1. Introduction

“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 of being treated by 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.”

It might surprise some of you here tonight that Bengt Lindqvist, the UN’s Special Rapporteur with responsibility for disability, felt the need to utter these powerful words as recently as 2000. Disability, however, has not traditionally been understood as a human rights issue and such an understanding remains very far from universal. For the past three decades the Disability Movement has worked tirelessly to challenge the assumption that, unless a person with an impairment can be cured or corrected (eg through a hearing aid or drugs), they must remain outside the mainstream of their society and, unable to participate in education or employment, become dependent on welfare or charity for their survival.

The Disability Movement has argued that disabled people should be valued as equals. They should be viewed, not merely as somewhat burdensome objects of pity and charity, but as human beings who, like their non-disabled counterparts, are entitled to enjoy the fundamental human rights granted to all. It is from this conviction that the emerging UN Convention on the Rights of People with Disabilities was born. Before examining that Convention further, it is worth devoting a few words to the nature and the extent of the exclusion and marginalisation currently experienced by disabled people.

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1 School of Law and Centre for Disability Studies, University of Leeds. Much of the material contained here was included in an earlier paper delivered at the Inter-rights satellite event in the Commonwealth Law Association Conference, London, 13 September 2005. I am grateful to the organisers of and participants at that event for their comments and contributions.

2. Extent of the Problem

There are an estimated six hundred million disabled people in the world, seventy per cent of whom live in developing countries. It is now well-established that there is a strong link between disability and poverty, disabled people tending to be amongst the poorest in all societies. In addition to poverty, disabled people generally face exclusion and isolation. This is sometimes the result of express policies to keep them hidden from view. More usually, however, it is the result of architectural, physical, social, legal and attitudinal barriers which (often unintentionally) make it impossible for them to participate in the world around them.

The extent of the global marginalisation of disabled people was documented in Liandro Despouy’s 1991 report (commissioned by the UN). He recognised that disabled people “frequently live in deplorable conditions, owing to the presence of physical and social barriers” with the result that millions of them “are segregated and deprived of virtually all their rights, and lead a wretched, marginal life”. Ten years later the Eurostat Report indicated that, within Europe, disabled people continued to face exclusion and marginalisation.

More recently, in two reports published as part of the International Disability Rights Monitor project, disturbing evidence of the problem continues to emerge. The first of these reports, published in July 2004, related to disabled people living in twenty-four countries in the Americas. According to it, in many of these countries, disabled people risked being declared legally incompetent simply by virtue of their impairment and thereby losing numerous important rights (including the right to vote and the right to liberty). The most common ground for such a fate was mental impairment but in seven of the countries sensory impairments (such as blindness or deafness) also provided grounds for such declarations of incompetence.

The report indicates that “many people with disabilities face involuntary institutionalisation in countries throughout the region resulting in some of the most blatant and abusive human rights violations”. Reference is made to cases in which such people “were kept in rooms soiled with their feces” or “denied clothing or forced

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7 Ibid p 15.
to eat off the floor”. In other cases, disabled people were kept in jail for decades without trial because they were thought to be “unable to go to court”.

Disabled people enjoyed a meaningful right to vote in only a few of the countries covered. Elsewhere they frequently faced “inaccessible polling places, a lack of information regarding the political process, and occasionally, disdain from election officials”. Accessible bus systems operated in the capital cities of only a fifth of the countries covered and fewer than half of them possessed an accessible post office.

Only an estimated twenty to thirty per cent of disabled children attended school in most of the countries; the problem being particularly marked in relation to children with more severe impairments and at post-elementary education level. Similarly, only thirty per cent of disabled people were estimated to find employment across the region. Even for those in employment, poverty was often inescapable. The report notes that:

“Mexico reports that 14% of those who are working receive no pay and another 22.6% receive less than a minimum wage. Similarly, in Brazil, 30% of persons with disabilities receive less than a minimum wage.”

