nonetheless attempts to redress this in its concluding observations. Moreover, despite the fact that some State party reports contain scant detail on children with disabilities, this does not prevent the Committee from making country-specific recommendations in its concluding observations.

Similarly, an overwhelmingly positive State party report in this area does not exempt the State from the Committee's criticism. Nor is such a report always followed up by a similar display of arrogance by the government delegation before the Committee. The Committee uses the list of issues to flag its concerns and puts the State party on notice in this regard. It is clear from the above data that the Committee's concerns are country-specific and not general in nature and this is a factor of major importance in maximizing the effectiveness of the reporting mechanism under the Convention.

It is difficult to identify which national non-governmental organizations, if any, were involved in providing the Committee with information on implementation in the cases of Cameroon, Cape Verde, the Gambia, Qatar and Portugal discussed above. It is apparent, however, that UNICEF and WHO play a particularly valuable role, both by providing statistical and other data to the Committee during the reporting process and by providing technical assistance to States parties in implementation. Moreover, regardless of NGO involvement in reporting, the Committee consistently stresses to government delegations the importance of cooperating with NGOs at the national level and the vital role that they play in raising awareness of children's rights and providing specific expertise and assistance to States parties in their efforts to implement the Convention.

Overall, it is apparent that the Committee is operating well within its severe resource constraints. It makes detailed practical recommendations (such as the need to seek technical assistance from UNESCO and UNICEF) alongside recommendations of principle. It is apparent, however, that the issue of disability is not being highlighted consistently as a non-discrimination issue and, given the fundamental nature of this principle, the Committee's failure to do so must be identified as a flaw in its approach.

8.5 The increasing prominence of the disability perspective in the CRC Committee

8.5.1 Observations of the CRC Committee in 1996

In 1996 the Sub-Commission on Prevention of Discrimination and Protection of Minorities (a subsidiary body of the Commission on Human Rights which has since been renamed the Sub-Commission on the Promotion and Protection of Human Rights) requested the Secretary-General to report on coordination endeavours affecting persons with disabilities.⁶⁶ The report included information received by the Committee on the Rights of the Child on its activities in the area. The Committee reported that it had examined the situation of disabled children in the light of article 23 of the Convention, focusing on the rights of mentally and physically disabled children, with a view to ensuring their active participation in the community and respect for their dignity and the promotion of their self-reliance. The Committee further stated that it was taking into account the general principles of the Convention, including article 2 (non-discrimination), article 3 (best interests of the child) and article 4. In this regard, it expressed the following concerns:

- Some societies are not sufficiently sensitive to the needs and situation of disabled children, in the light of article 2 of the Convention. The Committee was struck by the widespread discriminatory attitudes towards those children and recommended that strategies and educational programmes, along with the adequate dissemination of information, should be undertaken to avoid certain prejudices which affect disabled children negatively
- Some disabled children do not have adequate access to health and social care services and in many countries the number of disabled children enrolled in schools is low, which might reflect an insufficient attention to their specific needs. In this regard, it recommended that they should be offered more protection, including the possibility, through education, of integrating properly into

⁶⁶ Human rights and disability (E/CN.4/Sub.2/1996/27).

society and participating actively in family life. Efforts for the early detection of the incidence of handicap should also be made.

- Budgetary reductions have also affected disabled children who are particularly disadvantaged in their access to adequate health and educational facilities. The Committee therefore urged countries to take all necessary steps to minimize the negative impact of structural adjustment policies on the situation of disabled children. The Committee recognized, in the light of article 4, the priority of allocating the maximum extent of available resources to protect these children

It also noted that international assistance and the exchange of appropriate information were necessary to address more effectively the challenge of improving the situation of disabled children in conformity with article 23, paragraph 4, of the Convention.

It is apparent from the above case studies that these concerns are expressed throughout the Committee's consideration of State party reports and that they remain a source of valid concern regarding implementation of the rights of children with disabilities.

8.5.2 The relevance of general discussion days

In line with its view that the promotion of public debate is more fruitful than condemning the culpable behaviour of individual States, the Committee has developed the practice of holding one-day general discussions before each public session or at least on a biannual basis. Such discussions, in which United Nations bodies, NGOs and interested individuals and experts are invited to participate, address areas of children's rights of particular concern. So far the Committee has hosted general discussion days on the following subjects:

1. Children in armed conflict (1992)
2. Economic exploitation (1993)
3. Role of the family (1994)
4. The girl child (1995)
5. Juvenile justice (1995)
6. The child and the media (1996)
7. Children with disabilities (1997)
8. HIV/AIDS (1998)
9. Tenth anniversary commemorative meeting: general measures of implementation (1999)
10. State violence against children (2000)
11. Violence against children within the family and in schools

The Committee's aim in introducing the practice of holding general discussion days was to enhance understanding of the content and implications of the Convention on the Rights of the Child in the areas discussed. In the light of the results of several discussion days, it is clear that they are a useful method of promoting the discussion of children's rights under the Convention in a coherent and thematic way. They are also an important way of encouraging participants to share examples of good practice in putting the Convention into practice and effectively using its potential at the

national and international level. It is also instructive for the Committee to hear the concerns of others regarding difficulties in implementing the Convention at the domestic level and regarding the Committee's role of monitoring implementation.

The Committee has developed a practice for general discussion days, which now proceed as follows. First, the Committee introduces the discussion and highlights its concerns regarding the topic and any trends emerging from its consideration of State party reports. The main part of the day is spent listening to the views put forward by the parties present and a rapporteur concludes with a summary of the main points addressed. Most general discussion days lead to the drafting of recommendations, which can be addressed to the Committee itself or concern action to be taken by NGOs or other agencies. The discussion is covered in the Committee's report on the session and in 1999 the Office of the High Commissioner for Human Rights (OHCHR) combined all the Committee's reports on general discussions days in a single document which can be accessed on the OHCHR web site.

8.5.3 The significance of the day of general discussion on the rights of children with disabilities (1997)

The Committee on the Rights of the Child held a day of general discussion on 6 October 1997 on the rights of children with disabilities. It attracted a record attendance of about 100 representatives, including non-governmental organizations such as Disabled People's International, Inclusion International and Save the Children, United Nations bodies such as UNESCO, UNICEF, the World Bank, and the Special Rapporteur of the Commission for Social Development on Disability.⁶⁷ Young people with disabilities also participated and helped to keep the debate focused on challenging the widespread abuse of the fundamental rights of disabled children through the promotion of a process of participation and inclusion.

The following 14 recommendations were made for future action. The Committee should:

1. Promote the Standard Rules on the Equalization of Opportunities for Persons with Disabilities as providing relevant standards for the implementation of the Convention and work with the Special Rapporteur and the Panel of Experts;
2. Commit itself to providing an early general comment on disabled children;
3. Commit itself, during its consideration of the reports of States parties, to highlighting the situation of disabled children and the need for concrete measures to ensure recognition of their rights, including, in particular, the right to life and maximum survival and development and the right to social inclusion and participation, emphasizing that the monitoring of the situation of disabled children in all States must be undertaken to promote the collection of statistics and other information to allow constructive comparisons between regions and States;
4. Underline the need for States actively to challenge attitudes and practices, including infanticide, traditional practices prejudicial to health and

⁶⁷ See the summary records contained in documents CRC/C/SR.418 and CRC/C/SR.419. See also the Report of the Secretary-General to the General Assembly on the status of the Convention on the Rights of the Child, 20 August 1998 (A/53/281).

development, superstition and the perception of disability as a tragedy, which discriminate against disabled children and deny them equal opportunities to rights guaranteed by the Convention;

5. In view of the appalling impact of armed conflict in causing disability of hundreds of thousand of children, encourage the ratification of the Ottawa Convention as a matter of urgency;
6. Underline that persisting laws in many countries affecting disabled children are not compatible with the principles and provisions of the Convention, such as legislation which denies disabled children an equal right to life, survival and development, including, in those States which allow abortion, discriminatory laws on abortion affecting disabled children and discriminatory access to health services, legislation which denies disabled children the right to education and legislation which compulsorily segregates disabled children in separate institutions for care, treatment or education;
7. Work in cooperation with UNESCO, UNICEF and other relevant agencies to ensure that inclusive education is included in the agendas of meetings, conferences and seminars as an integral part of the debate on education;
8. Encourage the development of emancipation research with disabled children on methods of undertaking consultation, involving them in decision-making and giving them greater control over their lives;
9. Promote the dissemination of a system of good practice, backed up by the preparation of training material, such action potentially being undertaken by one of the aid agencies, such as the Swedish Organization of Handicapped - International Aid Foundation or Save the Children in collaboration with some disabled persons' organizations;
10. Encourage Governments to make such training materials available at the community level in appropriate forms for children and disabled people;
11. Work towards the inclusion of the rights and interests of disabled children in the agendas of multilateral and bilateral agencies, development agencies, donor agencies, funding organizations, such as the World Bank and regional banks, and technical cooperation agencies;
12. Encourage research into the provision of statistics and empirical evidence to:
 - (a) Promote awareness of the extent to which the right to life of disabled children is denied;
 - (b) Challenge the widespread existence of superstition, prejudice, social stigma and denial of access to education in relation to disabled children; and
 - (c) Encourage the prominence of the issue in the production and discussion of bio-ethical conventions; encourage relevant agencies to develop programmes which promote alternatives to institutionalization and formulate and promote strategies for deinstitutionalizing children;
13. Encourage all bodies providing information to the Committee during the consideration of the reports of States parties to ensure that their submissions include the perspective of disabled children; and
14. Consider what mechanism to introduce as part of the way forward, such as establishment of a working group to prepare a plan of action.

8.5.4 Follow-up to the Day of general discussion – the establishment and role of the NGO Rights for Disabled Children (RDC)

In view of the various contributions made and the importance of the issues considered at its day of general discussion in 1997, the Committee felt that there was a need to ensure follow-up.

It was decided to set up a working group on the rights of children with disabilities, which would include members of the Committee, representatives of relevant United Nations bodies and agencies, and non-governmental organizations of disabled people, including disabled children, to consider further the various recommendations and elaborate a plan of action to facilitate the concrete implementation of the various proposals.⁶⁸ The aims of the working group would be to:

- (a) Form a working group of key disability and children's rights organizations together with international experts in the field;
- (b) Prepare a plan of action in respect of the recommendations of the Committee on the Rights of the Child;
- (c) Develop a strategy for its implementation and implement the plan.

These aims would be pursued through the following activities:

- (a) Working closely with the Special Rapporteur on Disability of the Commission for Social Development and the panel of experts for the implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities;
- (b) Ensuring that the working group met and obtained the views of local groups of children
- (c) Raising awareness of the situation of children with disabilities through provision of statistical and personal evidence of violations of their human rights and challenging attitudes and practices such as infanticide, traditional practices prejudicial to health and development, superstition, the perception of disability as a tragedy and the segregation of children with disabilities;
- (d) Producing examples of good practices for projects, policies and legislation that uphold the principles and provisions of the Convention, such as legislation which ensures that children with disabilities enjoy the equal right to life, survival and development and which abolish discriminatory laws on abortion and access to health care.

Once funding for the working group was secured from the Swedish International Development Agency (SIDA), it was formally established in 1998 as Rights for Disabled Children (RDC). The organizations involved in RDC are Disabled Peoples' International, Inclusion International, Save the Children Alliance, World Blind Union, and the World Federation of the Deaf. The working group is chaired by Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission for Social Development and is attended by a member of the Committee on the Rights of

⁶⁸ See *Official Records of the General Assembly, Fifty-third Session, Supplement No. 41 (A/53/51)*, para. 1427.

the Child. The work of the group is administered by Disability Awareness in Action in London.

The working group held its first meeting in London on 23 and 24 January 1999. It was chaired by Bengt Lindqvist and attended by Esther Queenie Mokhuane from the Committee on the Rights of the Child, Rachel Hurst from Disabled Peoples' International (also of Disability Awareness in Action – London), Sue Stubbs and Ulrike Persson from International Save the Children Alliance, Kicki Nordstrom from the World Blind Union, Gerison Lansdown from the Children's Rights Office (United Kingdom) and Darryl Cowley, coordinator of the working group. The representatives of the World Federation of the Deaf and Inclusion International were unable to attend.

On behalf of the Committee, Ms. Mokhuane made a statement highlighting the Committee's efforts to promote the rights of children with disabilities. Through its dialogue with and recommendations to States parties, the Committee recommended the enactment of domestic legislation, the implementation of appropriate policies and programmes, and the allocation of adequate resources to guarantee and protect the rights of children with disabilities. The Committee had also urged States parties to take all necessary measures to improve the situation and protect the rights of children in armed conflicts and those affected by landmines.

The primary purpose of the first meeting was to develop a plan of action for the eighteen-month life of the working group, whose main aim was to strengthen and support the work of the Committee on the Rights of the Child in monitoring and promoting the rights of children with disabilities. Accordingly the following programme was agreed:

- (a) To organize a series of regional meetings to which disabled children and young people, and local disability organizations would be invited to present their experiences of respect or lack of respect for their rights, what they would like to see changed and their suggestions for future action. Initially, the Group will seek to organize meetings in Latin America and Africa. Further meetings will be held in Western Europe, Eastern Europe and, eventually, in Asia;
- (b) To collect examples of good practice in promoting the rights of children with disabilities - for example participation, inclusion, deinstitutionalization - for widespread dissemination. To collate data on social outcomes for children - for example the proportion of children with access to education, in mainstream education and supported in the community. The International Save the Children Alliance agreed to undertake this work;
- (c) To explore the possibility for the Committee on the Rights of the Child to adopt a general comment on article 23 of the Convention;
- (d) To hold a hearing in Geneva, and possibly also in New York, at which United Nations agencies and bodies would be invited to present to the Group current and planned work designed to promote the rights of children with disabilities;
- (e) To provide evidence to the pre-sessional working group of the Committee on the Rights of the Child on the situation of children with disabilities in the States parties under discussion;
- (f) To contribute, through the evidence gathered in the regional meetings, to the Children's Summit planned for 2001;

- (g) To contribute to the debate on bioethics from the perspective of the rights of children with disabilities;
- (h) To design a logo and leaflet to promote and explain the role and aims of the working group. It was agreed that the title of the Group would be “Rights of children with disabilities: a working group in consultation with the Committee on the Rights of the Child”.⁶⁹

Rights for Disabled Children (RDC) has begun preliminary work to achieve these objectives, highlighting the abuses and neglect experienced by children with all sorts of disabilities and health difficulties, and compiling and disseminating good practice in challenging those abuses. It has undertaken work in the following two areas:

First, it has begun to play a formal role in the Convention's reporting process by submitting information on the implementation of the rights of disabled of children. In particular, it has just completed its first year of submitting written and oral evidence to the Committee's pre-sessional hearings, which take place three times a year, the oral evidence being given by a disabled person. Initial indications suggests that the Committee is beginning to show a clearer understanding of the implications of the Convention for children with disabilities, although a longer-term analysis is required to confirm the success of this approach. RDC's practical and succinct approach to shadow reporting is effective in highlighting the issues governing the rights of disabled children.

RDC's second achievement has been the publication of *It's our World Too!* a report on the lives of children with disabilities.⁷⁰ Originally intended to be published in advance of the United Nations General Assembly Special Session on Children (due to take place in New York in September 2001 but postponed owing to the terrorist attacks), this excellent report highlights the limitations of the Convention's protection of children with disabilities and details a number of positive initiatives that illustrate effectively how children with different impairments can be empowered and included in mainstream society. The initiatives address the following issues:

- The right to be heard (South Africa, United Kingdom);
- Supporting parents to promote disabled children's rights (Kenya, Malaysia, Zimbabwe);
- Promoting inclusive education (Ghana, India, Mali, Nicaragua).
- Promoting social inclusion (Brazil, India, Mexico, Morocco, Thailand);
- Challenging prejudice and promoting positive attitudes towards disability (Philippines, United States),
- Respecting cultural rights (Cambodia, Zambia);
- Promoting the right to play (Albania, India, Pakistan);
- Implementing structures to respect the rights of disabled children (South Africa, Uganda).

⁶⁹ See *Official Records of the General Assembly, Fifty-fifth Session, Supplement no 41 (A/55/51)*, pp. 300-302.

⁷⁰ See Lansdown, *It's Our World Too!*

The working group's initiatives are important illustrations of the kinds of efforts that can significantly raise awareness of the rights of children with disabilities and exert a positive impact on the work of the Committee on the Rights of the Child. This work is continuing, with particular emphasis on collaboration with the Committee in monitoring State party performance from the standpoint of disabled children and documenting and researching abuses of their rights. The working group relies heavily on the efforts of its members and those that administer and fund its work. It is important to highlight that, while Rights for Disabled Children is chaired by a United Nations Special Rapporteur and attended by a member of the Committee on the Rights of the Child, it is not funded either by the United Nations or by its Member States but by the Swedish International Development Association. Without this funding, the working group would be unable to pursue its initiatives.

8.5.5 Non-governmental organizations: towards a coordinated approach

The significant impact of the work of the NGO Group for the Convention on the Rights of the Child as a general children's rights coalition and of Rights for Disabled Children as a disability-specific working group are highlighted above. It is unfortunate, however, that these bodies do not yet appear to have coordinated or cooperated in their approach to the monitoring process.

While it is clear that these international bodies are both undertaking excellent work and have had a considerable impact on the effectiveness of the Convention's reporting process, it is NGOs at the national level that will ultimately force Governments to bring about change. Thus, it is vital for the consistency and coherence of the process that national NGOs on disability prepare their own reports and take part in the reporting process. It is at the national level that NGOs must raise awareness about States parties' reports and the Committee's concluding observations and undertake advocacy for their implementation. Yet in a study of six countries whose reports were examined by the Committee in 1999, NGOs complained of a lack of opportunity to provide input because Governments had failed to distribute the report to them.⁷¹

Moreover, although NGOs participating in the reporting process were satisfied with the way in which the Committee used their information and found that the questions raised by the Committee reflected their concerns, they complained of a lack of resources for attempting to circulate and press for implementation of the State party report, the summary records of the Committee's meeting with the State party delegation and the Committee's concluding observations.

Thus, despite admirable and important activity at the international level, skills in advocacy and proposing policy are still wanting at the domestic level. As a result, Government in these countries simply do not come under pressure from the non-governmental children's rights community.

⁷¹ Lisa Woll, "The reporting process as a catalyst for domestic review and debate", paper prepared for the Tenth Anniversary of the Convention on the Rights of the Child: Commemorative Meeting: Achievements and Challenges, Palais des Nations, Geneva, 30 September – 12 October 1999. The document can be accessed on the OHCHR web site at www.unhcr.ch

One positive result of the reporting mechanism is that the process of preparing NGO reports is often a useful “organization-strengthening” exercise for the national coalitions, which provides them with a tool for defining their work in children’s rights, understanding weaknesses and setting priorities. For a number of coalitions, concluding observations have served as a guide or framework of reference for their plans, enabling them to focus on essential Convention issues and forming the basis for a coherent lobbying agenda. The extent to which this is encouraged and facilitated by information exchange between international and national NGOs and by the circulation of best practice will determine whether the coalitions can ultimately bring about real change that filters down from the Committee’s recommendations to the way in which disabled children are treated by the State.

Many NGOs in developing countries experience serious difficulties in gathering data on compliance with the Convention’s provisions. While in some countries there may simply be a lack of data inasmuch as initiatives or measures to implement the Convention are scarce, in others government agencies clearly seek to obstruct access to information on the real difficulties and problems that exist. The role of the Committee on the Rights of the Child in exposing both situations is absolutely crucial and can support the efforts of national NGOs to highlight situations of non-compliance and to work towards greater implementation.

