

## GUEST EDITORIAL

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### IT'S OUR CONVENTION: USE IT OR LOSE IT?

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#### ABSTRACT

*Unless action is taken now, at national and local levels, to ensure that the world's one billion people with disabilities derive real and lasting benefits, the United Nations Convention on the Rights of Persons with Disabilities is in danger of being consigned to the graveyard of missed opportunities. Although many governments have signed and ratified the Convention, evidence of actual implementation is an immediate priority, especially in the midst of a global recession.*

*The scene is now set for governments to bring their policies into line with the principles and Articles of the Convention and to provide regular reports to the Disabled Persons' Committee of the United Nations High Commission on Human Rights. Use of the internet can ensure that accountability is made public and includes the full participation of people with disabilities.*

**Key words:** CRPD, persons with disabilities.

#### INTRODUCTION

*"If the demands of justice have to give priority to the removal of manifest injustice (as I have been arguing throughout this work) rather than concentrating on the long-distance search for the perfectly just society, then the prevention and alleviation of disability cannot but be fairly central in the enterprise of advancing justice" (Amartya Sen, *The Idea of Justice*, 2009, p. 259).*

*"The Convention on the Rights of Persons with Disabilities is only as good as its implementation. And even though countries are competing with each other in a race to ratification, its implementation thus far is abysmally poor" (Javed Abidi, Chairperson, *Disabled Peoples' International*, 2011).*

*"We are the leaders of today. We have broken the status quo. And within the next five to ten years you will see persons with disabilities being leaders, being*

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*ministers, and ultimately holding the position of president in our countries”*  
(Seray Bangura, *Sierra Leone Young Voices*, 2012).

Unless immediate action is taken at national and local levels to ensure that the world’s one billion people with disabilities derive real and lasting benefits, the United Nations Convention on the Rights of Persons with Disabilities is in danger of being consigned to the graveyard of missed opportunities.

The passing of the CRPD into international law in 2008 marks the culmination of decades of struggle by people with disabilities to ensure that their basic human rights as citizens are respected and the barriers to their participation in society are removed. The UN has set the scene and is doing what it can to persuade its member states to translate its principles into practice. However, Disabled Persons’ Organisations and their supporters in civil society must now put pressure on national governments to implement the Convention. The fact that the Convention has coincided with a global economic recession creates a new urgency to turn rights into realities.

## **THE IMPORTANCE OF THIS CONVENTION**

The struggle for disability rights began as part of the wider civil rights movements of the 1960s. In 1980 it ‘went global’ at the now historic Rehabilitation International Conference in Winnipeg, when people with disabilities decided to form their own association which became Disabled Peoples’ International a year later (Driedger, 1989). DPI received strong support from the United Nations which had just launched its International Year of Disabled Persons. Since then, DPI, working with other international disability organisations, has played a leading role in shaping UN policy, starting with the World Programme of Action for Disabled Persons, the Regional Decades and the Standard Rules on the Equalisation of Opportunities for Disabled Persons. The Rules were influential, but lacked the force of law and international accountability now provided by the Convention.

The Convention does not aim to create new rights for people with disabilities but validates their full and equal access to the Universal Declaration of Human Rights promulgated in 1948. It was necessary in the light of overwhelming evidence of their exclusion from these rights, in all countries of the world. This exclusion will continue unless action is taken to implement the Convention.

The Convention was the first to include members of Disabled Persons’ Organisations (DPOs) as full and equal participants at every stage of its development, together with politicians, professionals and officials. Their participation is reflected in the

adoption and application of the social model of disability which highlights the wide range of obstacles confronting the rights of people with disabilities, and ways in which these can be overcome. The international disability NGOs continue to work together as members of the International Disability Alliance, which is actively promoting the implementation of the Convention and has produced detailed guidelines for monitoring and advocacy (IDA, 2010).

The United Nations and the wider international community now recognise disability as one of the major inequalities faced by people in all societies, along with inequalities related to poverty, gender and membership of a minority group. Consequently, the Convention now places an obligation on all United Nations agencies and organisations to ensure that people with disabilities are included in all policies and development programmes, and particularly in the eight Millennium Development Goals in which their needs were not explicitly identified or included in monitoring criteria. Since one-third of the 77 million children still excluded from school are children with disabilities, it is self-evident that the goal of universal free primary education for all by 2015 cannot be attained if their rights continue to be overlooked.