The second IDRM report, published in July 2005, covered seven countries in Asia. Similar marginalisation to that noted in relation to the Americas was reported in the fields of employment, education, health access and housing. In relation to institutions housing disabled people, too, human rights violations were noted. Reference was also made to the fact that the law itself, on occasion, operated to exclude disabled people. For instance, in four of the seven countries there were laws which prevented disabled people (generally but not exclusively those with mental impairments) from voting.

The two IDRM reports demonstrate clearly that disabled people continue to be marginalised and excluded from mainstream society in a great many ways. Although the information gathered to date under this project relates to only two continents, it reveals patterns which echo those revealed by earlier studies in other parts of the world. The problems faced by disabled people have clearly not yet been solved. In the words of Dr William Kennedy Smith (founder of the International Disability Network):

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8 Ibid.
9 Ibid.
10 Ibid p 12.
13 Ibid.
“The sad fact is that … few countries show signs of thinking about or planning to include people with disabilities in national life. People with disabilities are often invisible. Ignored by policy makers and planners, warehoused in institutions, forgotten, neglected and frequently abused.”

3. Response of the UN

3.1 The Need for a Disability-Specific Convention

The international human rights framework does not explicitly exclude disabled people from its protection. The rights conferred by it are universal in nature and therefore conferred on all people simply by virtue of their humanity. Thus, signatory States are required to grant to disabled people, as well as to everybody else, rights such as the right to life, to be free from torture and inhuman or degrading treatment, to liberty, to associate freely with others, to vote and to stand for office (conferred by the International Covenant on Civil and Political Rights); and the right to education, to health and to housing (conferred by the International Covenant on Economic Social and Cultural Rights).

The relevance of the rights conferred by the ICESCR to disabled people formed the basis of the Committee on Economic, Social and Cultural Rights General Comment No 5 in 1994. This stressed the essential link between the meaningful enjoyment of these economic and social rights by disabled people and their ability to participate actively in their communities. Indeed, the Committee specified that, within the context of the ICESCR, disability-based discrimination included “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” and, in order to counter it, urged States to introduce anti-discrimination legislation.

In 1982 the General Assembly adopted the World Programme of Action Concerning Disabled Persons (WPA) and declared the following ten years to be the UN Decade of Disabled Persons. It marked the end of the Decade by adopting the non-binding UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993. The emphasis of the Standard Rules is firmly on the need to promote the equality of disabled people and to facilitate their inclusion. Their message is powerful but their effect is merely persuasive and not mandatory.

15 IDRM Regional Report of the Americas, above note 6, p xxi.
17 Ibid at para 15.
18 Ibid at para 16.
Despite the theoretical availability of human rights to disabled people, and such efforts to promote them as those outlined above, there remained concern that these rights were not being conferred on disabled people in practice. This issue was fully explored in an extremely significant and influential study on disability and the UN by Gerard Quinn and Theresia Degener in 2002. It identified the “invisibility” of disabled people as the “core problem” underlying their inability, to date, to take full advantage of the UN human rights framework. According to it:

“Invisibility has … 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.”

Its authors (leading figures in the disability movement) argue that a thematic convention on disability would play an important role in the execution of this task and that it would “immeasurably advance the rights of persons with disabilities.” These points were echoed recently by Louise Arbour, the UN High Commissioner for Human Rights. According to her:

“There is no doubt that the existing human rights system was meant to promote and protect the rights of persons with disabilities. There is also no doubt that the existing standards and mechanisms have in fact, failed to provide adequate protection in the specific case of persons with disabilities. It is clearly time for the United Nations to remedy this shortcoming.”