8.5.6 Relevant activities of other United Nations bodies

In addition to the Committee on the Rights of the Child, the rights of children with disabilities have also been the subject of discussion and action in other United Nations bodies, particularly the Economic and Social Council, the Commission of Human Rights and the General Assembly itself.

(a) The Economic and Social Council

In 1997 the Economic and Social Council adopted a resolution on children with disabilities in which it highlighted the relevant legal provisions and significant action by United Nations agencies, specialized bodies and non-governmental organizations in the area.⁷² In particular, it drew attention to the fact that disability is not inability and noted the critical importance of taking a positive view of abilities as the basis of planning for persons, especially children, with disabilities. It then stated that the Economic and Social Council:

1. Recognizes the need for special attention to be directed towards children with disabilities and their families or other caretakers;
2. Notes with concern the large numbers of children who have become disabled physically or mentally, or both, as a consequence, inter alia, of poverty, disease, disasters, land mines and all forms of violence;
3. Urges both Governments and the Secretary-General to give full attention to the rights, special needs and welfare of children with disabilities;
4. Invites Governments, concerned United Nations organizations and bodies, including the United Nations Children’s Fund, the United Nations Educational, Scientific and Cultural Organization and the World Health Organization, and non-governmental organizations, especially those of persons with disabilities, to conduct awareness-

⁷² Economic and Social Council resolution 1997/20 of 21 July 1997.

- raising activities, with a view to combating and overcoming discrimination against children with disabilities;
5. Encourages further cooperation among Governments, in coordination, where appropriate, with the United Nations Children's Fund, other relevant United Nations organizations and non-governmental organizations, to nurture the talents and potential of children with disabilities by developing and disseminating appropriate technologies and know-how;
 6. Encourages Governments to include data on children when implementing rule 13 on information and research of the Standard Rules;
 7. Urges Governments to ensure, in accordance with rule 6 of the Standard Rules, that children with disabilities have equal access to education and that their education is an integral part of the educational system and also urges Governments to provide vocational preparatory training appropriate for children with disabilities;
 8. Invites the United Nations Educational, Scientific and Cultural Organization to continue its programme activities aimed at the integration of children and youth with disabilities into mainstream education and to provide appropriate assistance to Governments, at their request, in designing and setting up programmes to encourage the creative, artistic and intellectual potential of children, including those with disabilities;
 9. Calls upon Governments to ensure the participation of children with disabilities in recreational activities and sports;
 10. Emphasizes the right of children with disabilities to the enjoyment of the highest attainable standard of physical and mental health and urges Governments to ensure the provision of equal access to comprehensive health services and the adoption of holistic approaches to the total well-being of all children with disabilities, particularly children at highest risk, including refugee, displaced or migrant children, children living in situations of violence and its immediate aftermath, children living in disaster areas, street children and children in squatter colonies;
 11. Encourages Governments to contribute to the United Nations Voluntary Fund on Disability;
 12. Requests the Special Rapporteur, in monitoring the implementation of the Standard Rules, to pay special attention to the situation of children with disabilities, to pursue close working relations with the Committee on the Rights of the Child in its monitoring role with respect to the Convention on the Rights of the Child and to include in his report to the Commission for Social Development at its thirty-eighth session his findings, views, observations and recommendations on children with disabilities.

(b) Commission on Human Rights

This body has also drawn specific attention to the rights of children with disabilities in its resolutions on the rights of the child. For example, in the resolution adopted at its session in 2000, the Commission called upon States:

- (a) To adopt all necessary measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms by children with disabilities and to develop policy measures and to develop and enforce legislation prohibiting discrimination against children with disabilities;
- (b) To adopt an integrated approach to providing adequate support and appropriate education for children with disabilities and their parents, in a manner which promotes the child's achievement of self-reliance and the fullest possible social integration, individual development and active participation in the community.⁷³

⁷³ Resolution 2000/85 of 28 April 2000, para. 29.

At its 2001 session, the Commission again addressed the rights of children with disabilities and, in the context of non-discrimination, reiterated its call upon States:

to take all necessary measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms by children with disabilities and, where necessary, to develop and enforce legislation against their discrimination to ensure dignity, promote self-reliance and facilitate the child's active participation in the community, including adequate and effective access to education of good quality for children with disabilities and their parents, taking into account the situation of children with disabilities living in poverty.⁷⁴

(c) *United Nations General Assembly*

More recently the General Assembly adopted a resolution on the rights of the child in which it specifically addressed the rights of children with disabilities.⁷⁵ In particular, it encouraged the working group on the rights of children with disabilities to put into practice as soon as possible the recommendation of the day of general discussion and called upon all States:

to take all necessary measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms by children with disabilities, and to develop and enforce legislation against their discrimination so as to ensure dignity, promote self-reliance and facilitate the child's active participation in the community, including effective access to educational and health services.⁷⁶

The resolution also makes important recommendations regarding the implementation of the Convention on the Rights of the Child and, in particular, calls upon States and the Secretary-General to take all necessary measures to enhance the effectiveness and efficiency of the process of examination of State party reports by the Committee on the Rights of the Child.

8.6 Conclusions on the CRC and disability

8.6.1 Conclusions

Although the States parties to the Convention on the Rights of the Child are clearly beginning to realize that children with disabilities enjoy all the rights protected by the Convention, there is still a long way to go. The CRC is unique, however, in explicitly addressing the issue of disability and it therefore has great potential in that area. The day of general discussion on disability has already had a very positive impact.

A considerable amount of good practice is discernible both in the work of bodies such as the NGO Group for the Convention on the Rights of the Child and Rights for Disabled Children and in the approach of the Committee on the Rights of the Child. Organizations such as the Children's Rights Information Network (www.crin.org) and the International Save the Children Alliance also provide extremely useful and productive resources for all those dedicated to pursuing the implementation of the

⁷⁴ Resolution 2001/75 of 25 April 2001, para. 22.

⁷⁵ General Assembly resolution 55/79 of 22 February 2001.

⁷⁶ *Ibid.*, paras. 9-10.

rights of disabled children within the framework of the Convention on the Rights of the Child.

Notwithstanding the many positive initiatives highlighted above, implementation of the following recommendations would further enhance existing protection of the rights of disabled children:

The States parties should report more fully on children with disabilities under the CRC. Moreover, they should do so under all the rights protected and not just under article 23. Every State party should support the formation of domestic coalitions on children's rights, which should include NGOs concerned with the rights of disabled children.

The Committee should prioritize the rights of children with disabilities within the reporting process. It should take a closer look at its working methods and consider ways in which the problems faced by children with disabilities could be more fully integrated into the reporting process. The Committee should give urgent consideration to the drafting of a general comment on children with disabilities under all the relevant rights and not just under article 23. It should also draft a separate but related general comment on article 2 (non-discrimination). The United Nations should increase the Committee's membership so as to allow it to reduce the current backlog of State party reports awaiting consideration. Among other things, this would give the Committee more scope to focus on target groups such as children with disabilities.

Levels of awareness of the relevance of the CRC rights to children with disabilities need to be dramatically raised. Action to that end should be taken not only by disability NGOs but also by “mainstream” children’s rights NGOs. Non-governmental organizations such as the NGO Group for the Convention on the Rights of the Child and RDC need to pursue their efforts to maximize the benefit of the Committee’s reporting process. In particular, they should seek to coordinate their approach so as to integrate disability into the mainstream approach of all NGOs. To that end, they should cooperate in developing guidelines for parallel reporting to the Committee on the Rights of the Child on the rights of children with disabilities.

Chapter 9

Disability and racial discrimination: the International Convention on the Elimination of All Forms of Racial Discrimination (CERD)

Dr Joshua Castellino

9.1 Background to the Convention

The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) was adopted by the United Nations in December 1965 and entered into force in January 1969 once the requisite number of ratifications had been secured. It develops the promise of human rights protection set forth in the Charter of the United Nations in 1945.¹ It is premised on the notion that human rights protection needs to be guaranteed to all, irrespective of considerations based on race. Indeed it has been described as “the international community’s only legal tool in combating racial discrimination which is at one and the same time universal in reach, comprehensive in scope, legally binding in character and equipped with built-in measures of implementation”.²

The Convention was a response, spearheaded by Asian and African States, to mounting international concern in the 1950s and early 1960s over racial discrimination in the context of colonialism and apartheid. But the text of the Convention does not explicitly mention any particular kind of discrimination other than apartheid – and apartheid is covered in international law by a separate treaty.³

In recent times, the relevance of ICERD has been seriously questioned in the context of discussions of race that purport to establish conclusively that race – like disability – is a social construct.⁴ However, while the very existence of “race” may be successfully challenged by abstract analysis, “racial discrimination” certainly exists and in this sense the Convention seeks to put in place a human rights regime that

¹ T. Meron, “The meaning and reach of the International Convention for the Elimination of All Forms of Racial Discrimination”, *American Journal of International Law*, vol.79, No. 2 (April 1985), pp. 283 - 318.

² Statement by the Committee for the Elimination of Racial Discrimination at the World Conference to Combat Racism and Racial Discrimination, *Official Records of the General Assembly, Thirty-third Session, Supplement No. 18 (A/33/18)*, pp. 108 and 109.

³ The International Convention on the Suppression and Punishment of the Crime of Apartheid, 1973.

⁴ S. Hall, “New ethnicities”, *Race, Culture and Difference*, J. Donald and A. Rattansi (eds.) (Sage Publications, 1992) p. 254.

addresses the damage caused by racism. At a second level, the Committee on the Elimination of Racial Discrimination, which was entrusted with monitoring implementation of the Convention, has arguably sought to interpret the principal purpose of the Convention as being protection against discrimination.

There are two basic ways in which the Convention may extend protection to persons with disabilities.

First, in keeping with its fundamental purpose of combating discrimination based on race, it is obviously relevant to people with disabilities who suffer discrimination as members of a racial group or minority, i.e. double discrimination based on race and disability. The overlap between the two grounds of discrimination may not be great but it is nonetheless real and the Convention serves a useful purpose in this context.

Second, on a more theoretical level, if it is accepted that the Convention's primary goal is to create space for difference and to challenge attitudes and practices that use difference as a ground for exclusion or discrimination, it would appear logical to extend the grounds on which it is deemed to be applicable beyond those directly related to the idea of race, such as ethnicity and language, to include, for example, disability. This remains a theoretical possibility only at this juncture.

This chapter considers the scope for addressing issues relating to disability under the Convention. It is divided into four sections. The first examines the implementation mechanism for monitoring States parties' compliance with their obligations under ICERD. Particular attention is given to the Committee's general recommendations with a view to assessing whether it takes a broad view of the purpose of the Convention. The second section seeks to extrapolate from this assessment the direct or potential relevance of the Convention to persons with disabilities.

The third section highlights references to disability in State party reporting to the Committee with a view to demonstrating the context in which issues concerning disability are raised. The idea is to identify material relating to issues of discrimination on the ground of disability that has already come before the Committee. The final section presents a critical analysis of the scope of the Convention and again raises the question of the Convention's pertinence as an instrument for the protection of persons with disabilities.

It takes as its main point of departure the Declaration adopted at the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance held in Durban, South Africa, in September 2001, paragraph 2 of which reads as follows:

2. We recognize that racism, racial discrimination, xenophobia and related intolerance can occur on the grounds of race, colour, descent or national or ethnic origin and that victims can suffer multiple or aggravated forms of discrimination based on other related grounds such as sex, language, religion, political or other opinion, social origin, property, birth or other status⁵.

⁵ Text as finalized on 25 January 2002.

9.2 The Convention enforcement machinery

9.2.1 Committee on the Elimination of Racial Discrimination

The International Convention on the Elimination of All Forms of Racial Discrimination was the first international human rights treaty to establish its own treaty monitoring body.⁶ This model was subsequently followed by the other fundamental human rights treaty instruments such as the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights adopted in 1966, the Convention on the Elimination of All Forms of Discrimination against Women adopted in 1979, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment adopted in 1984 and the Convention on the Rights of the Child adopted in 1989.⁷ The mandate of the ICERD monitoring body, known as the Committee on the Elimination of Racial Discrimination, is contained in article 8 of the Convention:

There shall be established a Committee on the Elimination of Racial Discrimination (hereinafter referred to as the Committee) consisting of eighteen experts of high moral standing and acknowledged impartiality elected by State Parties from among their nationals, who shall serve in their personal capacity ...

The functions of the Committee are fourfold: it reviews State party reports, examines individual or collective complaints, considers inter-State complaints and drafts general recommendations interpreting the terms of the Convention. While these recommendations are not legally binding, they may be considered authoritative since they are based on the collective experience of the Committee.

9.2.2 State party reporting obligations under the Convention

States parties to the Convention are required to submit reports to enable the Committee to assess their compliance with their treaty obligations. The initial report, due within one year of accession, is envisioned as an audit of the State party's position vis-à-vis its obligations. Subsequent periodic reports are due every two years or whenever the Committee so requests. The primary purpose of the reports is to enable the Committee to monitor developments within the State party, especially in terms of legislative, judicial, administrative and other measures.

The reports are carefully examined by the Committee which, in turn, reports annually to the General Assembly, attaching its suggestions or recommendations to the States parties (concluding observations). As the Convention has now been in force for over 30 years, many States parties having already submitted numerous reports so that the Committee has a considerable body of material to draw on.

⁶ See Theo van Boven, "Prevention, early warning and urgent procedures: a new approach by the CERD", *Human Rights from Exclusion to Inclusion: Principles and Practice* (an anthology of the work of Theo van Boven), F. Coomans, C. Flinterman, F. Gruenfeld, I. Westendorp and J. Willems (eds.) (The Hague: Kluwer Law International, 1998), pp.199-217.

⁷ For more information on the treaty monitoring bodies see Alston and Crawford, *The Future of UN Human Rights Treaty Monitoring* (Cambridge: Cambridge University Press, 2000).

However, as many as 424 State party reports are currently overdue, a larger number than is the case for other human rights treaties. This may be partially due to the fact that ICERD has a large number of States parties. One aspect of the monitoring process that offsets to some extent the non-submission of reports is the provision whereby the Committee may examine the application of the Convention in a State party in the absence of a formal report. This also provides States parties with an incentive to submit a report.

9.2.3 *The individual and collective complaint mechanism*

The Convention allows individuals and groups of individuals to lodge complaints. Drawing heavily on the European Convention on Human Rights, article 14, paragraph 1, states:

A State party may at any time declare that it recognises the competence of the Committee to receive and consider communications from individuals or groups of individuals within its jurisdiction claiming to be victims of a violation by that State Party of any of the rights set forth in this Convention....

Complaints are only considered if the State party in question has made a declaration to that effect. The paragraph continues:

No communication shall be received by the Committee if it concerns a State Party which has not made such a declaration.

The issue of disability has not come up in any of the nine cases on which the Committee has issued “opinions” to date.⁸ Its absence from this fledgling mechanism is perhaps not unduly significant but the reporting mechanism could prove more relevant to disability issues in the future if the Convention is seen to be more widely applicable to other forms of discrimination (see below).

9.2.4 *The inter-State mechanism*

The third mechanism available to monitor compliance by States parties is the inter-State mechanism whereby a State party which considers that another State party is violating the Convention can bring the matter to the attention of the Committee. The purpose of this mechanism is twofold.

First, it operates as a collective defence mechanism against violation of the integrity of the treaty by a State party. As such it could be seen as a vital means of preventing any erosion of the values and rights protected by the treaty.

Second, it provides an avenue for complaint that might not exist in the State party itself. Thus, whereas both the reporting mechanism and the individual complaint mechanism require the State party’s express permission, the provisions of the inter-

⁸ The cases on which opinions have been delivered by the Committee are: Communication No. 1/1984, A. Yilmaz Dogan v. The Netherlands; Communication No. 2/1989, Demba Talibe Diop v. France; Communication No. 3/1991, Michel L.N. Narrainen v. Norway; Communication No. 4/1991, L.K. v. The Netherlands; Communication No. 6/1995, Z.U.B.S. v. Australia; Communication No. 8/1996, B.M.S. v. Australia; Communication No. 10/1997, Ziad Ben Ahmed Habassi v. Denmark; Communication No. 16/1999, Kashif Ahmad v. Denmark; Communication No. 17/1999, B.J. v. Denmark (CERD/C/390).

State mechanism seek to empower other States to file complaints against a violator of the Convention.

Despite its potential for combating State excesses in the area of racial discrimination, the inter-State mechanism has not been used in the manner the drafters had envisioned. Its invocation carries high political risks. This is, of course, true not only for ICERD but for all other human rights treaties containing a similar enforcement mechanism.

9.2.5 General recommendations under the Convention

General recommendations are tools for analysis of law or policy. They may be viewed as authoritative readings by the Committee of the provisions contained in the Convention. Moreover, given the dynamic nature of treaties as living instruments that may need to be reinterpreted in order to sustain the spirit that motivated the drafters, they provide an indication of the contemporary scope of the treaty concerned. Nevertheless, they cannot, strictly speaking, be viewed as legally binding.

Some of the general recommendations adopted by the Committee are particularly relevant to this study: General Recommendation XXV (gender-related dimensions of racial discrimination) and General Recommendations VIII, XI, XIV and XXIV (all of which deal with article 1 and the scope of the Convention).

9.3 Relevance of ICERD norms in the context of disability

9.3.1 Specific relevance of ICERD norms in the context of disability

As indicated at the outset of this chapter, two approaches are possible in considering the applicability of the Convention to disability issues.

First, the Convention is directly relevant when people with disabilities happen to belong to a racial group or minority and face discrimination on the grounds of both race and disability. As certain groups are discriminated against because of their race, it is patently clear that disabled members of those racial groups or minorities experience discrimination on account of both their race and their disability. If the Convention mechanism is to combat racism effectively, it will clearly have to take multiple discrimination of this kind into account.

The wording of General Recommendation XXV on gender-related dimensions of racial discrimination, adopted in 2000, usefully illustrates this notion of multiple discrimination based on race and other grounds:

1. The Committee notes that racial discrimination does not always affect women and men equally or in the same way. There are circumstances in which racial discrimination only or primarily affects women, or affects women in a different way, or to a different degree than men. Such racial discrimination will often escape detection if there is no explicit recognition or acknowledgement of the different life experiences of women and men, in areas of both public and private life.
2. Certain forms of racial discrimination may be directed towards women specifically because of their gender, such as sexual violence committed against women members of particular

racial or ethnic groups in detention or during armed conflict; the coerced sterilization of indigenous women, abuse of women workers in the informal sector or domestic workers employed abroad by their employers. Racial discrimination may have consequences that affect primarily only women, such as pregnancy resulting from racial bias-motivated rape; in some societies women victims of such rape may also be ostracized. Women may also be further hindered by a lack of access to remedies and complaint mechanisms for racial discrimination because of gender-related impediments, such as gender bias in the legal system and discrimination against women in private spheres of life.

3. Recognizing that some forms of racial discrimination have a unique and specific impact on women, the Committee will endeavour in its work to take into account gender factors or issues which may be linked with racial discrimination. The Committee believes that its practices in this regard would benefit from developing, in conjunction with the State parties, a more systematic and consistent approach to evaluating and monitoring racial discrimination against women, as well as the disadvantages, obstacles and difficulties women face in the full exercise and enjoyment of their civil, political, economic, social and cultural rights on grounds of race, colour, descent, or national or ethnic origin.

4. Accordingly, the Committee, when examining forms of racial discrimination, intends to enhance its efforts to integrate gender perspectives, incorporate gender analysis, and encourage the use of gender-inclusive language in its sessional working methods, including its review of reports submitted by States parties, concluding observations, early warning mechanisms and urgent action procedures, and general recommendations.