The United Nations Development Group (2011), which coordinates the work of 25 UN agencies at regional and country team levels, has issued detailed guidelines on strategies and mechanisms to ensure that people with disabilities are included in the whole range of UN-sponsored aid and development programmes from which they have previously been excluded. This document encourages UN country teams to work closely with Disabled Persons' Organisations. In addition, the UN is also working to ensure that people with disabilities are not overlooked in emergencies and humanitarian disasters, and has published a CRPD advocacy tool kit with particular reference to ensuring support to survivors with disabilities caused by landmines and cluster bombs (United Nations, 2008). The rights of people with disabilities also have to be taken into account by government reports on all other UN Conventions, sent to the Office of the High Commissioner on Human Rights - for example, those concerning women, children, torture, racial discrimination and civil and political rights (OHCHR, 2010).

The 2013 UNICEF *State of the World's Children* report (UNICEF, in press) will focus on children with disabilities and provide up-to-date information and examples of progress in all countries. This follows earlier reports, including *Promoting the Human Rights of Children with Disabilities* (UNICEF, 2007) and a child-friendly version of the Convention (UNICEF, 2008).

A comprehensive *World Report on Disability* has been published by the World Health Organisation and the World Bank (2011). The report takes the principles and priorities of the Convention as its starting point and provides a wealth of information with special reference to low and middle income countries. Consistent with the social model of disability and the *International Classification of Functioning, Disability and Health* (WHO, 2001), it emphasises environmental factors in creating disability, identifies obstacles to the expression of rights and to the development of services, and provides many examples of ways in which these obstacles are being removed or at least confronted by countries at all stages of development. It has been followed by an equally informative world report on dementia (WHO and Alzheimer's Disease International, 2012), again with particular emphasis on the health implications of an ageing population for middle and low income countries.

## CONVENTION PRINCIPLES

The Convention is based on a number of fundamental principles which can be used for purposes of monitoring or accountability: These include:

- Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and active participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the rights of children to preserve their identities.

## MAIN ARTICLES OF THE CONVENTION

The core articles of the Convention address substantive issues of importance for people with disabilities of all ages. Each focuses on specific domains in which barriers to participation are experienced by people with disabilities, and lays down broad principles and policies for their removal. These include:

Women; children; awareness raising; accessibility; right to life; situations of risk and human emergency; equal recognition before the law; access to justice, liberty and security of the person; freedom from torture, cruel, inhuman or degrading treatment and from exploitation, violence and abuse; protection of the integrity of the person; liberty of movement and nationality; living independently and being included in the community; personal mobility; freedom of expression and opinion and access to information; respect for privacy and home and family; education; health; habilitation and rehabilitation; work and employment; adequate standards of living and social protection; participation in social, political and cultural life, recreation, leisure and sport.

## **HOLDING GOVERNMENTS ACCOUNTABLE**

The scene is now set for national governments to be accountable to their own citizens, and for people with disabilities to insist on their right to participate in the process of national implementation.

Since its adoption by the UN General Assembly in 2006, 153 countries have expressed their broad agreement with the principles of the Convention by signing it. The 113 countries that have since proceeded to ratify it now need to be committed to a time-tabled plan of action to implement each Article of the Convention. Countries that have neither signed nor ratified it should be held to account and pressed to do so. Up-to-date information on the status of all countries in relation to the CRPD can be found on the UN and IDA websites.

Ratifying States accept a number of general obligations to:

- modify or repeal laws, customs or practices that discriminate directly or indirectly against people with disabilities
- include disability in all relevant policies (mainstreaming)
- refrain from any practice inconsistent with the CRPD
- consult with people with disabilities and their organisations in implementing the CRPD.

Consistent with the social model of disability the Convention, as well as many existing examples of national legislation, also imposes obligations on both public and private authorities to make “reasonable accommodations” to all relevant aspects of the environment so as to enable people with disabilities to exercise

their rights. Guidance documents have provided examples of accommodations that might be considered reasonable and unreasonable (OHCHR, 2007).