3.2 Progress to Date

On 26 February 2002, the General Assembly of the United Nations adopted a resolution to establish an ad hoc committee to consider proposals for a “Comprehensive and Integral International Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities”. That Committee has now met seven times. The latest session concluded on 3 February 2006 and included a merciful

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22 Ibid at para 1.3.
23 Ibid at para 1.3.
24 Ibid, Executive Summary.
25 Statement delivered to the Ad Hoc Committee on the elaboration of ??? on 27 Jan 2006.
27 Details of its meetings can be viewed on the UN Enable web site at: http://www.un.org/esa/socdev/enable/rights//
reduction in the length of the title, the new name being the “International Convention on the Rights of Persons with Disabilities.”

In January 2004, a working group produced a draft text of the convention. This formed the basis of the discussion of the Ad Hoc Committee in its third, fourth, fifth and sixth sessions but which, in October 2005, was replaced by a restructured version which formed the basis of discussion in the seventh session. Although intense debate about some of its provisions continues, the Committee aims to finalise the instrument by the end of its eighth session which is due to take place from 14-25 August 2006.

3.3 Content

Time constraints prevent a detailed examination of the content of the Draft Convention here. Nevertheless, a general idea of its nature and scope may be conveyed by mention of a few of its provisions.

The obligation on States to ensure that the needs of disabled people are met through the provision of reasonable accommodation is one which recurs throughout the draft convention. Article 5 (on Equality and Non-Discrimination) recognises that disabled people are entitled to the equal protection of the law and requires States to take all appropriate steps to ensure that reasonable accommodation is provided to them. It also obliges States to prohibit all discrimination based on disability.

Article 19 (on Living Independently and Being Included in the Community), would confer a right on disabled people to choose their own living arrangements on an equal basis with others, preventing States from requiring them to live in institutions against their will and requiring States to provide those who choose to live in the community with support designed to facilitate their independence and inclusion. Article 12 (on Equal Recognition before the Law) would require States to adopt a model of supported (as opposed to substituted) decision-making, for disabled people who would otherwise find it difficult to exercise their full legal capacity.

Article 25 provides that disabled people should be entitled to receive health services on an equal basis with others and that States should, in addition, provide them with services relating specifically to their impairment. Under Article 17, States would be required to protect disabled people from forced interventions or forced

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28 A change agreed on Day 11 (30 Jan 2006).
30 Set out in a letter from the Chair to all members of the Ad Hoc Committee dated 7 Oct 2005 and available on-line as one of the documents of the 7th Session (document no A/AC.265/2006/1).
31 This issue was identified by Ambassador McKay (chair of the Ad Hoc Committee) as one of particular difficulty in a press conference to mark the end of the 7th Session on 3 Feb 2006.
institutionalization aimed at correcting, improving or alleviating any actual or perceived impairment. Article 23 would give disabled people, on an equal basis with others, the right to marry, to retain their fertility and to have support from the State in the performance of parenting roles where this was needed. Finally, Article 20 would oblige States to facilitate the personal mobility of disabled people through measures designed to ensure their access to appropriate aids and training.

4. Examples of On-Going Concerns and Debates

4.1 Achieving the Appropriate Standard

Although the purpose of the proposed convention is to clarify and consolidate rights already conferred on disabled people, and not to confer new rights upon them, its provisions are far from uncontroversial. Some of them would require significant changes to the law and practice of many States.

The disabled people’s representative for the UK on the Ad Hoc Committee, Richard Light, reports a regrettable but perhaps inevitable reluctance on the part of some States to agree to provisions which will require them to depart from the status quo. In the conclusion to his report on the Fifth Session of the Ad Hoc Committee, he writes that:

“Too many UN Member States continue to take a restrictive approach to the Convention: rather than seeking to ensure equal protection of our human rights, States appear to seek text that requires little or no change to law and policy currently existing. Whilst it may be unrealistic to expect text that would require drastic change in most jurisdictions, I fear that the balance is tipped toward maintaining the status quo, to the detriment of ensuring effective protection.”