5. As part of the methodology for fully taking into account the gender related dimensions of racial discrimination, the Committee will include in its sessional working methods an analysis of the relationship between gender and racial discrimination, by giving particular consideration to:

- (a) The form and manifestation of racial discrimination;
- (b) The circumstances in which racial discrimination occurs;
- (c) The consequences of racial discrimination; and
- (d) The availability and accessibility of remedies and complaint mechanisms for racial discrimination.

6. Noting that reports submitted by States parties often do not contain specific or sufficient information on the implementation of the Convention with respect to women, States parties are requested to describe, as far as possible in qualitative and quantitative terms, factors affecting and difficulties experienced in ensuring the equal enjoyment by women, free from racial discrimination, of rights under the Convention. Data which have been categorized by race or ethnic origin, and which are then disaggregated by gender within those racial or ethnic groups, will allow the States parties and the Committee to identify, compare and take steps to remedy forms of racial discrimination against women that may otherwise go unnoticed and unaddressed.⁹

The logic and spirit of this recommendation are easily extendable to people with disabilities who might face racial or ethnic discrimination or additional discrimination based on a combination of race and disability. It would be particularly useful if the Committee were to indicate explicitly that the provisions of General Recommendation XXV also apply to people facing other forms of double and multiple discrimination. Racial discrimination may be experienced differently by disabled and non-disabled members of racial groups. The last line of paragraph 2 of the recommendation is particularly pertinent in that people with disabilities “may be ... hindered by a lack of

⁹ HRI/GEN/1/Rev.5.

access to remedies and complaint mechanisms for racial discrimination because of disability-related impediments.

It is therefore imperative for the Committee, when evaluating the persistence of racial discrimination in societies, to take into account the different way that discrimination is experienced by certain sub-groups.

In the workings of human rights bodies in general and the Committee in particular, it is important to acknowledge and take into account perspectives that keep the issue of disability in focus. It is particularly important for the Committee to seek information from States parties with regard to their treatment of people with disabilities. Some States have already covered disability issues in their reports to the Committee. It could prove useful to formalize this emerging practice by elaborating an explicit requirement to do so. This would also help to create a more sophisticated system of protection against racial discrimination. The content of paragraph 5 of the recommendation is particularly useful as a source of protection for people with disabilities. The four factors identified could be used to measure the extent to which people with disabilities experience racial or ethnic discrimination.

The monitoring of States parties' reports and data under the specific heading of disability, as requested for gender in paragraph 6 of the recommendation, would be a meaningful way of furthering the principles and purposes of the Convention.

9.3.2 General relevance of ICERD norms in the context of disability

Article 1 of the Convention reads as follows:

1. In this Convention, the term "racial discrimination" shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.
2. This Convention shall not apply to distinctions, exclusions, restrictions or preferences made by a State Party to this Convention between citizens and non-citizens.
3. Nothing in this Convention may be interpreted as affecting in any way the legal provisions of States Parties concerning nationality, citizenship or naturalization, provided that such provisions do not discriminate against any particular nationality.
4. Special measures taken for the sole purpose of securing adequate advancement of certain racial or ethnic groups or individuals requiring such protection as may be necessary in order to ensure such groups or individuals equal enjoyment or exercise of human rights and fundamental freedoms shall not be deemed racial discrimination, provided, however, that such measures do not, as a consequence, lead to the maintenance of separate rights for different racial groups and that they shall not be continued after the objectives for which they were taken have been achieved.

One of the most significant criticisms of the Convention has concerned its relevance to contemporary issues. The instrument was framed during the decolonization struggle as a direct response to apartheid, colonialism and anti-Semitism, but its pertinence to modern-day scenarios is sometimes questioned. This challenge can be summarized under three headings.

First, it is asserted that the very concept of race is problematic since it may be viewed as something that is not inherent but socially constructed by one group in a bid for domination. The argument that the term “race” lacks determinate substance has been discussed in many forums and remains crucial to the application of the Convention. However, the manner in which international human rights law interprets this debate is ultimately practical: while it does not seek to defend the existence or otherwise of “race”, it posits that the occurrence of racial discrimination as such is very real. It is an empirical fact that remains difficult to contest. Thus, the lack of an agreed definition of “race” does not in fact hamper the operation of the Convention.

A second general criticism of the Convention is that it allows citizens to be treated somewhat differently from non-citizens. While this provision was inserted primarily to reassure States that they were allowed to make qualitative differences in their treatment of their own citizens, it nonetheless begs the question of the value of protection if it cannot be extended to non-citizens or if its coverage of non-citizens can be restricted. This criticism should not be exaggerated since the web of other human rights treaties provides a bedrock of rights for non-citizens. This issue has been addressed in General Recommendation XI, which will be examined below.

By focusing on discrimination rather than on its specific “racial” form, the Convention could be seen to endorse the notion that “race” itself is a social construct. This is echoed in chapter 1, one of whose main themes is the notion of disability as a “social construct”. Such an approach would unveil this construct and focus attention instead on its effects, namely discrimination of different kinds.

If ICERD is fundamentally about protecting and enhancing identity and respecting difference, it should acknowledge the emergence of many different bases for such identity, especially in the context of General Recommendation VIII concerning the interpretation and application of article 1, paragraphs 1 and 4, which asserts that identification with a group should generally be based on self-identification by the individual concerned.¹⁰

This empowerment of the individual provides further ammunition for the extension of the Convention to people with disabilities, who could identify their category of discrimination as being based on abilities. The exception of non-citizens from the full scope of article 1 has been interpreted by the Committee in General Recommendation XI on non-citizens as not detracting in any way

from the rights and freedoms recognized and enunciated in other instruments, especially the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights.¹¹

If States parties are thus required to report on non-citizens who are specifically exempted from the full coverage of article 1, they have, a fortiori, considerable scope (if not an obligation) to report on disability. In any event, non-citizens who may also have disabilities are covered by the provisions of this recommendation.

¹⁰ HRI/GEN/1/Rev.5..

¹¹ Ibid.

General Recommendation XIV on article 1, paragraph 1, states:

2. The Committee observes that a differentiation of treatment will not constitute discrimination if the criteria for such differentiation, judged against the objectives and purposes of the Convention, are legitimate or fall within the scope of article 1, paragraph 4, of the Convention. In considering the criteria that may have been employed, the Committee will acknowledge that particular actions have varied purposes. In seeking to determine whether an action has an effect contrary to the Convention, it will look to see whether that action has an unjustifiable disparate impact upon a group distinguished by race, colour, descent, or national or ethnic origin.

3. Article 1, paragraph 1, of the Convention also refers to the political, economic, social and cultural fields; the related rights and freedoms are set up in article 5.¹²

This recommendation provides a useful standard against which to assess disability discrimination.

Other general recommendations that could be seen as having some relevance to persons with disabilities include General Recommendation XXII on article 5 of the Convention on refugees and displaced persons, General Recommendation XXIII on the rights of indigenous peoples, General Recommendation XXIV concerning article 1 (different national or ethnic groups and indigenous peoples); and General Recommendation XXVII on discrimination against Roma.¹³ All of these recommendations apply to persons with disabilities who also happen to fall into the categories they deal with.

9.3.3 The permissibility of affirmative action and the prohibition of hate speech

Having considered the possibility of including people with disabilities under the protection mechanisms provided by the Convention, this chapter will now take a closer look at the obligations that the Convention explicitly imposes on States parties.

An important obligation is that contained in article 1, paragraph 4, which states that:

Special measures taken for the sole purpose of securing adequate advancement of certain racial or ethnic groups or individuals requiring such protection as may be necessary in order to ensure such groups or individuals equal enjoyment or exercise of human rights and fundamental freedoms shall not be deemed racial discrimination, provided, however, that such measures do not, as a consequence, lead to the maintenance of separate rights for different racial groups and that they shall not be continued after the objectives for which they were taken have been achieved.

This provision, known as affirmative action or positive measures, lays the moral and legal basis for the creation of special regimes that address the particular needs of a group facing discrimination. Thus, special measures could be taken, under article 1(4), on behalf of individuals with disabilities with the express purpose of ensuring their equal enjoyment of rights. These measures could take the form of ensuring access to premises or cover broader issues such as employment opportunities and political

¹² Ibid.

¹³ Ibid.

representation. This tallies neatly with the stated goal of the disability rights movement worldwide, which is participation on the basis of equality.

Article 4 also contains provisions that are particularly worth highlighting. It reads as follows:

States Parties condemn all propaganda and all organizations which are based on ideas or theories of superiority of one race or group of persons of one colour or ethnic origin, or which attempt to justify or promote racial hatred and discrimination in any form, and undertake to adopt immediate and positive measures designed to eradicate all incitement to, or acts of, such discrimination and, to this end, with due regard to the principles embodied in the Universal Declaration of Human Rights and the rights expressly set forth in article 5 of this Convention, inter alia:

- (a) Shall declare an offence punishable by law all dissemination of ideas based on racial superiority or hatred, incitement to racial discrimination, as well as all acts of violence or incitement to such acts against any race or group of persons of another colour or ethnic origin, and also the provision of any assistance to racist activities, including the financing thereof;
- (b) Shall declare illegal and prohibit organizations, and also organized and all other propaganda activities, which promote and incite racial discrimination, and shall recognize participation in such organizations or activities as an offence punishable by law;
- (c) Shall not permit public authorities or public institutions, national or local, to promote or incite racial discrimination.

This article could provide a legal basis for legislation that seeks to challenge the dissemination of ideas of superiority aimed at denigrating people with disabilities.

In terms of remedies under the Convention itself, individuals with disabilities could potentially gain protection via the implementation mechanisms provided for in ICERD. If States parties were required to include disability as a category in their periodic reports to the Committee, it would be possible for an international body to monitor the extent to which disability discrimination has a negative impact on the enjoyment of all human rights.

In the case of States parties that have made the requisite declaration under article 14, individuals with disabilities would be able to approach the Committee with specific complaints. In addition, recognition of disability as a ground for discrimination would advance the cause of people with disabilities in broadly the same way as that suggested in General Recommendation XXV on gender-based discrimination, namely identification of a ground of discrimination is the first step towards setting in place policies to deal with it.

It is fascinating to note that an implicit link is drawn between racism and disability discrimination in the draft declaration of the World Conference against Racism (Durban, September 2001). The initial draft stated:

81. We recognize that certain persons and groups may, in addition to experiencing acts of racism, racial discrimination ... also/simultaneously experience other forms of discrimination on the basis of/ground of their gender, age [mental or physical ability], disability, [genetic condition, disorder] ... resulting thus in multiple discrimination. We stress that special attention should be given to the elaboration of strategies, policies and programmes aiming at equal opportunities, which may include [positive measures aimed at removing systemic

barriers and other forms of discrimination and intolerance/affirmative action] for such persons (ONGOING)...

82. We also recognize that some persons are victims of multiple discrimination, including on the grounds of race, colour, descent, ethnic, linguistic or national origin...disability...(ONGOING)...

Regrettably, the specific reference to disability was not carried forward into the final text. Reference was made to “other status”, which is taken to include disability. However, the fact that it was made at all is highly significant, even though the final text did maintain an explicit reference to persons living with HIV.

9.4 Case studies on State party reports with a disability dimension

9.4.1 Disability in State party reports

As noted earlier, the inter-State reporting procedure has not been used so far and the individual or group complaint procedure has not yet been widely used.

The following material is therefore taken in all cases from State party reports. In describing their general anti-discrimination legislative regime, many States parties specifically and sometimes extensively cover measures taken to combat discrimination against persons with disabilities. It is true that such reporting takes the form of general or background information on anti-discrimination law and policy. Nevertheless, the mere fact that disability is included is striking and offers a basis for dialogue between the Committee and the States parties on disability discrimination.

The States parties concerned include Armenia (1997),¹⁴ Australia (1993),¹⁵ Canada (1994),¹⁶ Colombia (1999),¹⁷ Egypt (1994),¹⁸ Finland (1998),¹⁹ France (1996) (reference to the overseas territory of New Caledonia),²⁰ Haiti (1998),²¹ India (1996),²² Latvia (1999),²³ Mongolia (1997 and 1998),²⁴ Nigeria (1994),²⁵ Republic of

¹⁴ CERD/C/289/Add.2.

¹⁵ Ninth periodic report (CERD/C/223/Add.1).

¹⁶ Summary record of the 1043rd meeting (CERD/C/SR.1043).

¹⁷ Summary record of the 1357th meeting (CERD/C/SR.1357).

¹⁸ Twelfth periodic report (CERD/C/226/Add.13).

¹⁹ Fourteenth periodic report (CERD/C/320/Add.2).

²⁰ Summary record of the 1014th meeting (CERD/C/SR.1014).

²¹ Summary record of the 1285th meeting (CERD/C/SR.1285).

²² Fourteenth periodic report (CERD/C/299/Add.3).

²³ Third periodic report (CERD/C/309/Add.1).

²⁴ Summary record of the second part (public) of the 1213th meeting; and fifteenth periodic report (CERD/C/338/Add.3).

²⁵ Thirteenth periodic report (CERD/C/263/Add.3).

Korea (1999),²⁶ Sri Lanka (1993),²⁷ and the United Kingdom (1995, 1996 and 1997, references to Hong Kong).²⁸

9.5 Conclusions on CERD and disability

9.5.1 Conclusions

The International Convention on the Elimination of All Forms of Racial Discrimination was negotiated in the 1960s. As it entered into force before the ICCPR and the ICESCR, it was the first human rights instrument to provide for the establishment of a treaty monitoring body. Before the adoption of the Convention on the Rights of the Child (1990), it was the most ratified of the human rights instruments. There are currently 161 States parties.

The Committee monitors State party compliance with the Convention on the basis of initial and periodic reports and it considers individual and collective complaints against States parties that have recognized its competence to do so. It can make recommendations to States parties in the light of their reports, which are also communicated to the General Assembly. In addition, as the guardian of the Convention, it adopts general recommendations of an interpretive nature.

The Convention is of obvious relevance and use to persons who experience discrimination on account of a combination of their racial status and disability. Racial discrimination can itself cause disability. In health services, for example, it may result in failure to treat conditions that can deteriorate into a disability.

Many State party reports already contain references to disability. This demonstrates that a wide array of States parties already consider disability to be an issue worth reporting on under the Convention. While they may not view disability as a separate ground for reporting (i.e. separate from race), the fact that they report on disability at all provides a basis for useful dialogue between the Committee and States parties.

To further heighten the visibility of people with disabilities under ICERD, the Committee should consider issuing a more explicit general recommendation built constructively on General Recommendation XXV, which acknowledges the existence of double discrimination based on race and gender.

NGOs representing persons with disabilities and persons with disabilities themselves should make more use of the individual and collective complaints procedure in the case of States parties that have made the relevant declaration under article 14. Although the overlap between race and disability may not be as pronounced as that between gender and disability, it is nevertheless very real and ICERD offers some scope for tackling the issue through its mechanisms.

²⁶ Summary record of the 1307th meeting (CERD/C/SR.1307).

²⁷ Sixth periodic report (CERD/C/234/Add.1).

²⁸ Thirteenth periodic report (CERD/C/263/Add.7, Part II); summary record of the 1141st meeting (CERD/C/SR.1141); summary record of the 1186th meeting (CERD/C/SR.1186).

Part 3

**Options for the future: towards maximizing the
potential of the United Nations human rights
instruments in the context of disability**

Chapter 10

Civil society: current use of the United Nations human rights system and future choices

Gerard Quinn

At the outset of this study it was decided to consult widely with disability NGOs. First of all, it is a moral imperative to listen to the voices of those most directly affected. Secondly, the disability NGO perspective on how well the United Nations human rights treaty system is working at present is indispensable to the credibility of our findings. Thirdly, any recommendations for the future would lack credibility if they failed to take full account of the views of disability NGOs.

A detailed questionnaire was designed with disability NGOs specifically in mind. Drafts of the questionnaire had been commented on by several disability NGOs before circulation. It was distributed widely in English, Spanish and Braille from late July 2001. We would like to record our special thanks to the bureau of International Disability Alliance (IDA) for its efforts to transmit the questionnaire to as wide a constituency as possible. We would also like to record our gratitude to the ONCE Foundation of Spain for translating the document into Spanish and to the National University of Ireland (Hardiman Library, Galway) for producing the questionnaire in Braille. In addition, Professor Quinn and one of his research assistants (Anna Bruce) met with members of the IDA in New York for an extended weekend seminar on 1 and 2 September 2001. Many aspects of this study and the questionnaire were reviewed in detail at that seminar.

All in all, over fifty responses, covering most disabilities, were received from all parts of the world. Given the limited time available, this was not a bad response. While our analysis is not scientific, we nevertheless feel that it gives a good flavour of the attitudes and experiences of the international and national disability NGO community.

Responses were received from the following four international non-governmental organizations (INGOs, i.e. either regional or international groupings of NGOs): Inclusion International, Multiple Sclerosis International Federation, Rehabilitation International and World Blind Union.

Four responses were received from regional INGOs: Autism Europe, Inclusion Europe, Latin American Union of the Blind and Mental Health Europe.

Responses were received from the following domestic disability NGOs: All Russian Association of the Deaf, ASBL-Invalides du Travail (Belgium), Asociación Columbiana de Sordociegos (SURCOE, Colombia), Asociación Dominicana de Sordociegos (Dominican Republic), Associação “A casa de Betania” (Portugal), Associação dos Paraplegicos de Unerlandia (APARU, Brazil), Associação Portuguesa

de Deficientes (Portugal), Association of Swedish Deaf Blind, Australian Association of the Deaf, Austrian Association of the Deaf, Canada Association of the Deaf, Centre for Independent Living (CIL, Ireland), China Association of the Deaf, Confederação Nacional dos Organismos de Deficientes (Portugal), Considering Alternatives Together can Help Inc. (United States), Danish Council of Organizations of Disabled People (DSI),

Danish Society of Polio and Accident Victims, Deaf/Blind Association of Peru, Deaf/Blind Association of Poland, Deafblind NZ Incorporated (New Zealand), Disability Awareness in Action (DAA, United Kingdom), Disabled Organization for Legal Affairs and Social Economic Development (DOLASED, United Republic of Tanzania), Federación Guatemalteca de Asociaciones de Padres de Personas con Discapacidad (Guatemala), Foundation for Psycho-pedagogical Assistance to Children, Adolescents and Adults with Mental Retardation and/or in Specially Difficult Situations (FASINARM, Ecuador), Helen Keller Stichting (Netherlands), Hungarian Association of the Deaf, Irish Council of Civil Liberties, Irish Deaf Society, Japanese Federation of the Deaf, KAMPI (Phillipines), Landmine Survivors Network (LSN) (United States), Mental Disability Rights International (MDRI, United States), National Association for Mental Health (NAMHI, Ireland), National Federation of Disabled Persons' Associations (Hungary), National Organization of Disabled People in Romania, National Uruguayan Association of the Blind, Norwegian Federation of Organizations of Disabled People (FFO), People with Disabilities in Ireland (PWDI), Slovak Association of the Deaf, Spanish Association of the Deaf Blind, Swiss Federation of the Deaf, TAMIR Welfare Organization (Pakistan), Union of the Deaf in the Czech Republic, Union of the Deaf of Bulgaria, VIA Sdruzeni hluchoslepych (Czech deaf/blind organization), Western Care Association (Ireland).

The questionnaire was divided into the following parts:

Part I requested organizational details of the respondents.