## MONITORING

Since Conventions incorporate international law, the UN provides a comprehensive framework for monitoring and accountability. Accessibility of the internet ensures that this process can take place in the public domain, rather than in closed committees or official reports. Monitoring tools are increasingly available in accessible language (Inclusion International, 2008; Equalities and Human Rights Commission, 2010; World Blind Union, 2012). Both the High Commission (OHCHR, 2010) and the International Disability Alliance (2010) have published helpful guidelines on the preparation of civil society submissions, stressing that they need to refer to the specific principles and Articles of the Convention in framing their comments.

All ratifying states have to submit regular reports on their progress to the new Disabled Persons' Committee of the UN Office of the High Commissioner for Human Rights which has overall monitoring responsibility for all UN Conventions. In addition to reports submitted by governments, the committee is open to submissions by non-governmental and civil society organisations. These are published on the internet, together with the Committee's own report and recommendations on the degree to which the Member State is compliant with the Convention. Since the Committee's recommendations are not legally binding, it is important for national organisations of persons with disabilities to use and publicise the Committee's findings in their advocacy campaigns.

A press release and full report of the Committee's conclusions and recommendations relating to individual countries can be found on the OHCHR website. The Committee has already published its findings on Peru and Spain and will consider reports from Argentina, Hungary and China (with Hong Kong and Macau) in September 2012. Some sessions can be watched live or viewed via the IDA website, which also includes a link to the Hungarian national disability consortium's response to the policy of their government.

In the case of Peru, the Committee commended the government for its draft bill on the rights of persons with disabilities, the adoption of a law on sign language and an increase in funding for programmes for persons with disabilities, but expressed strong criticisms concerning forced sterilization as a method of contraception and

the fact that 81 % of people with disabilities had no rehabilitation services and only 1.42 % were covered by social security programmes. The Committee also expressed its concern about the forcible use of medication and the poor conditions in psychiatric institutions where some persons had been institutionalised for more than ten years without appropriate rehabilitation services.

The report on Spain commended the adoption of a new long-term strategy (from 2012 to 2020) including objectives over the short and medium term, and welcomed the high percentage (78.35%) of enrolment of children with disabilities in the mainstream education system. Recommendations included measures to ensure the active participation of persons with disabilities in public decision-making processes, including the right to vote at the regional level and the inclusion of children with disabilities at all levels, and a more comprehensive consideration of women and girls with disabilities in public programmes and policies, in order to promote their autonomy and full participation in society and to combat violence against them.

The Committee has a backlog of reports from Austria, Azerbaijan, Bahrain, Belgium, Brazil, Bulgaria, Cook Islands, Costa Rica, Croatia, Czech Republic, Dominican Republic, Ecuador, El Salvador, Finland, Germany, India, Indonesia, Mexico, Mongolia, Morocco, Netherlands, Paraguay, Philippines, Poland, Republic of Korea, South Africa, Sweden, Turkmenistan and the United Kingdom. All these reports will be on the OHCHR website and should also be in the public domain at national level. Therefore, there is still time for NGOs in all these countries to make independent representations to the Committee.

### **Optional Protocol**

The Optional Protocol, which has so far been ratified by 65 States, enables individuals or groups of individuals who believe that their rights are being violated to submit a complaint to the Disabled Persons' Committee. In addition, it gives the Committee the authority to examine grave or systematic violations of rights under the CRPD. DPOs can use both of these procedures to report on violations of rights under the CRPD (OHCHR, 2010; International Disability Alliance, 2010).

The Committee has received its first complaint from an individual under the Optional Protocol, and supported her objection to a Swedish municipality's refusal of permission to extend her property for installing a hydrotherapy pool,

considered essential to her treatment and rehabilitation programme (CRPD/C/7/D/3/2011).

## **AN AGENDA FOR CHANGE**

Over the last 50 years there have been many recommendations to implement sustainable policies, designed to support people with disabilities to take their rightful place in society. Although significant progress has been made in many parts of the world, including some of the poorest countries, there is still abundant evidence of people with disabilities being ignored and marginalised everywhere. The Convention therefore provides a unique opportunity for every country to do a rethink about the quality of life of its citizens with disabilities, and to make a fresh start in fixing its priorities. This is not only a task for all governments, but also a challenging opportunity for citizens.