The convention, however, will serve its purpose only if its elaboration of the human rights to be enjoyed by people who are disabled is set at a standard comparable with that set for people who are not disabled. On this there can be no compromise. Nevertheless, in the view of Richard Light and other disability activists, it is not clear that such a compromise will not be made. Although Richard Light’s review of the Chair’s revised text identifies a number of areas of concern in this regard, one example is all that space permits here. Article 17(4) currently regulates, but permits the involuntary treatment of disabled people in situations where they might oppose the intervention concerned. It would thus, according to Light, appear to allow practices such as the “forced cochlear implants on children who are Deaf or hard of hearing and the fitting of leg braces for people who would prefer to use a wheelchair”. There is thus a danger that it would permit disabled people to be

32 www.un-convention.info
33 Review of the Chair’s Draft Text Prepared Subsequent to the Sixth Session of the Ad Hoc Committee,
33 www.un-convention.info
subjected to treatment against their will when non-disabled people’s wishes would have to be respected. According to Light:

“No legislation can be better than poor legislation; ... A Convention that authorises a new – and reduced – standard of human rights for disabled people remains, in my estimation, a very real possibility.”\(^3^4\)

### 4.2 Monitoring

The issue of monitoring is widely acknowledged to be one of crucial importance to the success of the Convention. Although it is to be discussed in depth at the next session of the Ad Hoc Committee, the preliminary discussion of it on the last day of the seventh session indicates that agreement may not be easily reached. In its summary of those discussions, Disabled Peoples International observed that:

“The USA disappointed many in the room with its opposition to a new treaty body and call for “mainstreaming” monitoring of the new convention into existing bodies. Perhaps the USA has forgotten that mainstreaming disability rights into the existing human rights system has been a complete and utter failure and it is the very reason we are now negotiating a comprehensive convention on the rights of persons with disabilities!”\(^3^5\)

### 4.3 The Definition of Disability

In his letter to all members of the Committee, setting out the restructured text of the Convention, the Chair indicated a preference for not including a definition of disability.\(^3^6\) His reasons for this preference lay in the complexity of the task and in the risk that certain groups of people might unintentionally be excluded. Similar concerns are expressed by Richard Light, who stresses the importance of “the inclusive nature of human rights” and points out that the introduction of a definition of disability would risk creating an impression that the Convention was attempting to establish a separate and specific regime of rights for disabled people rather than attempting to ensure their full enjoyment of universal rights.\(^3^7\) The experience of the UK’s Disability Discrimination Act 1995 (as amended) provides ample corroboration of the reality of the difficulties which may be generated by an attempt to define disability. It was

\(^{34}\) Report of 4\(^{th}\) session, www.un-convention.info
\(^{35}\) http://www.riglobal.org/un/index.html
\(^{36}\) Note 30 above, para 17.
\(^{37}\) Review of the Chair’s Draft Text Prepared Subsequent to the Sixth Session of the UN Ad Hoc Committee (in his discussion of Article 2) www.un-convention.info
agreed in the seventh session of the Ad Hoc Committee, however, that the Convention should contain a definition of disability. Accordingly, this delicate and dangerous task lies ahead.

5 Conclusion

As already indicated, a key aim of the Draft Convention is to increase the visibility of disabled people as human beings entitled to the same fundamental rights as their fellow citizens. The following words of Quinn and Degener, though actually referring to the Disability Movement as a whole, are equally applicable to the Convention:

“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.”

To some extent, the very process of elaborating the Convention has helped to achieve this goal. It has undoubtedly raised the profile of disability as a human rights issue throughout the world.

There is potential, however, for the Draft Convention to achieve far more. Disabled People’s International describe this period between the seventh and eight sessions of the Ad Hoc Committee as “critical for Convention advocates” and adds that:

“Though the draft convention is nearly finalized, there remains both the potential to improve it and the danger that it may be compromised. We must be vigilant, positive and focused to ensure the continued momentum toward our definition of success: a voice of our own – and the opportunity for that voice to be heard through the recognition of our rights in every country on the planet.”

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38 G Quinn and T Degener, above note 6, para 1.4.
40 Ibid.