Part II sought information on whether and how the human rights perspective on disability was reflected in the aims or objectives of the respondent organizations. The information gathered sheds light on the question of whether the NGO sector is absorbing the human rights message on disability.

Part III asked the INGOs and NGOs to evaluate their capacity to advance the human rights perspective on disability. The information produced is useful in that it shows where the gaps are and points to how capacities can and should be raised.

Part IV sought information about current levels of engagement by the disability NGO sector with the United Nations human rights treaty system. The information produced is useful because it reveals inhibiting factors. It also points to some good practice.

Part V asked the NGO sector to reflect on the outcomes of engagement with the United Nations human rights machinery (assuming that such engagement had taken place). Again, the information reveals the experience of disability NGOs with the treaty machinery and their estimate of the usefulness of that involvement.

Part VI asked the NGOs to speculate on the future and on how the treaty system could be improved in the disability context. The very last question was left open-ended to allow NGOs to speculate on other matters including the possibility of adopting a thematic convention on the rights of persons with disabilities. We did not specifically advert to a thematic treaty since our main focus was on the existing treaty machinery. Many of the NGO comments on a convention were revealing and were scattered throughout their responses.

The questionnaire permitted the disability NGOs to submit confidential replies if they so wished. A number of them did so and we respected their wish for confidentiality.

10.1 Part I: Organizational details

This part asked a series of background questions in an attempt to identify the nature of the respondent NGOs, what their aims were, the composition of their membership, whether they were associated with traditional human rights NGOs, whether they had consultative status with the United Nations system, their main source of funding and contact details.

The most important of these questions had to do with the aims of the disability NGOs, their affiliation with other human rights NGOs and whether they had formal consultative status with the United Nations.

(a) *Aims of NGOs*

Nineteen respondents stated that the achievement of human rights or equality was their main aim. Most of the others stated that empowerment, inclusion, full representation, improving the quality of life or defending people with disabilities was their main aim. These aims are, of course, fully compatible with the achievement of human rights for people with disabilities.

(b) *Affiliation with traditional human rights NGOs*

This information is interesting since it reveals the kinds of bridges that are being built across the NGO sector on the issue of advancing the human rights of persons with disabilities.

Thirteen respondents claimed to have a formal relationship with a traditional human rights NGO. Bearing in mind that the question focused on whether disability NGOs had a “formal” relationship with traditional human rights NGOs, this figure is probably high and increasing. In any event, many of the remaining respondents claimed to have periodic and informal relations with traditional human rights NGOs. This shows that disability NGOs are beginning to build the necessary bridges to advance their cause. Only one disability NGO claimed to have tried to build bridges and been rebuffed.

(c) *Consultative status with the United Nations*

Ten respondents claimed to have formal consultative status with the United Nations. However, this does not convey the full picture since the vast majority of the remaining

respondents also have affiliate status with INGOs that have formal consultative status with the United Nations. It follows that most of the respondents had access to the United Nations machinery by one route or another. Some respondents reported that they were in the process of either acquiring such status or reflecting on it (Landmine Survivors Network (United States), Centre for Independent Living (Ireland), PWDI (Ireland)).

10.2 Part II: Self-understanding of disability NGOs as human rights defenders (questions 1-6)

This set of questions was designed to elicit information on how disability NGOs saw themselves and, in particular, on whether the achievement of human rights was one of their main objectives.

Question 1: Would you describe your organization as a human rights organization?

All eight INGOs and regional NGOs saw themselves as human rights organizations. A further twenty-nine disability NGOs saw themselves as human rights organizations, bringing the total to thirty-seven. This is a remarkable figure which shows just how deeply rooted the switch to a human rights perspective has become. Autism Europe's reply was typical of the positive responses:

Yes, our main objective is to promote the rights of people with autism. We therefore published the "Charter of Rights for Persons with Autism" in 1992...which was formally adopted by the European Parliament as a Written Declaration (1996).

The Norwegian Federation of Organizations of Disabled People (FFO) likewise stated:

Yes, the basis of all activities of the FFO is the defence of disabled peoples' human rights and solidarity.

KAMPI of the Philippines replied:

Yes, because we work for the elimination of barriers against the participation of PWDs [persons with disabilities] in all aspects of life and this can only be realized as long as PWDs are aware of their rights and the society respects [those]...rights...

Most of those who replied in the negative stated that they were beginning to shift to a human rights perspective. One NGO (Danish Council of Organizations of Disabled People, DSI) stated that it saw itself as an organization for the advancement of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities:

DSI is not a traditional human rights organization, but has – since the Standard Rules emerged – worked within the frame of the Standard Rules regarding policy and activities, etc.

To a large extent the aims of the Standard Rules overlap with human rights.

These are remarkable findings and show how far NGOs have progressed in the shift from a welfare to a rights-based approach.

Question 2: Is the human rights perspective written into your mission statement or strategy?

One indication of the seriousness of the switch to a human rights perspective is whether it has been written into the underlying constitutional documents of the NGO in question.

Thirty-seven INGOs/NGOs stated that the human rights perspective had been explicitly written into their charters or similar documents. This figure includes all eight INGOs and regional NGOs that responded.

It is a remarkable finding which shows that there is a strong desire in all parts of the world to move from rhetoric to reality.

Question 3: If you recently shifted to the human rights paradigm, when did this shift take place and how?

Six NGOs responded that the human rights perspective had been adopted either from the very outset or a long time previously. MDRI (United States), for example, stated:

MDRI was founded in 1993 with the primary goal of promoting the inclusion of people with mental disabilities within the international human rights framework.

Most dated the switch to human rights from the early or mid-1990s, which coincides with the adoption of the United Nations Standard Rules (1993) and General Comment No. 5 of the United Nations Committee on Economic, Social and Cultural Rights (1995).

Some reported that the switch had only recently taken place, partly because their larger affiliates had taken the lead. One NGO responded that the switch was taking place but was meeting with resistance.

Again these findings are remarkable. They show that a solid core of disability NGOs adopted the human rights perspective as far back as the early 1980s when the World Programme of Action was adopted and when DPI (Disabled Persons International) was formed. It shows a second tranche of NGOs making the switch against the backdrop of the United Nations Standard Rules and a third tranche who are currently undergoing the process of change.

What is interesting is that the switches seem to have taken place in response to major United Nations initiatives.

Question 4: Has your organization made any organizational changes to facilitate or reflect the paradigm shift to human rights? If so, what were these changes?

Twelve NGOs reported having made organizational changes on switching to the human rights perspective.

Interestingly, Inclusion International stated:

In 1998 Inclusion International left its headquarters in Brussels, Belgium, in order to settle close to Geneva with the expectation of greater involvement in human rights issues at United Nations level. Concurrently, Inclusion International created the new position of CEO [chief executive officer], so that this work would be attentively coordinated and developed.

Some NGOs had made the organizational change of designating a particular officer to follow human rights developments.

Most of the other respondents did not reply to the question. Of those that replied in the negative (seven in all), it is perhaps fair to say that they lacked the resources to make major institutional changes and the switch to the human rights perspective probably permeated all their work in any event.

Question 5: If you belong to a consortium of disability organizations, to what extent does that consortium subscribe to the human rights dimension of disability?

This question was designed to gauge the ripple effect of the human rights dimension throughout the disability organizations to which the respondents were affiliated.

Twenty-seven respondents replied that the organizations to which they were affiliated had fully subscribed to the human rights perspective on disability. This is a remarkably high response. It shows that the commitment to the human rights perspective is not just lateral across most ordinary NGOs but also vertical in terms of the higher organizations to which they belong.

Autism Europe stated:

The EDF [European Disability Forum]...[of which we are part]...plays a key role in raising awareness of the European Institutions on issues relating to disability in general and notably in the framework of the rights of the disabled persons.

Mental Health Europe reported that “[a]ll the organizations we are linked with have human rights in their remit.”

Only one NGO replied in the negative.

The others did not respond to the question.

Question 6: Has your organization ever led a human rights campaign?

It could be argued that nearly all disability campaigns are human rights campaigns. So this question was designed to test whether disability NGOs are beginning to see their campaigns in human rights terms.

Twenty-five responded in the affirmative. One went so far as to say that all its campaigns were human rights campaigns. Many saw themselves as campaigning on a mix of issues: some were human rights issues; others had to do with services. Some worked on human rights campaigns with others.

Mental Health Europe reported that the “1998 World Mental Health Day was devoted to the Human Rights of people with mental health problems.” DAA (United

Kingdom) replied: “Yes, frequently. The latest is our global campaign for a Convention on the Rights of Disabled Persons”. Canada Association of the Deaf cited its involvement in two high-profile disability cases in the Canadian courts.

Seventeen respondents replied in the negative. However, in many cases they may have declined to characterize their activities as human rights activities because they did not directly involve a United Nations instrument. For this reason, the number and proportion of those who engage in broad human rights campaigns are probably even larger than indicated in the responses.

10.3 Part III: Self-evaluation of human rights capacities (questions 7-18)

This section was divided into two parts. The first part (questions 7-14) inquired about the general human rights capacity of disability NGOs. The second part (questions 15-18) inquired about human rights personnel in disability NGOs.

A: How adequate are levels of human rights awareness and education?

Question 7: Do you feel that your organization is adequately equipped to understand the human rights paradigm and to make the best use of the existing United Nations human rights treaties in the field?

Twenty-four responses were in the affirmative. Many of these stressed the need for ongoing education.

For example, DAA (United Kingdom) stated:

Our organization was specifically started to raise awareness on disability as a human rights issue. The organizations all knew that, despite the World Programme of Action etc., disability was still seen as an individual/medical problem. As disabled people we were much more aware than anyone else of the human right paradigm... We are all well versed in the human rights treaties and know the best ways to use them. One of the objects of our newsletter is to urge disabled people to influence their governments in their country reports, etc.

NAMHI (Ireland) reported:

NAMHI has the mechanisms needed to understand the human rights paradigm and use United Nations human rights treaties but would have difficulty addressing international treaties adequately and continually due to a small staff and would sometimes have to draw on external expertise in the area for assistance.

Most of those who responded in the negative stressed that lack of knowledge – or easy access to knowledge – was the main inhibiting factor and that they were more than willing to learn.

Question 8: Do you frequently work with governmental (e.g. human rights commissions) or non-governmental human rights organizations?

Thirty NGOs replied in the affirmative. Most of them reported working closely with Governments as well as with human rights commissions and other NGOs. The

Australian Association of the Deaf reported working very positively with the Australian Human Rights and Equal Opportunities Commission. KAMPI (Philippines) stated that it had worked positively with its Commission on Human Rights in the promotion and protection of the rights of persons with disabilities.

There were twelve negative responses. The other respondents did not reply to the question. The responses confirm that NGOs are beginning to have an influence in framing policy.

Question 9: Do you utilize United Nations General Assembly resolutions and other human rights “soft law” policy instruments (i.e. other than the conventions?)

This question was designed to ascertain the extent to which “soft law” instruments (e.g. the United Nations Standard Rules) are used by the NGO community. These instruments are in a different category from the six core United Nations human rights treaties.

Thirty four respondents replied in the affirmative. At least six mentioned the specific use of the United Nations Standard Rules. DAA (United Kingdom), for example, stated:

Yes, through our newsletter and special resource kits

- as models for domestic legislation – we have encouraged local authorities to use the Standard Rules as a basis for local disability policy,
- as universal standards of assessment of human rights reporting – all the time and we are now, through Rights for Disabled Children, providing written and verbal reports to the Committee on the Rights of the Child,
- as advocacy tools pressing Governments for policy and legal changes – we have produced resource kits to do this,
- as tools for promoting the political participation by people with disabilities – ongoing,
- as guidelines for the operation of domestic rights enforcement, quality assurance or other oversight mechanism... We have also produced measurable indicators based on environmental factors of the ICF (the new ICIDH) for use in monitoring grass-roots projects.

Many respondents referred to lack of resources to make more meaningful use of the “soft law” instruments.

Eight NGOs did not respond to the question. Perhaps this indicates a lack of familiarity with the soft law instruments. It is impossible to tell from the documentation supplied.

Those who replied in the negative gave no reason.

Question 10: Do you utilize the United Nations conventions (“hard law”) for any or more of the above?

This question was designed to establish whether the NGOs themselves drew a distinction between United Nations “soft law” instruments in the field of disability

and the six core United Nations human rights treaties and whether they used those treaties in their own work.

Twenty four disability NGOs replied that they used the United Nations human rights treaties either when required on very specific points or often. This is quite a high figure given that knowledge of the “soft law” disability instruments is much more widespread. It shows that many NGOs are crossing the bridge between “soft law” and “hard law”. One NGO (Danish Society of Polio and Accident Victims) focused on the Convention on the Rights of the Child. Another NGO (Landmine Survivors Network, United States) focused on the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

Nine replied that they did not use the conventions. Most of these indicated a willingness to do so if they could equip themselves with more knowledge.

Some other responses confused the conventions with instruments such as the Universal Declaration of Human Rights (leaving aside the debate about whether it constitutes customary international law) and the United Nations Standard Rules.

At least eight of the respondents did not answer the question.

Question 11: Does your organization hold internal staff seminars for staff or general seminars for the public on the human rights dimension of disability?

This question was designed to elicit information on what measures the NGOs were taking to inform themselves and their staff as well as the public about the human rights perspective on disability.

Twenty-eight NGOs reported holding such seminars. DAA (United Kingdom), for example, stated:

We held a seminar in Zimbabwe for disabled people all over Africa on the media and human rights, with a special focus on disability. This was part of work with the BBC World Service with whom we had done a collaborative series of programmes on disability and human rights in Central and Eastern Europe and Africa.

Those that answered in the negative stressed their lack of resources as the main reason. Many hoped to organize such seminars in the near future.

Five NGOs did not respond to this question.

Question 12: Has your organization ever published or commissioned the publication of material on the human rights dimension of disability?

This question was designed to ascertain whether NGOs had taken steps to propagate the human rights message on disability through publications.

Thirty-two disability NGOs replied that they had published material on the human rights perspective on disability. This is a remarkably high figure. Inclusion International, for example, stated:

Frequently. The most notable examples are

- innumerable articles in the Inclusion International Newsletter (published three times a year in four languages,
- a number of documents on human rights and bioethics, published in collaboration with the Roeher Institute (Canada),
- “Making the Most of the United Nations” published in 1992, now expanded and updated as “Working with the United Nations”,
- “50 Years of Human Rights” first published in 1998, now expanded and updated as “Human Rights and Intellectual Disability”.

Autism Europe cited its publications on the *Charter of Rights for Persons with Autism*, and its *Code of Practice on the prevention of violence against persons with autism*. FFO (Norway) cited its work on a book dealing with rights for disabled people in Europe, a booklet on user participation and a book entitled *Disabled Peoples Rights in Welfare – Norway*. It further stated that “in all FFO publications the HR [human rights] aspect is reflected directly or indirectly.”

DSI (Denmark) stated:

Together with the University of Aarhus, DSI created a unique disability index based on the Standard Rules... The index has been mentioned in Reports of the Third Committee of the United Nations General Assembly by the unit responsible for disability and in many other places.

Associação Portuguesa de Deficientes (Portugal) reported:

Yes. A White Book on Disability Rights, which includes the speeches of the International Conference on Human Rights, testimonies of disabled persons on their own experiences of violation of human rights, and the Universal Declaration of Human Rights and several articles/papers based on the disability human rights framework presented in seminars, congresses, workshops at national and international level. Additionally in our monthly newsletter.

LSN of the United States replied:

We are currently working on several projects which will lay out the human rights dimensions of disability. We have incorporated brief discussions on this topic in grant proposals.

Question 13: Does your organization use General Comment No. 5 on the rights of persons with disabilities adopted under the ICESCR?

General Comment No 5 is perhaps the most famous document adopted by a United Nations human rights treaty monitoring body on disability. This question was designed to determine levels of awareness of the document and to assess whether disability NGOs had begun to use it proactively in their own countries.

The results were startling. Despite claiming a certain level of general knowledge about the United Nations human rights treaty system, twenty-six NGOs replied that they did not know about General Comment No. 5. One NGO stated:

No, we ignore the General Comment No 5. We tried unsuccessfully to find it on the United Nations websites!

Two NGOs were not sure, which is in itself quite revealing. Only eight NGOs claimed to have some knowledge of the general comment and to have made very limited use of it.

Obviously much still needs to be done to propagate the positive accomplishments of the United Nations human rights treaty system in the disability context. This document – above all others – should be well known by all disability NGOs throughout the world, especially as it has now been in existence for at least six years.

Question 14: Does your organization visit the human rights web sites of the United Nations frequently, sometimes, very infrequently or never?

Knowledge about the United Nations treaty system is now widely disseminated over the Internet. This question was designed to find out whether the disability NGOs log on to the relevant sites frequently enough to keep themselves informed and to obtain their views about the content and presentation of the web sites.

Nine disability NGOs said that they never visited the United Nations human rights web sites. The reason given was not lack of information technology equipment (except for one case). Scepticism about the value of the information was one reason given.

Fourteen NGOs replied that they log on to the United Nations human rights treaty web sites “sometimes” and seven replied that they log on “very infrequently”.

Only three disability NGOs replied that they log on to these sites “frequently”. The rest replied that they logged on “now and again”.

Six NGOs did not respond to the question. It is hard to know how to interpret these disappointing figures. It could mean that levels of awareness of the existence of United Nations human rights web sites are dismally low. This is clearly so in some cases. Or it could mean that the web sites are not amenable to easy navigation, especially for a group (people with disabilities) that is searching for case law and developments of direct relevance to their concerns. This is no doubt true, since the sites were not designed with a group such as the disabled in mind. Finding the right information entails high opportunity costs, as was pointed out by one disability NGO in response to the last question. That NGO gave up trying to find General Comment No. 5 on the United Nations web sites. These figures perhaps point to the need for redesigned web sites or at least a dedicated web site drawing together all the relevant disability information. Any redesign should be undertaken in consultation with the disability NGOs.

B: Do you have dedicated human rights personnel?

The first two questions (15 and 16) under this heading sought information on the in-house human rights capacities of disability NGOs. The second set (17 and 18) sought information on whether disability NGOs use outside human rights expertise on an ongoing basis or on a need-to-use basis.

Question 15: Does your organization employ any staff specifically dedicated to human rights issues in the context of disability?

We did not expect many disability NGOs to have in-house human rights expertise, as this could be seen as a luxury compared with the urgent tasks that consume a great deal of time and effort. Seventeen respondents replied that they did in fact have in-house human rights expertise. We were surprised that the number was so high. It signals that disability NGOs are serious about acquiring human rights capacities.

The form of this expertise is varied. Some organizations have designated a person to work on human rights. Other disability NGOs divide a person's time between human rights and other issues. Still others claim that all members are familiar with human rights and are human rights workers.

Inclusion International, for example, stated:

No, not exactly. Inclusion International generally delegates specific portfolios to staff from member societies or to volunteers. To better ensure this collective effort, Inclusion International created its "Task Force on Human Rights" in 1999.

FFO (Norway) reported:

The most relevant initiative is the establishment of a "Rights Officer" in FFO where dedicated lawyers and staff assist disabled users from all over Norway to find, explain and defend their (mostly legal) rights.

DAA (United Kingdom) stated that "we are all employed in that regard." NAMHI (Ireland) stated:

Not specifically as part of staff structure but NAMHI is currently contracting an individual on a part-time basis to produce material on (the) issue of human rights, legislation, etc. for persons with intellectual disabilities.

LSN (United States) reported:

Yes, our new Legal Counsel and Disability Rights Coordinator is specifically dedicated to human rights issues with specific application to disability and the rights of landmine survivors.