Since the 1981 International Year of Disabled Persons, the UN and NGOs have highlighted a number of priority areas which have proved effective in countries at varying stages of development.

### **1. Develop a National Disability Strategy**

Governments should be urged to create a high-level focal point for disability, responsible directly to the Head of State or Prime Minister, who should publicise their full commitment to promote the rights of all citizens with disabilities and to combat discrimination at every level. These are already working well in some countries, including the Philippines, Japan, Turkey and South Africa.

This group should be entrusted with the development of a Convention Implementation Programme as one element of an overall national disability strategy, with clear targets, time-frames and mechanisms for monitoring and accountability at local levels.

The group must include a representative consortium of national DPOs. These must be granted time and resources to meet in accessible environments before and between meetings, in order to develop a common strategy. It goes without saying that all documents and proceedings have to be accessible to all participants.

In addition to high-level representation from ministries with existing responsibilities, such as health, education, employment and social welfare, other ministries such as finance, housing, transport and justice will also need to commit to a comprehensive national strategy.

Information about the work of this coordinating committee should be reported to Parliament and to regional and local bodies, and be freely available on the internet, preferably in an interactive form so that members of the public can express their views.

## **2. Support People with Disabilities and their Organisations**

At the heart of the Convention lies the participation of people with disabilities in the process of reform. This involves much more than inviting them to join committees. It calls for support and strengthening of DPOs, and the creation of a climate of debate and discussion of a kind which brought the UN Convention into being in the first place.

## **3. Promote Access to Mainstream Services**

Each public and private agency needs to conduct an audit of its buildings, facilities and procedures with a view to removing barriers to participation. This can be done with the help of DPOs with experience of access audits based on the needs of people with a wide range of physical, mobility, sensory, cognitive and mental health impairments. These are already active in many places like Malaysia (WHO and World Bank, 2011, p. 176) but could be replicated more widely given the opportunity. Governments should also support the development of access standards for all services and amenities available to the general public, including vocational and professional training.

Incentives for Universal Design should be put in place, whereby provisions for access are incorporated into the original specifications for pavements, buildings, transport and other amenities. Most personal computers already include basic access software, but people with disabilities should be able to receive additional software needs free of charge.

## **4. Improve Services for People with Disabilities**

Global surveys such as those carried out by WHO (2007, 2011) make it clear that no country can be satisfied with the quantity or quality of the supports and services provided for its citizens with disabilities.

While access to mainstream services is fundamental, many people with disabilities will always need supports and services to use them. These include not only low vision, hearing and mobility aids, but also personal support for

people with intellectual and mental health impairments, to help them become more independent as well as contributing members of their community.

## **5. Develop Appropriate Quality Assurance Processes**

There have been reports of poor quality services, inhumane treatment and abuse of people with disabilities even in countries with highly developed provisions. This is despite elaborate quality assurance mechanisms and inspections by organisations funded by government or professional bodies.

Quality assurance is essential but a balance has to be struck between procedures and guidelines agreed between service providers and their clients on the one hand, and national standards imposed from the centre on the other. Accountability must be to individual service users who have to be at the centre of decision-making, and must be supported if they wish to make a complaint. Organisations of people with disabilities are increasingly involved in quality assurance and accreditation processes, but should be more fully supported in evaluation of services and supports.

Two very different but complementary approaches to quality assurance have just been published. A new *WHO Qualityrights Toolkit* (WHO, 2012) provides detailed guidelines for the assessment of a range of mental health and social care facilities in all countries, by NGOs and human rights organisations as well as accreditation agencies and government bodies. Assessments are carried out under five broad thematic headings, each based on relevant articles of the CRPD. For example, theme 5 focuses on Article 19 which deals with four components of 'the right to live independently and be included in the community'.

In contrast to evaluations which focus on services and staff, Verdugo and his colleagues (2012) have come out with a proposal to assess the impact of the Convention by asking those whom it is intended to benefit about their Quality of Life (QoL), drawing on three decades of international research in which QoL measures have been developed with populations of persons with disabilities, the elderly and the disadvantaged. Their paper demonstrates that the eight domains identified by QoL research can be both conceptually and operationally related to specific Articles of the Convention (Verdugo et al, 2012).