Sixteen NGOs replied in the negative. However, many of them indicated that lack of financial resources was the main obstacle to hiring in-house human rights staff.

The rest of the respondents did not reply to the question.

Question 16: If so, how does this staff person interact with others in your hierarchy? What status does s/he have in your organization?

This question applied only to those who had replied affirmatively to the previous question. It was designed to obtain information on whether the human rights personnel were on the periphery or at the core of the organization's activities.

We expected to find human rights personnel in minor research/internship posts and were therefore surprised by the results. Most of the disability NGOs that had human rights personnel used their talents in all aspects of the work of the organization. For example, Inclusion International stated:

The CEO is one of the coordinators of the “Task Force on Human Rights”. Besides keeping track of her specific mandates, she tracks and coordinates the efforts of the various members.

MDRI (United States) reported:

MDRI’s Executive Director is an internationally recognized expert in international human rights. MDRI’s Europe Regional Director works throughout Central and Eastern Europe to promote the international recognition of human rights. MDRI’s Communications Officer publicizes MDRI’s international human rights work.

FFO (Norway) stated:

The head of the office is (human rights) project leader...The others are external lawyers from one of FFOs member organizations.

PWDI (Ireland) stated:

All our organization’s work is the empowerment of people with disabilities in the pursuit of negotiating their rights in our society.

The National Organization of Disabled People in Romania reported: “All our staff should be dedicated to human rights issues in the context of disability.”

TAMIR (Pakistan) stated:

We have [a] lady staff member who is acting General Secretary and she is a great human rights activist and work[s] for marginalized people. [The] Present Government has awarded her “Good Citizen” title.

Question 17: Does your organization hire any outside expertise on human rights and disability?

We expected that disability NGOs without in-house human rights staff might hire outside expertise. Eighteen disability NGOs reported hiring such expertise. Interestingly, they were evenly spread between those who answered in the affirmative and in the negative to question 15. Thus, about half of those who had in-house expertise also contracted outside human rights expertise. This shows that the human right projects – or the human rights dimensions of ongoing projects – were treated extremely seriously.

Many of those who replied in the negative to this question referred to lack of resources as the main reason for not hiring outside human rights expertise.

Question 18: If so, is this arrangement on an ongoing basis or on a need-to-hire basis?

This question was designed to ascertain whether organizations that hired outside human rights expertise did so on a regular basis or simply on a need-to-use basis.

Five NGOs responded that they used outside human rights expertise on an ongoing and regular basis. Four of these NGOs also had their own in-house human rights expertise.

The rest replied that they only used outside human rights expertise on a need-to-hire basis.

10.4 Part IV: Current levels of DPO/INGO engagement with the United Nations human rights machinery

In this part we asked four sets of questions designed to ascertain why NGOs engage with the United Nations human rights machinery, why they do not engage with the machinery, how they engage with the treaty machinery and how they engage with States parties.

A: Why do you engage with the treaty monitoring bodies (questions 19-27)?

To a large extent these questions assumed that some form of engagement existed with the United Nations human rights treaty monitoring bodies.

Question 19: Does your organization send delegates to attend the annual meeting of the United Nations Commission on Human Rights? If so, how often do they go (every year?)?

Only seven NGOs responded that they had attended meetings of the United Nations Commission on Human Rights. One of the seven (Mental Health Europe) reported that “we are always going”. Another (Danish Society for Polio and Accident Victims) stated: “No, but we follow the work and have twice participated as NGO members of the Danish delegation.”

These figures are not high. On the other hand, disability issues only figure on the agenda of the United Nations Commission on Human Rights every two years and not as a prominent item.

Question 20: Does your organization have a worked-out strategy for general engagement with the United Nations treaty monitoring bodies?

Only three NGOs claimed to have a worked-out strategy for engaging with the United Nations treaty monitoring bodies. The rest either replied in the negative or did not respond to the question. Four NGOs reported that the matter was under discussion or that change was imminent.

These findings are interesting. They show that although NGOs are clearly gearing up intellectually to harness the potential of the human rights framework, they are nevertheless only beginning to put together coherent strategies on how best to use the existing United Nations treaty machinery.

Question 21: Which treaty monitoring body do you engage with most? CCPR, CESCR, CAT, CEDAW, CRC, CERD?

Curiously, there were twelve affirmative responses to this question. This should not have been the case if only three had a worked-out-strategy. It either means that they engaged with the treaty bodies without any strategy (unlikely) or that they misunderstood the question, taking it as an inquiry as to which treaty were they most interested in. There is perhaps no way of knowing.

In any event, most of those who responded cited CEDAW and CRC as the treaties they used or watched most. Many of them also used or watched developments under the ICCPR and ICESCR, despite the fact that very few NGOs claimed any knowledge of General Comment No. 5 under the latter treaty.

Question 22: Is your organization aware of which if any of these treaties your Government has signed/ratified?

This question was not really relevant to the INGOs since they are not located in a particular country.

A large number of respondents (sixteen) replied that they were not aware of which human rights treaties their Governments had ratified. Thirteen respondents did not reply at all to the question. Others (mostly INGOs) stated that the question was not relevant to them.

These findings show that a great deal more education concerning human rights law is still necessary. The NGOs have indicated that they are keen to learn and to use such knowledge.

Question 23: Is your organization aware of the declarations, reservations or derogations that your Government has made to these treaties (if any)?

Likewise, this question was not really relevant to the INGOs.

Eighteen respondents replied that they did not know what reservations, etc., had been made to the United Nations human rights treaties by their own Governments. Fourteen NGOs did not respond at all to the question. Only nine NGOs claimed to have the knowledge referred to. These findings are in line with the findings under question 22.

Question 24: Before your organization engages with the treaty monitoring bodies, does it develop a worked-out strategy of what it would like to achieve?

Thirteen respondents stated they had no strategy for engaging the United Nations human rights machinery. Twelve NGOs did not respond. Only eight claimed to have a worked-out strategy.

DSI (Denmark) stated:

In the case of the Social Summit meeting especially, DSI worked out concrete proposals of what to achieve. The same was the case during the Vienna meeting with the addition of paragraph bis 12. DSI has not worked out a strategy for any of the other events.

This reveals a strategy for engaging with United Nations bodies other than the human rights treaty bodies. The only possible conclusion is that the NGOs are still somewhat distant from the human rights treaty system.

Question 25: For example, does your organization engage with the treaty monitoring bodies?

- *To bring about an end to a perceived and specific violation of rights of persons with disabilities?*
- *To sensitize and educate the treaty monitoring bodies to the disability perspective in their work?*
- *To highlight a thematic issue of general concern (e.g. equal and effective access to education for children with disabilities)?*
- *To highlight an issue of specific concern in a specific country or region (e.g. violations of rights of people with intellectual disabilities in institutional settings in country x, y, z)?*
- *For another reason?*

Only six NGOs reported that they engaged with the United Nations human rights treaty system for one or more of the above reasons.

DOLASED (United Republic of Tanzania) replied affirmatively to all options. The World Blind Union and Inclusion International replied in the affirmative to the first three options. NAMHI (Ireland) emphasized the fourth option (specific issue in a specific country). The China Association of the Deaf and the Polish Deaf/Blind Association replied yes to the whole question.

What was remarkable was the number of NGOs that either did not respond to the question or replied in the negative.

These findings underscore the fact that most disability NGOs have not actively thought about using the United Nations human rights machinery.

Question 26: Does your organization work closely with other mainstream human rights NGOs?

How (at their invitation or your request) and to what effect?

This question was designed to ascertain whether any pattern for forming alliances with more traditional human rights NGOs was beginning to emerge. This is important since the older human rights NGOs have useful skills and insights to impart and could join forces with the disability NGOs to mutual advantage. Sixteen NGOs replied in the affirmative. Their answers were revealing in terms of the potential of such alliances.

Rehabilitation International reported: “[W]e interact primarily with other organizations in the disability field, but also with other organizations.” Inclusion International stated:

Inclusion International recently participated in a fact-finding mission to Kosovo, invited by MDRI. Inclusion International has corresponded with Amnesty International on the issue of capital punishment aimed at people with intellectual disability in the US. We contacted them.

ASBL (Belgium) replied “Several organizations have only their own goals. Cooperation with others ... is not easy to realize.” NAMHI (Ireland) came close to providing a model for useful interaction, stating:

Yes, both at their invitation and NAMHI's invitation to discuss issues pertaining to intellectual disability in their work; to inform them of the state of play of intellectual disability in a wide range of spheres; by sitting on consultative committees, with the result of keeping intellectual disability on the agenda of any NGO working for human rights.

TAMIR (Pakistan) reported: "[W]e are a member of a local NGO network and work with them on human rights at their invitation." MDRI (United States) stated:

YES. MDRI dedicates considerable efforts to educate mainstream human rights NGOs. This work is almost exclusively at MDRI's initiative, but MDRI has received a growing number of requests for assistance from international human rights organizations.

Question 27: In your experience, are the mainstream human rights NGOs open to incorporating a disability perspective in their work?

This question was designed to elicit the disability NGOs' perception of the receptiveness of the mainstream human rights NGOs to their requests for cooperation.

Twenty disability NGOs felt that the mainstream human rights NGOs were open to cooperation. Many of these responses were ambivalent. One said: "Sometimes. We have tried to talk to organizations such as Amnesty but with limited result. Our agendas are slightly different." Another said:

Only within strict limits. Amnesty International, for example, was unwilling to get involved in the issue of human rights violations regarding people with intellectual disabilities in institutional settings.

It must be stressed that the vast majority of disability NGOs highly praised Amnesty's work.

Mental Health Europe said that such cooperation was "not easy". Revealingly, DSI (Denmark) replied:

Yes. These organizations are open, when you contact them, but they are not actively including the disability perspective [in their own work].

MDRI (United States) stated:

They are open in a very limited way. Where they are open to disability rights issues that MDRI brings to their attention, they do very little work on these issues on their own. Even when MDRI brings these issues to the attention of mainstream human rights groups, the concerns of people with mental disabilities are an extremely low priority for these organizations.

It emerges from these findings that educational work is also necessary within more traditional or mainstream human rights NGOs to sensitize them to the human rights problems of persons with disabilities. A natural alliance should emerge between disability NGOs and mainstream human rights NGOs.

B: Why do you not engage with the treaty monitoring bodies?

Question 28: If your organization does not engage with the treaty monitoring bodies, why not?

This was a general question and was followed up with a more specific question on the reasons for non-engagement.

Fifteen respondents did not reply to the question.

The vast majority of respondents claimed that their absolute or relative non-engagement was due to:

- Lack of awareness and knowledge about the system;
- Lack of personnel;
- Lack of material resources;
- Lack of time.

Inclusion International, for example, replied: "Unaware of potential advantages; limited staff time". The Latin American Union of the Blind stated: "[W]e do not have specialized staff and we lack the necessary knowledge." CIL (Ireland) stated: "[L]ack of resources and a need for training on the roles of the various Treaty Monitoring Bodies". FASINARM (Ecuador) replied:

One consideration is that the intense controversy such bodies often carry with them would demand considerable time to face them adequately, time which we can use more effectively in our areas of expertise.

LSN (United States) reported:

Our organization is small, but growing and so engagement with the treaty-monitoring bodies has not been our United Nations focus. Instead we have focused on our leadership role in the implementation process of the Mine Ban Treaty and in the work of the Working Group on Victim Assistance which we now chair.

The deaf/blind organization of the Czech Republic stated:

Our capacity is totally absorbed by acting in the work with deaf/blind individuals. Our organization is a voluntary and self-help one of deaf/blind persons.

Question 29: Does your relative or absolute lack of involvement have to do, for example, with:

Awareness deficits?

- *Not enough outreach information on the part of the United Nations human rights machinery?*
- *Lack of awareness of the concrete possibilities for engagement?*
- *Lack of awareness about how the treaty monitoring bodies work?*
- *Lack of awareness about the disability dimension to the human rights treaties and the perspective of the treaty monitoring bodies on disability?*
- *Resource deficits?*
- *Lack of material resources?*
- *Lack of appropriate personnel?*

- *Judgements about the utility of engagement?*
- *A judgement that other priorities in your own country are more pressing?*
- *A judgement that involvement might tie up a disproportionate amount of time and resources relative to any possible positive outcome?*
- *A judgement that the outcome itself – even when positive – might have a limited impact on State practice?*
- *A judgement that your Government and/or media are uninterested?*
- *Previous negative experience that may have deterred you for the future?*

This question was, in essence, the same as the previous one although it prompted more detailed responses. Ten of the respondents did not reply to the question. The answers did not differ from those to the previous question, the only difference being that, while NGOs emphasized lack of awareness and knowledge and lack of sufficient resources, most did not attribute non-engagement to any form of judgement that such engagement would not serve a useful purpose.

Putting it the other way round, NGOs clearly felt that engagement would be positive at some level but simply felt they lacked the material resources, the staff, the time, and the levels of knowledge and awareness needed to engage effectively.

Only one NGO stated: “[W]e can work on our own and do not feel the need to ask for cooperation from the monitoring bodies.”

C: How do you engage with the United Nations human rights machinery?

Question 30: Have any of the treaty monitoring bodies ever approached you for an input into their work?

Twenty-nine NGOs reported that they had never been approached by treaty monitoring bodies for information or perspectives. Only six NGOs reported that they had been approached. Most of the others left the slot blank.

These figures are not surprising in that the treaty monitoring bodies probably rely on the specialized agencies for additional information.

Question 31: Has your organization ever submitted a “parallel report” on the rights of persons with disabilities to any of the United Nations human rights treaty monitoring bodies? If so, please give details.

Thirty-two disability NGOs replied that they had never submitted a “parallel report”. Many left the slot blank.

Only five NGOs claimed to have submitted “parallel reports”. One of them, however, confused a “parallel report” to a human rights treaty monitoring body with a report to a world conference. The treaty monitoring body that figured most prominently was the Committee on the Rights of the Child.

MDRI (United States) stated:

Yes. The Inter-American Commission on Human Rights and the European Committee for the Prevention of Torture have both requested assistance from MDRI.

Question 32: Has your organization ever interacted with the United Nations human rights treaty monitoring bodies generally or in the context of compiling particular State party reports. If so, please give details.

Thirty responses were in the negative. Only six replied in the affirmative. Of these, two confused their work on the United Nations Standard Rules with contributing to the human rights treaty monitoring bodies. These findings are in line with the results obtained under previous questions.

MDRI (United States) stated:

MDRI sponsored a Russian activist to present testimony to the CRC. MDRI has met with members of the Human Rights Committee to propose the adoption of improved general comments on the rights of people with mental disabilities. MDRI has interacted extensively with members of the Inter-American Commission on Human Rights with regard to our findings on Mexico, specific cases before the Commission, and future strategy regarding the recognition of people with mental disabilities under the American Convention on Human Rights.

Question 33: Has your organization ever filed a complaint (or assisted in the filing of a complaint) or made a communication to one or other of the treaty monitoring bodies? If so, please give details.

Thirty-two NGOs reported that they had never filed a complaint with a treaty monitoring body. Most of the others left the slot blank. Only three NGOs reported having filed or supported a complaint (ICESCR, ICCPR).

MDRI (United States) replied:

MDRI presented factual material to the United Nations Human Rights Committee, leading to a finding that the US violated the CCPR regarding the rights of people with disabilities subject to medical experimentation. MDRI has presented factual material and testified before the Inter-American Commission on Human Rights, the CRC, the ECPT. MDRI is currently working on the development of a complaint to present to the Inter-American Commission on Human Rights. MDRI is working with the Bulgarian Helsinki Committee to plan a case to bring to the European Court of Human Rights.

On the whole, these findings represent considerable under-usage of the complaints system by or on behalf of persons with disabilities.

D: How do you engage with States parties?

Question 34: Have the States parties to the conventions ever contacted you for an input into the compilation of their own periodic State party reports under the conventions as they touch on the issue of disability? Did you accept the invitation?

This question was designed to ascertain whether States parties are actively involving the disability NGOs in compiling their reports. Such involvement is at least morally required of States.

Thirty-one disability NGOs reported no such involvement. Many of them emphasized that they were “never” involved, which intimates a sense of alienation from the State party reporting system. Most of these respondents expressed an eagerness to contribute.

Six NGOs indicated that they had been involved in the past by way of consultation in helping to prepare State reports. Two of them were INGOs. The rest were European disability NGOs.

Again, these findings are not unexpected. They indicate that more use of the knowledge and expertise of the disability NGO community could be made by States parties.

Question 35: For your part, have you ever initiated contact with States parties in order to be consulted about the compilation of their periodic reports? Did the State agree to involve you in the process?

Twenty-seven NGOs reported not having made contact with States parties in connection with the drafting of reports. These findings are not surprising given that levels of knowledge about the United Nations system are not high and given that the disability NGOs are not aware that openings should exist for such consultation.

Seven NGOs claimed to have initiated contact. Three of them were INGOs, who expressed general satisfaction that the States concerned had responded positively. Perhaps this indicates a receptiveness and untapped potential on the part of States parties.

Question 36: If you have been involved in the process of compiling periodic State party reports (whether at the invitation of States or as a result of your own initiative), how seriously, in your view, was your contribution taken by the States parties?

Five NGOs replied that their contributions had been taken seriously by States parties when compiling their reports. Most did not respond to this question, which was in keeping with the low rates of consultation reported between States and NGOs.

One NGO stated:

There is a tendency ...[in]...government thinking that State reports is a business of the Government itself. [There is] No wider participation of stakeholders.

10.5 Part IV: Outcome of engagement with the human rights treaty monitoring bodies

A: Process

Question 37: What was your general experience of the process involved?

Very few responded to this question since it assumed some level of engagement with the treaty monitoring system.

Those who responded gave interesting replies. Rehabilitation International stated that it “is a process that takes time”. Inclusion International viewed its involvement to date as a learning opportunity: “The CESC in 1999 was a first experience... We’ll be more and more familiar with the proceedings and expectations as time goes on.” DAA (United Kingdom) stated:

Our relationship with the CRC is good... It’s early days to know whether our presence and input are going to be effective.

MDRI (United States) stated:

MDRI’s experience with the United Nations Human Rights Committee was positive but limited. The Committee had so many agenda items it had little time to dedicate to the issues raised by MDRI. However, I was pleasantly surprised to obtain a favorable factual finding in the final report of the United Nations Human Rights Committee.

MDRI’s experiences with the Inter-American Commission on Human Rights have been excellent. MDRI’s experience with the United Nations Human Rights Committee has been good. MDRI’s experience with the European Committee to Prevent Torture has been good but would have been much better if the Committee were able to share information more openly with us.

Question 38: Did you form the impression that the treaty monitoring bodies understood your arguments and were sufficiently open to, and familiar with, the disability perspective?

Again, very few responded to this question because of their low or non-existent levels of engagement with the treaty bodies. Eight NGOs responded in the affirmative.

The World Blind Union stated that “there seem to be more important issues to discuss regarding the treaty to the treaty monitoring bodies”. In a way this reflects the reality that each of the six human rights treaties has a wide variety of objectives and constituents to look after.

One NGO stated:

It depended on individual Committee members. Some were obviously sympathetic: others were unbelieving if not hostile to issues related to intellectual disability.

DSI (Denmark) replied:

In the Human Rights Commission and in the CEDAW and Children’s Convention, as well as during the Vienna Conference, DSI finds that the treaty monitoring bodies were open and familiar to the disability perspective.

MDRI stated:

The United Nations Human Rights Committee was open to MDRI’s arguments though it placed little priority on the issues MDRI raised.

The Inter-American Commission on Human Rights has been extremely open to mental disability rights issues and has been of great assistance. Members of the Inter-American Commission have actively encouraged MDRI to take further action before the Commission.

As a result of information MDRI provided to the ECPT regarding the placement of people in cages, the Committee visited psychiatric facilities in Hungary. As a product of those visits, Hungary stopped placing people in cages in all the homes visited by the ECPT. However, Hungary continued to keep people in cages in the homes not visited by the ECPT. A public reporting process would have had much greater impact on Hungary and the region.

Question 39: Did you form the impression that your contribution was put to good use by the treaty monitoring bodies?

This question tries to bring to light the distinction between listening to a perspective and putting the knowledge thus gained to good use. Seven NGOs replied in the affirmative. This was high given the low level of engagement by the NGOs.

MDRI (United States) stated:

Yes in all three cases. The United Nations Human Rights Committee issued a favorable finding against the United States. As a result of MDRI's testimony before the Inter-American Commission, the Commission issued a finding against the government of Mexico. In accordance with MDRI's requests, the Inter-American Commission has also begun to conduct in loco visits to psychiatric hospitals in Latin America. The first such visit was conducted in Panama in 2001 and the Commission has promised to conduct additional visits in 2001.

On the other hand, one NGO stated:

No. But this situation can be improved if we are provided with the means to better supply the Committee with the type of information it is prepared to acknowledge.

To an extent, this points to a skills gap – a gap which means that the information in the possession of the NGOs cannot find an effective bridge into the system. Obviously, the question of enhancing the skills of disability NGOs with respect to the United Nations system is of vital importance.

B: Positioning to use the output

Question 40: Did your organization have a worked-out political strategy on how best to utilize the outcomes of international engagement in the domestic political arena? What did this strategy involve and did it work?

This question seeks to ascertain whether the disability NGOs anticipated positive results (from their perspective) and, if so, whether they had given any forethought to how to use this to advantage in the domestic context.

Five NGOs reported that they had given the outcome considerable forethought. One NGO confused the Standard Rules with the United Nations human rights treaty system. Most did not answer this question or replied in the negative.

It was generally the more resource-rich NGOs that reported the luxury of having a worked-out strategy on how to use a positive outcome of engagement. In reality, however, it is not a luxury but an absolute necessity if engagement with the United Nations machinery is to be successful for the people who count most.

C: Output

Question 41: What emerged concretely from your engagement with the treaty monitoring bodies?

There were very few responses to this question – which again reflects the low level of engagement by the disability NGOs with the treaty system.

One NGO stated that one result of engagement was “[a] few mentionings without any commitments”. As a positive outcome of engagement, Inclusion International mentioned:

Familiarisation with the process, and the means to better explain to our members how the CESC functions so that they can make use of it, in turn. Apparently, the Irish complaint was positively resolved.

The Deaf/Blind Association of Peru stated that “we will continue working on this engagement”. As a concrete outcome of engagement, the Deaf/Blind Association of Poland stated:

Improvements to Human Rights Commission; change in mental health legislation; advances in emergency legislation and police accountability; improvements in equality law.

Most of these outcomes did not directly affect people with disabilities. Nevertheless, the NGO was drawing a link between general domestic improvements and the capacity of the system to deliver specific improvements in the context of disability.

MDRI (United States) stated:

As a result of publicity generated by hearings in the Inter-American Commission of Human Rights (and the publication of a detailed investigative report), Mexico closed one of its most abusive psychiatric facilities. However, numerous facilities of this kind remain open in Mexico and much more attention to this issue is needed.

Attorneys litigating in New York Courts were able to use the factual finding by the United Nations Human Rights Committee on the abuse of research subjects. The New York Court of Appeals ruled that the use of people with disabilities in research violated US law, but the court did not cite the decision of the United Nations Human Rights Committee.

As a result of visits by the European Committee for the Prevention of Torture, a number of social care homes in Hungary terminated the use of cages. However, many other facilities continue to use cages in Hungary and other countries of Central and Eastern Europe.

Question 42: How did the States parties respond?

Again, very few NGOs responded to this question.

Inclusion International again cited improvements at an Irish mental health hospital as a result of engagement.

MDRI (United States) stated:

None of the States Parties responded through the oversight body, but in each case they did improve the protection of rights

The Irish Deaf Society stated “only promises and little action”.

DOLASED (United Republic of Tanzania), commenting on the State’s response, said: “[T]he truth is admitted. Lack of resources are still a major obstacle.” It is interesting that DOLASED focuses on the advantage that consists in getting Governments to face up to the truth and reality. The Polish Deaf/Blind Association reported that “the State response [depends]...on the issue involved”.

Question 43: Did you detect any change in domestic law or policy as a result of engagement?

It is often difficult to disentangle the effects of engagement with the United Nations human rights treaty machinery from other causes of law reform. More often than not, the reform comes about as a result of other factors. For example, the Polish Deaf/Blind Association stated that the United Nations engagement:

may have affected [the timing of change] as much as the content of the change.

Eight NGOs expressed the view that engagement either had been or could be of great use in moving the domestic reform agenda onwards. One of them again confused the United Nations human rights treaty system with the United Nations Standard Rules. The most positive response was from DOLASED (United Republic of Tanzania) which stated:

Yes. Legal reforms are going on to incorporate provisions of international law into domestic law.

It was unclear whether this was part of a general phenomenon of transcribing international law into domestic law or whether it had specifically to do with international law as it applies to persons with disabilities.

MDRI (United States) stated:

In every case we detected significant changes in practice. Changes in domestic law have been much more limited. Governments have promised changes in policy.

Question 44: Are States, in your view, beginning to anticipate possible negative outcomes (from their perspective) and is this inducing States to accelerate their programmes of law reform in order to deflect potential international criticism?

The interesting thing about this question was that, although very few NGOs actively engaged in the United Nations treaty system, they nevertheless acknowledged its growing significance in the context of disability. Thirteen NGOs felt that States were becoming more aware of the relevance of the international instruments in the context of disability and were taking steps in order to deflect criticism. This may be a negative reason for reform – but at least there is a perception that it is taking place.

Inclusion International stated:

We do observe a number of States either drafting and adopting disability legislation, or revising outdated laws so that they are more in line with contemporary expectations. But we observe that often this legislation is insufficiently put into practice, and that there are little or no sanctions to check implementation.

The FFO (Norway) reported recent developments in Norwegian anti-discrimination law without specifically relating them to fears by the State of potential exposure to international criticism.

An interesting twist was given to the question by DSI (Denmark) which stated:

The administration [State] fears that a disability convention will have an impact, also economically, and the negative attitude from the official side towards a convention is caused by the fear that it will give disabled people a right to go to court and get decisions that “disturb” the decided political decisions regarding the changes concerning people with disabilities.

One NGO stated:

Definitely, but States can be cynical about this and [it is] vital that NGOs remain engaged as outside third parties.

10.6. Part VI: The future

A: Your general judgement about the value of engagement

Question 45: Do you see engagement with the treaty monitoring bodies as beneficial?

The vast majority of the NGOs (37) responded in the affirmative. One or two pointed out that, though positive, such engagement was difficult.

Question 46: Would you like to enhance your level of engagement with the treaty monitoring bodies?

This was the more significant of the two questions as it probed an NGO’s willingness to engage with the machinery in the future. Again, 37 NGOs responded in the affirmative. This shows that there is a hunger for engagement. Only one NGO responded in the negative.

B: Improvements you might like to see in the performance of the treaty monitoring bodies

Question 47: What improvements, if any, would you like to see made to the existing arrangements for engagement with the treaty monitoring bodies?

Most NGOs stated that more information was needed on the operation of the treaty monitoring bodies and their remit in the disability field. A few addressed the need for financial support to enable NGOs to engage with the machinery.

MDRI (United States) gave a detailed response:

- (a) Much more detailed general comments are needed to explain the application of general human principles to people with mental disabilities.
- (b) Governments tend to ignore their obligations to people with mental disabilities under international human rights treaties. Very specific reporting requirements regarding the enforcement of human rights of people with mental disabilities would be of great assistance in bringing attention to these matters.
- (c) Human rights oversight of United Nations agencies and international development organizations would be of great assistance. MDRI has documented the abuse of human rights by international development organizations (run by the United Nations,

inter-government organizations, and private organizations that receive government funds), yet these groups are not held accountable to international human rights law.

- (d) Substantive improvements in the law are needed in a number of critical areas, including (1) better protections against discrimination, including the requirement of reasonable accommodations for people with psychiatric and developmental disabilities (2) a requirement that governments create better safeguards to protect against the abuse of people detained in psychiatric facilities, social care homes, orphanages, and other institutions for people with disabilities (3) stronger protections against coercive psychiatric or other treatment (4) stronger protections against arbitrary detention in psychiatric facilities (5) and requirements that governments provide funding to train and support advocacy by people with disabilities to assist in the implementation of the United Nations Standard Rules on Equalization.
- (e) More time and a greater focus on the rights of people with disabilities in the hearing schedule and public reports of oversight agencies.

Question 48: Would you like to see general comments developed under all the United Nations human rights treaties in the specific context of disability?

Interestingly, the vast majority called for the elaboration of general comments on disability under each of the human rights treaties. They clearly understood what general comments were and their significance in fleshing out the meaning of the treaties in the context of disability. CIL of Ireland stated:

Yes, in the spirit of building an inclusive society, it is the most appropriate way to progress. However, we support the call for a United Nations convention on the rights of disabled people as this would be a model of best practice and would provide the impetus and framework for the disability perspective and context to be woven into all United Nations human rights treaties.

C: Improving your own human rights capacities to take advantage of engagement possibilities

Question 49: What changes would you like to make to your organization, if any, in order to better equip your entity to have more of an impact through the treaty monitoring bodies?

Most NGOs responded that new or dedicated human rights staff and appropriate training were the most important factors in raising their own capacities. Some mentioned the need to build links with other disability NGOs. Resources were seen by most as a key to raising capacities.

D: A role for human rights training?

Question 50: Does your organization see a role for some body (whether INGO, university or research institute) in educating disability NGOs and INGOs in the human rights paradigm and equipping them to make the best possible use of the United Nations instruments?

About 30 NGOs responded positively to this question. Some were hesitant since they feared that control might not lie in the hands of the disability NGOs themselves. But most were enthusiastic about the need for more education and training.

Question 51: Do you have any ideas about how this might be done?

Many interesting ideas surfaced in answers to this question. Many NGOs were keen to stress that education and training should be undertaken with NGOs and not for them. Some were enthusiastic about engaging with universities, especially with the prospect of encouraging them to teach human rights and disability courses. One NGO (DAA, United Kingdom) was adamant that a welfare or charity approach should not be adopted in such courses.

E: Any other comments, observations or recommendations

Please use this space to make whatever comments, observations or recommendations you feel are relevant to the terms of this questionnaire.

Not many NGOs availed themselves of the opportunity to answer this question – presumably because most of the previous questions had given them plenty of scope for presenting their perspectives. A few NGOs stressed the importance of drafting an international convention on the rights of persons with disabilities. Some stressed the need for more information about the operation of the United Nations system in the context of disability. A few made welcoming comments on the initiative of undertaking a study. Two commented negatively on the questionnaire itself.

MDRI stated:

In addition to the formal use of international human rights oversight bodies, MDRI has used international human rights law in human rights reports. These have served as the basis of international human rights campaigns that have put political pressure on governments to make significant changes. While these successes demonstrate the tremendous value of international human rights law as it now stands, MDRI investigations in fourteen countries have demonstrated that existing international human rights law is still widely violated. Thus, in addition to developing better law, additional attention is needed by human rights oversight bodies and United Nations agencies to promote international attention and enforcement of existing law. Improvement of general comments, the creation of specialized oversight agencies (or a Special Rapporteur on Human Rights), or the development of a specialized convention on the rights of people with disabilities would be of great assistance.

MDRI has also worked extensively with mainstream human rights organizations that generally do not take disability rights seriously. The development of a specialized convention, or other specialized human rights oversight or enforcement mechanisms, would go a long way to raising interest and support of mainstream human rights organizations.

10.7 Conclusions on the NGO questionnaire

All in all, the results of the questionnaire were extremely interesting. The disability NGOs had clearly made the switch to the human rights perspective with vigour and enthusiasm some years ago. Yet they lacked knowledge and resources (including human resources) to capitalize on the switch and to begin using the United Nations human rights treaty machinery effectively. They were very honest and aware of their

shortcomings. Indeed, these are generally not shortcomings for which they can be held responsible.

NGOs that had engaged with the United Nations system were on the whole optimistic about its potential. Notwithstanding the relative lack of capacity of most NGOs to engage the United Nations machinery, they were mostly keen to do so. Clearly, there is a gap between supply (what the treaties have to offer) and demand (how the NGOs can articulate their claims). The NGOs can do a great deal, within existing capacity, to bridge that gap. But much more education and training are needed, as are as the resources to make this possible.

Chapter 11

National human rights institutions – catalysts for change

Gerard Quinn

At the beginning of this study it was asserted that using the United Nations human rights machinery should not be seen as an end in itself but rather as a means to an end. That end has to do with moving the process of domestic reform forward. National human rights institutions (national institutions) have the potential to make a meaningful contribution to this process. They can impart authority to the disability rights movement by validating it as a human rights movement. They can raise levels of awareness of the rights of persons with disabilities throughout society and in the policy-making apparatus. They can help to build the human rights capacities of the disability NGO sector. They can use their own resources to carry out research and conduct investigations into alleged violations of the rights of persons with disabilities.

It was therefore decided to complement the NGO questionnaire with a separate questionnaire targeted at national human rights institutions. This questionnaire was first circulated to national institutions when they met in Geneva during the 2001 session of the United Nations Commission on Human Rights (17 April 2001). It was further repeatedly circulated worldwide with the assistance of the Office of the United Nations High Commissioner for Human Rights.

Responses were received from all over the world: Danish Human Rights Centre, Disability Ombudsman of Sweden, Equal Opportunities Commission of Hong Kong, Equal Treatment Commission of the Netherlands, Human Rights Advisory Council of the Kingdom of Morocco, Human Rights and Equal Opportunities Commission of Australia (HREOC), Human Rights Commission of Mongolia, Human Rights Ombudsman of Bosnia and Herzegovina, Irish Human Rights Commission, Malawi Human Rights Commission, National Human Rights Commission (CNDH) of Mexico, Uganda Human Rights Commission, Zambian Human Rights Commission.

As not all national institutions responded to the questionnaire, the following analysis does not purport to be scientific or exhaustive. It does, however, give a flavour of the kinds of active steps that are being taken by national institutions to give greater effect to the rights of persons with disabilities and it amply demonstrates their potential in this regard.

The first three questions had to do with current levels of awareness in national institutions of the rights of persons with disabilities. Questions four to seven inquired about whether disability was currently on the agenda of national institutions. Question eight sought information about national institutions' record of action on disability. Questions nine and ten sought information about public inquiries or reports on

disability carried out by the national institutions or in association with other bodies. Question eleven focused on the relationship between national institutions and other specialized bodies in the field (e.g. disability commissions). Questions twelve to fourteen addressed litigation in the area of disability rights. Questions fifteen and sixteen focused on the role of national institutions in the field of disability rights education and in raising the human rights capacities of disability NGOs. Questions seventeen and eighteen looked at the contribution of national institutions to the broad disability law reform process. The responses are analysed below.

11.1 Level of disability awareness (questions 1-3)

This part of the questionnaire sought information about levels of awareness of the human rights perspective on disability among national institutions.

Question 1: Is your institution aware (or as aware as it would like it to be) of the human rights perspective on disability?

All national institutions that responded indicated that they were fully aware of the human rights perspective on disability and of its significance. This is heartening news.

Question 2: Is your institution aware (or as aware as it would like to be) of the various United Nations developments in the field of human rights and disability?

A majority of respondents stated that they were well aware of relevant United Nations developments in the field of human rights and disability. Again, this is very heartening news. The Irish Human Rights Commission claimed expertise in the field. The Mexican CNDH stated that its executive secretariat had carried out research on all the international instruments on human rights and disability.

Only three respondents replied that were not as aware as they would like to be. One of these respondents linked its relative lack of knowledge to the haphazard availability of disability rights information on United Nations web sites (see question 3 below).

Question 3: Where are the main knowledge gaps as you see them?

Most of the respondents identified areas in which major gaps in knowledge existed. One respondent (HREOC of Australia) stated:

Use of the Internet could be improved to make it easier to access all relevant international and comparative national experience on disability. For example, the resources on the United Nations Social and Development Commission's disability page...are very far from comprehensive even for resources within the United Nations system, providing no apparent reference to ILO activity in this area or of a consideration of disability activity by the treaty based human rights committees. Linkages to national institutions with significant disability roles...could also be expanded...

Other respondents pointed to the lack of adequate statistics, the lack of accessible information on disability issues in the United Nations specialized agencies, the lack of

any links between the OHCHR and national institutions on disability rights issues. One respondent (Equal Treatment Commission of the Netherlands) stated:

[Gaps occur in the following areas:] How to weight the various needs/rights of people with (different) disabilities? How to apply the – sometimes – rather vague standards in a national context? What should the Commission do to guarantee equal access to information, procedures, the right to a fair trial, etc. to people with disabilities, notably with mental disabilities?

These gaps are more relevant in a domestic context. But the fact that they are reported demonstrates that the respondent in question has a relatively good grasp of United Nations standards but is already taking the next step of trying to translate them into practical domestic policies.

The Mexican Human Rights Commission responded:

On occasion, it can be noticed that even when the complainants are people with disabilities, the complaints are not described as specific violations against people with disability, but rather as violations for given reasons. Greater rigour in the description of the complaint would be useful, and similarly, it would be important to be able to make the personnel of this Commission more sensitive to the different types of disability that exist and how these affect the life of the people who live with them.

11.2 The status of disability rights on the agenda of national institutions (questions 4-7)

This part of the questionnaire sought information about the status of disability as an issue on the agenda of national institutions.

Question 4: Does disability rank as a priority with your institution? If so, when and why?

The vast majority of the respondents stated that disability was a priority on their agendas and some said it had been since their establishment. The Danish Human Rights Centre answered that:

[Disability is a priority] [o]nly to the extent that the centre is heard and chooses to give a statement for the decision-making procedures at the Parliament.

The Human Rights Commission of Mongolia expected disability to become a priority shortly. The Australian Human Rights and Equal Opportunities Commission stated that disability was a priority partly because its parent legislation specifically referred to relevant United Nations soft law (United Nations Declaration on the Rights of Disabled Persons and United Nations Declaration on the Rights of Mentally Retarded Persons).

The Irish Human Rights Commission (established in July 2001) reported that disability ranked high in its Draft Strategic Plan.

The Mexican Human Rights Commission stated:

In 1995, with the aim of providing a more specialised way of dealing with the complaints presented by members of this vulnerable group, and thus produce the corresponding studies,

the National Human Rights Commission formed a working team made up of personnel of the State Complaints Office of the three Inspectorates (then in existence) and from the Executive and Technical Ministries.

Question 5: Does your institution make any operational distinction between physical and mental disability or between the various kinds of disability? If so, why?

Most respondents claimed that they made no operational distinction between the various kinds of disabilities. The attitude of this set of respondents was best summed up by the Australian HREOC:

No. The definition of disability in our legislation was intended to focus attention as far as possible on whether people are being discriminated against rather than on which specific type of disability they should be categorized as having: to avoid over-medicalisation of approach to disability in a human rights context; to avoid previous problems in achieving broad representation of disability community views because of the community being divided along diagnostic lines for service provision purposes...as well as avoiding problems with some previous legislation where people (for example with epilepsy) may fall between categories of mental and physical disability. Priorities for strategic action by our institution are set principally by reference to consideration of where there are options for effective action rather than by some sort of quota for each category of disability. Obviously, however, some issues and projects are more relevant to some disability categories than others.