## **6. Develop a National Training Strategy**

Since many staff lack appropriate qualifications, the training and retraining of staff at all levels can be seen as an investment in human rights.

A national and regional staff development and support strategy has been shown to be an indispensable component of reform. Priority should be given to locally-based staff who are in daily contact with persons with disabilities and their families. Education, health and community workers may need support in extending their skills to these people, or may be prevented from doing so by discriminatory practices or attitudes. They in turn need support from more experienced itinerant multi-disciplinary teams who themselves need access to refresher courses to update their knowledge and skills and to provide leadership in changing outdated attitudes and practices. National or regional centres for advanced study, research, training and dissemination are also needed.

People with disabilities can make a major contribution towards training, but to do this systematically they need to be paid, supported and treated as experts in the same way as other contributors.

### **Community-Based Rehabilitation**

CBR is more relevant than ever in the light of the new imperative to implement the Convention. It is now the accepted strategy in 90 countries, providing supplementary training to health, education or social welfare staff who already work in the community but often lack the confidence to extend their skills to people with disabilities. WHO has recently published radically revised *CBR Guidelines* on the basis of experience and evaluation in many countries (WHO, UNESCO, ILO & IDDC, 2010).

Equally important is a well-designed strategy of providing awareness, information and confidence to people working in general community services who may have only occasional contact with people with disabilities but whose attitudes and actions are critical to the lives of these fellow citizens. This includes the whole range of health, social welfare and education professionals, as well as public officials, the police, the judiciary and the media.

### **7. Public Awareness**

Perhaps the biggest obstacle to the participation of people with disabilities is society's persistent under-estimation of their ability to do so. Implementing the Convention provides an opportunity to promote a more inclusive society (Mittler 2010, 2012).

People with disabilities are their own best ambassadors, especially when the general public becomes aware not only of their presence but also of the contribution

that they can make to the community once barriers to their participation are removed.

Full involvement of the media is essential at a number of levels. These include awareness-raising about the rights, abilities and achievements of people with disabilities of all ages, in contrast to portrayals which reflect a charity or welfare model. The media should be provided with accurate and up-to-date information about government policy and its progress in implementing the UN Convention in ways which will have a direct and positive impact on the lives of people with disabilities and their families.

## **8. Think Regionally**

The power of regional networks and partnerships has been demonstrated in the UN Decades of Disabled Persons, with the Asia-Pacific region launching its third decade in 2013. All are strongly supported by UN regional offices and by the UN Development Group. Most of the international disability NGOs such as DPI, Inclusion International, World Blind Union, and World Federation of the Deaf also have a strong regional base and should now be fully supported by UN regional offices. The European Union and most of its member states have ratified the Convention and is in dialogue with a very active European Disability Forum.

## **CONCLUSION: CONFRONTING THE ECONOMIC CRISIS**

Setting an agenda for change in the midst of a world economic crisis is likely to meet with resistance.

We are used to governments – and even the United Nations in earlier days – using phrases such as ‘within existing resources’ or ‘as resources become available’, which is usually an excuse for doing little or nothing. Such language is unacceptable where fundamental human rights are concerned. Few politicians would now say that there is no money for the education of girls, so how can lack of resources be used as a justification for the exclusion of girls and boys with disabilities from education?

The UN knows that its 190 member states are at vastly different stages of development and that implementation of this Convention will require resources, especially for countries with limited provision for all its citizens. That is why the Convention speaks of the need for evidence of “progressive realisation” of its

principles and policies. That means targets, time-lines and accountability. Good intentions or even legislation are not enough.

The Convention was drafted by realists and ratified by politicians in full knowledge that it had resource implications. However these should not be exaggerated. Many resource-poor countries have made remarkable progress by harnessing community support and by judicious investment in human resources, including people with disabilities themselves. Resources tied up in institutional provision can be responsibly diverted to community services. People with disabilities, considered as ‘the poorest of the poor’, have become economically active as a result of job creation and start-up loans.

People with disabilities are not asking for a disproportionate share of resources but they do want to be given opportunities to develop what the economist-turned-philosopher Amartya Sen has called their ‘*individual capability*’ – a wish expressed by the novelist Katherine Mansfield many years earlier when she wrote, “*I want to be what I am capable of becoming*”. Such a wish is universal but is particularly apt for people with disabilities.

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