The Human Rights Ombudsman of Bosnia and Herzegovina replied that the office makes distinctions “because it seems appropriate”. The Zambian Human Rights Commission replied that it makes distinctions because “the physically disabled persons can easily be trained to do some activities in different areas while for mentally disabled you have to rehabilitate the mental part and train them to do some activities.” Obviously, the Zambian Commission has in mind positive action for mentally disabled persons. The National Human Rights Commission of Mexico distinguished between three different categories of disability but used the same human rights rubric for all.

Question 6: Does your institution place any emphasis on gender and disability or on multiple forms of discrimination based on disability or overlapping with disability?

The national institutions were fairly evenly divided on this topic. The view of those who responded in the affirmative were best summed up by the Australian HREOC. It stated:

Yes. Principal emphasis is on ensuring that these multiple dimensions to a person’s identity do not exclude them from effective access to...participation in our activities – so, for example, ensuring that sex discrimination complaint processes and information are accessible to women with disabilities – rather than seeing people with disabilities as presenting only disability issues. Within disability work, the issue of the unlawful or unjustified sterilisation of women and girls with intellectual disabilities has been identified as a priority by women’s and disability organizations alike...

None of those who replied in the negative gave reasons.

Question 7: Do you set aside a person or body of persons in your institution to deal with the rights of persons with disabilities. Please specify?

Practically all national institutions replied that they set aside personnel to deal with disability rights issues. One national institution conducted disability rights work through a thematic working group on disability (Malawi). Another conducted its disability rights work through a thematic group on economic, social and cultural rights (Morocco). Most of the others reported that either members of their institutions or research staff or lawyers associated with their institutions possessed competence in the disability rights field and bore specific responsibility in this regard. The Equal Opportunities Commission of Hong Kong has a director with responsibility for disability. The Australian HREOC has a Disability Discrimination Commissioner appointed by law.

The only respondent not to have competence in this area was the Equal Treatment Commission of the Netherlands. It hoped to obtain such competence shortly through legislative changes.

These findings are remarkable. They show that national institutions are poised to make a meaningful contribution in the disability rights field. It could be held that designating staff to work on disability rights militates against mainstreaming. On the other hand, national institutions that have designated staff are very active on the disability issue or at least more active than national institutions that have not. It could be argued that the designation of staff is necessary at least in the medium term to bring the competence of national institutions on disability matters up to an acceptable international standard.

11.3 The disability rights record of national institutions (questions 8-11)

This set of questions focused on the activities of national institutions to date in the field of disability rights.

Question 8: Do you get many complaints from persons with disabilities or their representative NGOs? What kinds of complaints figure most prominently?

The great majority of national institutions had received complaints alleging violations of the rights of persons with disabilities. At least three respondents stated that most of the disability complaints concerned employment, access to goods and services, and education in that order (Mongolia, Sweden and Hong Kong).

The Zambian Human Rights Commission stated that many complaints concerned the resettlement of homeless persons with disabilities. The Danish Human Rights Centre received complaints but redirected them to another competent body. The Ugandan Human Rights Commission stated that it had not yet received many complaints. The Mexican Commission reported that 222 complaints concerning disability had been filed.

All in all, the national institutions were beginning to experience a rise in complaints alleging violations of the rights of persons with disabilities which, in turn, indicated a rise in the level of awareness of such rights and of the role that national institutions could play in providing redress.

Question 9: Has your institution held any general or public inquiries into the status of persons with disabilities (or specified groups of persons with disabilities) or their treatment within your jurisdiction? If so, please specify?

About half the respondents replied that they had held such inquiries and published major reports as a result.

The Australian HREOC held a major inquiry on the human rights of people with a mental illness in 1993. It also conducted a public inquiry on accessibility of electronic commerce and new service and information technologies to people with disabilities and older people. Other HREOC public inquiries concerned complaints dealing with cinema captioning for deaf and hearing impaired people, accessibility of mobile phones to people with hearing impairments, accessibility of the electoral process, and accessibility of railway stations to people using wheelchairs.

The Swedish Disability Ombudsman conducted a public inquiry into the extent to which Swedish municipalities comply with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1996, 1998 and 2000).

The Equal Opportunities Commission of Hong Kong has conducted several studies on disability rights: Case Study of the Kowloon Bay Health Centre (1999); Study on the Accessibility of Persons with Disabilities in Public Housing Estates (2000); Study on the Procedures and Training Needs of the Immigration Department in Handling Persons with Disabilities (2001).

The Uganda Human Rights Commission conducted a public hearing into the status and rights of persons with disabilities in late 2000. Its report on this topic is due out soon. It dedicated two recent issues of its journal (*Your Rights*) almost entirely to the rights of persons with disabilities (August 1999 and November 2000). These two issues of the journal are impressive as, among other things, they provided a forum for people with disabilities to speak for themselves and recount their experience in their own words.

The Human Rights Commission of Zambia carried out a survey of visually impaired persons who survived by begging in order to ascertain how they thought they might be resettled.

All of this activity is impressive. It shows that national institutions are sufficiently engaged to begin serious analysis of the various factors impeding the enjoyment of human rights by persons with disabilities within their jurisdictions. Sometimes this leads directly to change. More often than not, the resulting information and analysis contribute to or help to accelerate change.

Question 10: Does your institution contribute to inquiries held by other public authorities into the status of persons with disabilities or their treatment within your jurisdiction?

The vast majority replied that they had already actively contributed to inquiries conducted by other competent public bodies. The “other bodies” included law reform commissions. The Australian HREOC gave the example of contributing to a study by the Australian Law Reform Commission on the important topic of genetic discrimination. The Mexican Commission cooperated fully with a project on the incorporation and development of disabled people. Three national institutions stated that they would contribute to such inquiries if requested or if they felt they could add value.

These findings are positive. They show that the commitment of national institutions to the disability issue has reached the point where they are willing to reach beyond themselves to add value to the work of related bodies.

Question 11: Does your institution have an agreement (formal or informal) with other disability public bodies (e.g. national disability commissions or authorities) on how to work best together on disability matters? If so, please specify?

Just over half the respondents replied that they had either formal or informal agreements with disability-specific public bodies. Most of the agreements were informal. The Mexican Commission was particularly active. This phenomenon reveals that human rights bodies are beginning to find common cause with disability bodies and authorities – an excellent sign for the future.

11.4 Litigation on disability rights

This set of questions focused on how or whether national human rights institutions were using the legal process to advance the rights of persons with disabilities.

Question 12: Has your institution assisted persons with disabilities (individually or as groups) with litigation... What factors led you to support the litigation? What was the subject matter of the litigation? What were the outcomes?

Surprisingly, no national institution reported having assisted persons with disabilities to litigate through the courts. Two of them had not done so because it would be their responsibility to hear the case and assisting NGOs in this regard would create a conflict of interests (Australia HREOC and Swedish Disability Ombudsman). Most of the others stated either that they lacked the competence to do so or that they had not yet exercised that competence.

Question 13: Has your institution supplied amicus briefs in litigation involving persons with disabilities? If so, please specify?

Amicus briefs are submitted by third parties to ongoing litigation in order to add public interest perspectives that the courts might not otherwise be privy to.

Only one national institution (HREOC of Australia) reported having submitted an amicus brief to the courts. The issue concerned the sterilization of girls. All the others stated that they had not done so, but two affirmed that they had the competence to do so (Hong Kong Equal Opportunities Commission and Mongolia Human Rights Commission). One respondent replied that the submission of amicus briefs was beyond its competence (Danish Human Rights Centre). Another replied that there was no tradition of submitting amicus briefs in its country (Netherlands Equal Treatment Commission).

This finding is somewhat disappointing since national institutions can have a decisive bearing on ongoing litigation, or can at least indicate to courts where matters of principle arise and how they should be approached from the perspective of international human rights law. But perhaps this will be the next step as national institutions become more familiar with the human rights perspective on disability and the actual situation of persons with disabilities in their own jurisdictions.

Question 14: Has your institution instituted legal proceedings in its own name or on behalf of persons with disabilities?

Only one national institution (Swedish Disability Ombudsman) had instituted legal proceedings either in its own name or on behalf of individuals or groups of persons with disabilities. The Swedish case involved a man with a hearing impairment who had been refused employment allegedly because of his impairment. The Swedish Disability Ombudsman brought the case to court and is still awaiting the outcome. At least three other institutions indicated that they had the capacity to do so (Mongolia Human Rights Commission, Hong Kong Equal Opportunities Commission and Uganda Human Rights Commission). Most of the remainder simply responded in the negative without indicating whether they had the capacity to do so.

This is a somewhat disappointing finding. But perhaps again it simply reflects the differing capacities of national institutions with respect to litigation. Again – assuming a capacity to do so – this phenomenon will probably grow as national institutions become more familiar with the field and better appreciate the actual situation of persons with disabilities in their respective jurisdictions.

11.5 Education and capacity-building (questions 15 and 16)

This set of questions focused on national institutions' action to raise levels of awareness of the rights of persons with disabilities and to assist in developing the human rights capacities of disability NGOs.

Question 15: Do you include disability rights awareness as part of your overall education programme?

Only two national institutions replied that disability rights awareness was not included in their education programmes. The reason given related to competence (Danish Human Rights Centre and Netherlands Equal Treatment Commission).

All the others had included disability rights awareness, in varying degrees, in their educational programmes.

The Australian HREOC stated:

There is a particular disability focus in our education work for schools and in the promotion of our complaint procedure. Part of the function of the Office of the Commissioner in particular is to provide a public focus for disability and human rights issues.

The Mongolian Human Rights Commission stated that disability would be an important topic in its forthcoming human rights education and training programme.

The Swedish Disability Ombudsman does not specifically engage in education and awareness but many of the office's activities and reports have had an indirect positive impact on awareness.

The Hong Kong Equal Opportunities Commission stated:

Yes, in our educational programmes we always include the theme of disability rights, the need to mainstream disability perspectives in programme design, policy formulation and decision-making, and the protection afforded to persons with disabilities under the law.

These findings are welcome news as they indicate that national institutions are taking proactive steps to educate others about the rights of persons with disabilities. It is especially heartening to see such steps being taken in mainstream education programmes.

The Mexican Commission stated:

The Executive Secretariat has promoted the issue of people with disabilities, both from the international arena, and with the collaboration of the NGOs in line with the *Mechanism for Dialogue between the Interministerial Commission and the Organisations of Civil Society*, convened under the State Bureau of Human Rights of the Ministry of External Relations. Since November 2001 this Office has been heading the work of the roundtable of Vulnerable Groups, incorporating the views of people with disabilities within it.

Question 16: Do you help NGOs (whether traditional human rights NGOs or disability NGOs) to raise their capacity to participate in the democratic process in order to achieve the rights of persons with disabilities? If so, please specify?

Only four respondents replied that they did not help to raise the capacities of disability NGOs, one because it had no competence in this regard (Netherlands Equal Treatment Commission) and two because they had the capacity but had not yet used it (Uganda Human Rights Commission, Moroccan Human Rights Advisory Council). The fourth institution gave no reason (Zambian Human Rights Commission).

All the others replied in the affirmative. The Australian HREOC stated:

Yes. Introduction of disability discrimination was accompanied by the production of a manual for advocates on using the legislation. We have conducted a public inquiry on accessibility of electoral processes and are continuing to negotiate with electoral authorities following that inquiry. A major purpose in dealing with this issue in a public manner was to enable the participation of disability NGOs rather than treating it as an individual matter of concern only to an individual complainant.

The Mongolian Human Rights Commission stated that one of the goals of its new Strategic Plan was:

The enhancement of the human rights capacity in non-governmental organizations and other civil society organizations through training and partnerships.

The clear implication was that disability NGOs are specifically included.

The office of the Swedish Disability Ombudsman linked its activities in this regard to compliance with Rule 18 of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

These findings are good news. They show that national institutions are keenly aware of the importance of raising levels of understanding about human rights in disability NGOs and raising their levels of competence to use existing remedies and to participate effectively in the democratic process.

11.6 Disability and the law reform process (questions 17 and 18)

These two questions focused on the role of national institutions in keeping legislation that affects people with disabilities under active review.

Question 17: Does your institution make comments on draft legislation that affects persons with disabilities? Has that legislation been changed as a result of your comments/observations? If so, please specify

Only three national institutions replied that they had not commented on draft legislation or recommended changes in existing legislation in the context of disability. All three stated that it was within their capacity to do so.

The Australian HREOC replied that, owing to a lack of resources, it focused on questions relating to the improvement of disability discrimination legislation. The Swedish Disability Ombudsman stated:

According to the Act on the Disability Ombudsman, the Ombudsman has the task to work for correcting imperfections in national legislation and other statutes that affect persons with disabilities.

The Disability Ombudsman receives new proposals for legislation and proposals for amendments on reference for consideration. It is difficult to name situations when legislation has been changed solely because of our comments or observations, but the Disability Ombudsman has certainly contributed to improve the Act that prohibits discrimination of persons with disabilities in Labour life. The Disability Ombudsman has also provided basic data to the Government that has contributed to the National Action Plan for Disability Policy. Also the Disability Ombudsman has contributed to stop changes for the worse in support services.

The Hong Kong Equal Opportunities Commission replied:

The Government has consulted us on several occasions on the preparation of subsidiary legislation and codes of practice that would affect persons with disabilities. For example, the Labour Department consulted us on their proposed regulations requiring pre-employment and periodic medical examinations in respect of specified hazardous occupations. We advised that the proposed regulations would not conflict with the DDO if they were concerned with the protection of persons with disabilities. The Government made it public when enacting the regulations that they were for the protection of the safety of the workers.

The telecommunications Authority has also consulted us on their Code of Practice on the Provision of Telecommunications Services for the Elderly and People with Disabilities and accepted a number of our recommendations relating to accessibility and making reference to the DDO.

Recently the Social Welfare Department has been consulting us on their proposed code of conduct for drug treatment centers. We have commented on their proposed arrangements regarding pre-admission medical examinations. So far they seem to be receptive to our comments, though the drafting work has not been completed yet.

The use made by the Government of the Hong Kong Special Administrative Region (China) of the disability rights expertise of the Hong Kong Equal Opportunities Commission is highly commendable and a model for other Governments.

The Zambian Human Rights Commission stated:

Yes. The Institution made a recommendation to the Ministry of Social Welfare on how the disabled could be resettled [homeless disabled persons]. In turn the Ministry called an Inter-Ministerial Workshop [as a result of which] Guidelines on resettlement were agreed upon.

The Netherlands Equal Treatment Commission stated that it had made submissions to Parliament with respect to draft legislation on disability discrimination. It was too early yet to assess the impact.

The Mexican Commission stated:

At present it has two important projects imminent. This year it has participated in the working group that the Health Secretariat convened to revise and modify Official Mexican Norm NOM-001-SSA2-1993, which establishes the requisite frameworks to ensure that people with disabilities have access to and may be able to stay in the hospital establishments of the National Health System. It has also participated in draft bill of the General Law for the Social Integration of People with Disabilities.

The participation of the CNDH in the work of the Subcommission for Legislation and Human Rights of the National Consultative Council for the Integration of People with Disabilities has produced the bill for the General Law for the Social Integration of People with Disabilities, which will be presented to the Senate before the end of 2001. This bill contains the outlines established on the part of the CNDH for the protection of the human rights of people with disabilities, in line with how this institution has similarly pushed for the protection and promotion of human rights.

The above findings are positive. They show that national institutions are beginning to have an impact on the framing of public policy and legislation insofar as they touch on the rights of persons with disabilities. Equally striking is the extent to which Governments now seek the views of national institutions on how draft legislation may affect people with disabilities.

Question 18: Has your institution produced any general reports to your Government on disability matters? If so, what changes came about as a result?

All respondents except three replied in the affirmative. Those who replied in the negative stated that they had the capacity to report but had not done so yet.

In addition to its report on local authorities, the Swedish Disability Ombudsman has published (1) a report on strengthening the rights of pupils with disabilities; (2) a comparative study on the right to support in education; (3) a report on accessibility to administrative courts for persons with disabilities; (4) an interpretation of the Transport Services Act from a gender perspective; and (5) a report on discrimination in working life.

The Hong Kong Equal Opportunities Commission stated:

Our Report on the case study of Kowloon Bay Health Centre...contained two recommendations that have legal and judicial implications. One recommendation was that the EOC should be given the power to seek declaratory and/or injunctive relief in its own name in respect of unlawful acts under the anti-discrimination laws...The Government has agreed to this in principle and is working on the drafting of the necessary legislative amendments. The other recommendation is that the courts should exercise their discretion and order that the names of persons with a disability who are vulnerable, particularly persons with HIV/AIDS, should not be disclosed in court actions or reported in the media.

Although new, the Irish Human Rights Commission has already publicly endorsed an important NGO publication on advocacy for persons with disability. Such endorsement has helped to register the issue with the public at large.

The responses demonstrate that national institutions are highly active in producing research and practical reports aimed at influencing public policy and changing the law.

11.7 Conclusions

Our conclusions are tentative since the response level was not high, owing no doubt to pressure of work. Nevertheless, national institutions from all parts of the world responded. Our conclusions, while not scientific, give an indication of how national institutions are beginning to engage with the human rights agenda of persons with disabilities.

First, national institutions are generally well aware of the human rights perspective on disability and relevant United Nations developments. Some drew attention to the need to enhance disability rights information on United Nations web sites. Perhaps this suggests the need for a composite United Nations web site on the rights of people with disabilities – one that covers the United Nations Commission for Social Development, the United Nations specialized agencies and the United Nations human rights treaty monitoring bodies.

Second, disability now ranks high on the agenda of the respondent national institutions, either because the law so requires or because the institutions have raised its standing. Most institutions make no general operational distinctions between different impairments or disabilities but work from a general human rights or non-

discrimination perspective. Distinctions tend to be made only where they are clearly required to do full justice to the individual. The respondents seem evenly divided over whether gender and disability require particular attention. Some national institutions have designated specific staff (or members of the commissions) to deal with disability. Although this may not be politically correct since it appears to militate against mainstreaming, it tends to have worked well in practice, perhaps because the institutions are in a transitional phase.

Third, national institutions are beginning to experience an increase in the number of complaints filed by persons or groups with disabilities. This reflects the fact that people with disabilities are far more educated about their rights. National institutions have begun to undertake research on disability issues and their publications have a measurable impact. The institutions are beginning to link up effectively with other public bodies in order to advance the rights of persons with disabilities.

Fourth, litigation does not figure prominently yet as a tool for advancing the rights of persons with disabilities. This is partly for reasons of legal competence but it may have even more to do with the fact that national institutions are still at the lower end of the learning curve relating to disability and litigation will be the next step in their ascent. In any event, litigation is not always the best answer to complex problems. If national institutions can have a meaningful impact on the law reform process, this will alleviate to some extent the need for litigation. Still, levels of litigation are currently disappointing.

Fifth, national institutions are very active in raising levels of awareness about the rights of persons with disabilities and in equipping disability NGOs to make the most of the existing legislation. This is very positive news. Over time, the process of change should take on a momentum of its own as disability NGOs become more adept at using domestic legislation, international law and the democratic process. Here, the value of national institutions as catalysts for change more than proves itself.

Sixth, many national institutions have begun to play a very active role in commenting on draft legislation or making proposals to reform outdated legislation from the perspective of the rights of persons with disabilities. Again, this is very positive. Equally positive is the proactive use that Governments (e.g. that of the Hong Kong Special Administrative Region (China)) are making of such national institutions in disability matters. This shows that national institutions have the capacity to work as constructive partners with Governments in bringing about appropriate changes in law and policy.

If we have a recommendation to make from the foregoing analysis, it would be that some sort of forum should be established with the assistance of the Office of the United Nations High Commissioner for Human Rights in which national institutions could engage on a more ongoing basis with each other on disability rights matters (a **standing forum of national institutions on the human rights of persons with disabilities**). This would enable national institutions to exchange experience on how best to advance the rights of persons with disabilities.

We were also very favourably impressed with the recommendation of the Australian HREOC to the effect that a composite United Nations web site on the rights of persons with disabilities should be developed (incorporating the Department of

Economic and Social Affairs (DESA), the United Nations specialized agencies, the United Nations human rights treaty monitoring bodies, etc.) and that part of this web site should have a section devoted to the major initiatives of national institutions (reports, studies, case law, inquiries, seminars, etc.).

Chapter 12

Recommendations: Making the United Nations human rights machinery work better in the context of disability

Gerard Quinn, Theresia Degener

The analysis in Part 2 of the way in which the six human rights instruments are currently used in the context of disability and the results of the NGO and national institution questionnaires (chapters 10 and 11) provide the basis for our reflections, observations and recommendations on how the United Nations human rights treaty system could be made to work better for the estimated 600 million persons with disabilities worldwide.

These recommendations address the visibility – and therefore the effectiveness – of the disability perspective in the human rights machinery. Many directly address the human rights machinery. Some range further afield and are not so much recommendations as observations on what needs to happen in a holistic sense if real change is to occur.

12.1 States parties – towards a more sustained focus on persons with disabilities as the beneficiaries of the human rights treaties

Many States parties already report actively on disability as part of their periodic reporting obligations. There is a marked trend away from disability as a welfare issue and towards disability as a rights issue. This good practice is encouraging. It is based on the philosophy that people with disabilities are not problems but have rights. The problems are largely due to social and economic processes that are insufficiently sensitive to accommodate the difference of disability.

1. The time is right for States parties to step up their efforts to treat disability as a broad human rights issue and to report regularly on progress made and obstacles encountered in achieving equal rights for the disabled.
2. States parties should be encouraged to consult more closely with disability NGOs – especially NGOs of persons with disabilities - in the drafting of their periodic reports. Naturally, final responsibility for the drafting of such reports rests exclusively with the States parties. Nevertheless, dialogue with the ultimate beneficiaries of human rights can only serve to raise awareness of the rights of persons with disabilities and of the peculiar human rights problems that can arise.
3. States Parties should be encouraged to nominate persons with disabilities for election to the treaty monitoring bodies.

12.2 Treaty monitoring bodies – towards the mainstreaming of disability

The treaty monitoring bodies have shown themselves to be receptive to the idea of disability as a human rights issue. Naturally, many different issues and groups compete for their attention. Nevertheless, scope still exists for greater enhancement of their focus on the situation of persons with disabilities.

1. To clarify the relevance of the various human rights standards in the context of disability, the treaty monitoring bodies should give active consideration to the elaboration of disability-specific general comments or recommendations.
2. The treaty monitoring bodies should give active consideration to setting aside a day of discussion or a similar occasion for reflection on ways of enhancing their understanding of disability issues and on the relationship between disability and their respective treaties.
3. The list of issues sent to States parties should regularly include disability even when disability is not mentioned in the report. Exploring the human rights dimension of disability should become a more routine part of the work of the treaty monitoring bodies. It should not depend on whether disability has been mentioned in a State party report.
4. The dialogue with States parties should regularly include references to disability.
5. The concluding observations/comments and recommendations of the treaty monitoring bodies should contain references to disability, if only to request more detailed information from a State party in its next report.
6. When States parties refer to disability and showcase positive developments in their reports, these developments should be alluded to in the concluding observations/comments in order to highlight good practice.

12.3 The Office of the High Commissioner for Human Rights – advancing disability as a human rights issue

The OHCHR is to be commended for the attention it gives to the issue of the human rights of persons with disabilities. People with disabilities are, as a result, becoming much more visible and prominent within the human rights system. More can be done to build on the current momentum and to carry forward this positive development.

1. Disability issues (and knowledge about disability issues) are widely dispersed throughout the United Nations system at present. The Department of Economic and Social Affairs (DESA) of the United Nations Secretariat has made excellent progress in presenting as much information on disability as possible on its web site. There is a need for a counterpart web site in the human rights field, a site that

would direct users – whether States parties, treaty monitoring bodies or persons with disabilities themselves – to all relevant human rights documentation on disability. It should enable users to access relevant developments with respect to disability in the workings of the treaty monitoring bodies. It should be linked to the DESA site and to the disability activities of the relevant specialized agencies and the various national human rights institutions.

2. This study represents a first step towards clarifying the relevance of human rights standards in the context of disability. A great deal more needs to be done. Further thematic studies of disability from a human rights perspective are needed, particularly on intellectual disability and the double discrimination experienced by women with disabilities. Other priority topics that suggest themselves in the light of our analysis in Part 2 include the right to education for children with disabilities and the situation of persons with disabilities in institutions. Practical manuals and guides will also need to be compiled to assist actors in civil society.
3. At least one staff member should be assigned on a full-time basis at OHCHR to work on disability and human rights issues. Among other things, such a person could coordinate useful studies and other activities, including the organization of high-profile human rights seminars on the rights of persons with disabilities.
4. The Office should clearly signal that it welcomes applications for internships from persons with disabilities.
5. The Office could play a useful role in stimulating teaching and research relating to disability as a human rights issue. Universities have played a crucial role in disseminating general human rights knowledge for the benefit of all. However, they have been considerably under-utilized in spreading the message about disability as a human rights issue. There is a need for a network of disability human rights studies and the Office should explore ways and means of facilitating the emergence of such a network.
6. There are many players in the area of disability in the United Nations system, not least DESA and the various specialised agencies. In some respects, the human rights system is the latest player to emerge. It is important to ensure that the human rights perspective on disability is owned by all actors. The Office can play a useful lead role in clarifying the significance and implications of the human rights perspective on disability. All players in the United Nations system have something important to offer and all should find ways of searching in common for innovative approaches to disability. If an inter-agency group on disability does not yet exist, it should be established with the Office as one of its key members.

12.4 United Nations Commission for Human Rights – bringing disability onto the agenda

The Commission on Human Rights has begun to take a very active interest in disability issues, as reflected most clearly in its 1998 and 2000 resolutions on disability. This momentum is of tremendous significance, as it demonstrates that disability is a mainstream human rights issue.

1. The Commission should sustain and enhance the process of mainstreaming disability as a human rights issue. It might do so by setting aside a thematic day of discussion on disability and human rights. As disability has only recently entered the mainstream, this would provide a learning opportunity for all.
2. The Commission should consider appointing a special rapporteur on the human rights of persons with disabilities. At a symbolic level, such an appointment would indicate the gravity and urgency with which the Commission treats the issue of disability. It would ensure that people with disabilities at last enjoy visibility in the world's foremost human rights organ and would also create a useful focal point in the human rights treaty system. The rapporteur could help to provide the treaty monitoring bodies with appropriate insights and perspectives. S/he could alert them to negative trends or impending issues requiring analysis and forethought. Obviously, such a special rapporteur would have to develop a close working relationship with States parties and civil society throughout the world.

12.5 National human rights institutions – enabling reform to come about

National human rights institutions are already actively involved in the issue of disability and human rights. This is highly encouraging since international law will always need to be interpreted and applied in a way that corresponds to local circumstances.

1. National human rights institutions – whether operating on a regional basis or otherwise - should actively consider forming a working group on disability and human rights. Such a forum would enable them to deepen their understanding of disability as a human rights issue and to engage in useful exchanges of experience. National institutions should be facilitated in this regard, to the extent possible, by the Office of the High Commissioner for Human Rights.

12.6 Civil society – disability NGOs as human rights NGOs

Disability NGOs now generally see themselves as human rights NGOs. This matches the move towards a human rights framework of reference in the field of disability. They are slowly beginning to look towards the United Nations human rights system as a source of inspiration and of useful legal doctrine.

1. We recommend the establishment of some form of “international human rights disability watch”. The human rights system responds to relevant information and insights. Our analysis shows that disability NGOs clearly possess the knowledge but often fail to engage with the human rights system. Although they have the knowledge, they are unable to harness its full potential. There is therefore a need for a new kind of disability NGO – or amalgam of NGOs – with a clear mandate to monitor human rights developments around the world as they affect persons with disabilities. It could usefully engage in local and regional training and education programmes on human rights and disability. The formation of such a group could have multiplier effects throughout the world.
2. Innovative ways of funding such an entity should be sought. To its credit, the Swedish International Development Agency (SIDA) already funds a major and very successful disabled children’s rights NGO project which is headquartered in London. The success of this venture demonstrates what can be done. The development agencies of other countries should be encouraged to follow suit.
3. Disability NGOs should work more closely with established or traditional human rights NGOs in order to benefit from their experience and to help them, in turn, to mainstream disability in their own agendas.

Chapter 13

Expanding the system: the debate about a disability-specific convention

Gerard Quinn, Theresia Degener

It must be said that at the end of the period [since the adoption of the World Programme of Action], persons with disabilities are going to find themselves in a legal disadvantage in relation to other vulnerable groups such as refugees, women, migrant workers, etc. The latter have the protection of a single body of binding norms [the text then lists the thematic conventions].

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

Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Human Rights and Disabled Persons* (United Nations, 1993), paras. 280 and 281.

13.1 Growing support for a thematic convention

The debate about whether a thematic convention on the rights of persons with disabilities should be drafted and adopted is not new. It was first seriously mooted in 1987 at a Global Meeting of Experts to Review the Implementation of the World Programme of Action. The draft outline of a convention was in fact prepared by Italy and submitted to the General Assembly. At a subsequent General Assembly, another effort at placing a convention on the agenda was made by Sweden but with no success (see chapter 2).

The idea of a convention has been ardently supported by many disability INGOs and NGOs in recent years. A World NGO Summit on Disability was held in March 2000 in Beijing. It was attended by leading INGOs, including Disabled People's International, Inclusion International, Rehabilitation International, the World Blind Union and the World Federation of the Deaf, and by other NGOs of and for people with disabilities from all continents. It produced the Beijing Declaration on the Rights of People with Disabilities in the New Century, through which the disability INGOs lent their very considerable moral authority to the idea of a convention. It stated:

5. We share the conviction that the full inclusion of people with disabilities in society requires our solidarity in working towards an international convention that legally binds nations...
6. We believe that the inception of the new century is an opportune time for people with diverse disabilities and their organizations ... members of the United Nations system ... to collaborate closely in an inclusive and wide consultative process aimed at the development and adoption of an international convention...
7. We therefore urge all heads of state and government ... to immediately initiate the process for an international convention ...
- ...
9. We hereby send out a call to action ... to ensure the adoption of an international convention on the rights of all people with disabilities.
10. We commit our respective organizations to strive for a legally binding international convention...

The Rehabilitation International Charter for the Third Millennium (1999) specifically calls on States to “support the early promulgation of a United Nations Convention on the Rights of People with Disabilities”.

The 1998 resolution of the Commission on Human Rights on disability initially contained a paragraph on the need for a convention but it was withdrawn when it appeared not to attract sufficient support. In November 2001 the Third Committee of the United Nations General Assembly came out squarely in favour of a convention subject to the recommendations of the Commission on Human Rights and the Commission for Social Development (see chapter 2).

The move to a human rights framework in the field of disability makes it all the more important to ensure that the existing instruments are used to best advantage. Even if the Commission on Human Rights and the Commission for Social Development endorse the concept of a convention, it will take some time for an appropriate instrument to be drawn up. It is certainly not something that should be rushed.

Indeed, even if a convention is adopted at some point in the future, it will still be necessary to obtain maximum advantage from the existing human rights instruments. As the Hong Kong and New York expert meetings reported (see chapter 2), the adoption of such a convention should be seen as a complement to, and not an enemy of, the existing instruments.

13.2 A thematic convention as a way of enhancing the “visibility” of people with disabilities in the human rights system

The most important argument for a convention is perhaps that of “visibility”. As may be gathered from the analysis in Part 2, it has proved extremely difficult to keep people with disabilities in focus in the proceedings of the treaty monitoring bodies. To some extent this is due to the relative lack of engagement of the disability NGOs with the treaty monitoring machinery. And to some extent it is due to the lack of general comments by the treaty monitoring bodies on disability - or the kind of forethought that these general comments represent.

Action on the recommendations in chapter 12 will hopefully go a long way towards remedying this invisibility. However, it must be frankly acknowledged that the treaty monitoring bodies will continue to have many different constituencies to keep in focus and many intractable and general issues to wrestle with. The pressure they are under is bound to increase. In other words, there is probably a limit to the extent to which these bodies can focus on disability – a limit that is explained by other pressing priorities. This is in no sense a criticism of the bodies concerned. It is simply a recognition of the reality that other matters will always compete for their attention.

The thrust of the visibility argument is that a sustained focus on the rights of persons with disabilities is needed to ensure consistent treatment of their rights. In time, such a focus would broaden and deepen genuine human rights expertise on disability. It could lead to more telling and probing reporting guidelines – guidelines that might encompass areas that are not covered at present such as the institutionalization of people with intellectual disabilities. This expertise would inevitably have a positive impact on the operation of other treaty monitoring bodies. In other words, a disability-specific convention could prove to be the best possible catalyst for the mainstreaming of disability in the existing treaty monitoring machinery. The adoption of the Convention on the Elimination of All Forms of Discrimination against Women has certainly led to heightened awareness among the treaty monitoring bodies of the gender dimension of all human rights issues.

The visibility argument is also symbolic. To consign six hundred million people to the episodic consideration of six different treaty monitoring mechanisms does not do full justice to them. A specific convention would at least signal to the world that this section of the population exists and has equal rights, hopes, dreams and aspirations.

13.3 The practical benefits of a thematic convention

We have found dismally low levels of engagement by disability NGOs with the treaty monitoring machinery. However, these levels should rise if the recommendations contained in chapter 12 are acted on. There is at present little incentive to engage and disability NGOs who do so encounter high opportunity costs. Sometimes they have to juggle with calculations about whether it is best to agitate domestically for a better deal for their members or to engage in a principle-based process at many removes from local issues.

Moreover, disability is something that affects every sphere of human existence. Although it is possible at an intellectual level to separate these spheres (the social sphere, the environment, health care, abuse, culture), it is not possible to fragment the persons concerned. As an intellectual exercise, the Standard Rules are successful precisely because they adopt a holistic approach. All issues (or most of them) that affect people with disabilities may be combined in a single intellectual structure. At present, however, in the area of binding international law, disability NGOs have to disperse their attention and scarce resources among six different instruments.

It would make much more sense to encapsulate the relevant human rights standards in a single legal instrument. It would clarify States parties' obligations and it would give disability NGOs a clear target – one that is dedicated to disability rights in a holistic sense. The tightness of this focus would encourage NGOs to use the system to a

greater extent and in a better way. This, in turn, could potentially enable international law to accelerate positive developments within States.

13.4 The human values of dignity, autonomy, equality and social solidarity as the key to the content of a thematic convention

To some extent, the content of such a convention is a question of detail best left to potential drafters. Yet it is also a question of principle since it has a bearing on the arguments for and against a convention. It is commonly said, for example, that such an instrument should merely involve cutting and pasting norms that are directly relevant to disability from those already contained in the six human rights instruments and that anything else might undermine existing human rights norms. Clearly, such a mechanical approach to the task would be fruitless.

The key to the question of content lies in the related human values of dignity, autonomy, equality and social solidarity – notions that cut across all six instruments and manifestly underpin the United Nations Standard Rules. It will be recalled that the two most recent disability resolutions adopted by the United Nations Commission on Human Rights drew a clear link between violations of equality and non-discrimination (as evidenced by the United Nations Standard Rules) and violations of human rights. It follows that the basic task is to tailor the relevant norms of the existing human rights treaties to the circumstances of disability in such a way as to clear a path into the mainstream and to create genuinely inclusive and equal societies. Such tailoring should be informed by the need to secure equal rights and equal opportunities for all without discrimination. Moreover, such tailoring of the lofty generalities of the general treaties is normal in thematic conventions that address group situations. It should not be seen as undermining the general norms themselves but rather as endowing them with life in a particular context.

13.5 The new freedom agenda and disability: the interdependence of all human rights

Still on the subject of content, reference should be made to another important matter of principle. The need for a holistic approach to disability is consonant with the postulate that civil and political rights, on the one hand, and economic, social and cultural rights, on the other, are interdependent and interrelated. Tangible material support is necessary to convert formal freedoms into real freedoms for people with disabilities. This is not the freedom of welfare, which places people with disabilities in gilded cages and locks them into cycles of dependency and despondency. It is economic, social and cultural justice, which liberates people with disabilities so that they can play their part in – and contribute their share to – inclusive societies.

People with disabilities have made considerable headway within the jurisprudence of the Committee on Economic, Social and Cultural Rights. It is time to marry social justice with the freedom agenda. There can be few more fitting subjects on which to ground the interdependency thesis than disability. Indeed, the drafting of a convention relating to disability without thinking creatively about marrying the two sets of rights is inconceivable.

13.6 A thematic convention as an aid to the mainstreaming of disability in United Nations human rights instruments

It may be argued that drawing even more attention to people with disabilities through, for example, a disability-specific treaty will only serve to heighten their difference and perhaps, in turn, increase their marginalization. This fear generates what is called the dilemma of difference. The theory is that if policy-makers draw attention to the difference by handling it in a separate instrument, they may end up perpetuating the stereotypes that create the problem of marginalization. However, if they ignore the difference – or bury it in a general or common legislative template – they may avoid fuelling stereotypes but at the cost of ignoring the difference that actually exists.

This is a genuine fear and it may create a backlash in times to come. However, it should be pointed out that no such fears prevented the adoption of thematic conventions on women, children and racial minorities. It is hard to see why this negative reaction should occur in the field of disability and not in other fields. Indeed, if the objection had been taken literally, even the United Nations Standard Rules would not have been adopted. In any event, one of the main motivations for a disability-specific convention is precisely to accelerate the mainstreaming of disability in the six existing instruments. International law is not like domestic law. The elaboration of a disability-specific convention does not come at the cost of excluding disability issues from the mainstream instruments. Quite the reverse.

13.7 The mutually reinforcing roles of a thematic convention and the United Nations Standard Rules

It may be objected that a convention would undermine the Standard Rules. But the Standard Rules and the existing human rights instruments share the same bedrock commitment to dignity and equality. These values could only be amplified in a legally binding instrument. Hence, the adoption of a convention could be seen as a triumph for the logic and spirit of the Standard Rules.

In any event, the Standard Rules could continue to play a highly useful role even after the adoption of a convention for a very important reason. Legal instruments tend to focus on violations. A cautious approach is adopted to the inclusion of programmatic dimensions in order to avoid over-legalizing matters that should best be left to the discretion of policy-makers (at least within broad parameters). Thus, the Standard Rules could usefully complement the convention by continuing to focus on broad policy and systemic issues. Their programmatic focus would thus serve to enrich the analysis of violations under a convention.

On balance, we do not view the urgency of enhancing the use of the existing instruments and the option of adopting a disability-specific or thematic human rights treaty as a zero-sum game. Hopefully, action on the recommendations in chapter 12 will go some way towards making the existing system more effective for people with disabilities. The need to do so will arise and persist whether or not a convention is adopted. By the same token, a convention would mark a huge step forward and should not undermine but underpin the protections provided in the existing six human rights treaties.