

**GUEST EDITORIAL**

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**HUMAN RIGHTS AND DISABILITY -  
NEW AND DYNAMIC PERSPECTIVE WITH  
THE UNITED NATIONS CONVENTION ON DISABILITY**

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**ABSTRACT**

*The Convention for the Protection and Promotion of the Rights and Dignities of Persons with Disabilities is currently being negotiated by the United Nations. This international instrument is potentially of seminal importance within the history of the disability rights movement, for it will be the first time that disabled people's rights are enshrined in an international legally binding treaty. This article provides the historical context of the convention, the process by which it is being enacted, and the crucial role played by civil society (disabled people's organisations and non-governmental organisations) in the substantive negotiations of the Convention. It argues that it is vital to ensure that disabled people's organisations from developing countries take a more active role within the Convention process. It is also imperative to ensure that a specific Article regarding international cooperation is included in the final text of the Convention. This article considers some of the difficulties that are foreseen in implementing the substance of the Convention, once it is ratified. These include the need for effective monitoring systems at both national and international levels, to ensure that the Convention, once ratified, can be enforced.*

**INTRODUCTION**

The United Nations is currently in the process of negotiating a Convention for the Protection and Promotion of the Rights and Dignities of Persons with Disabilities. This proposed new international legal instrument has the potential to have a profound effect upon the lives of

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disabled people, for it will be the first time that disabled people's rights are enshrined in an international legally binding treaty. After ratification it will ensure that signatories must uphold the rights of disabled people, and be seen to do so.

This article seeks to explain the context of the convention, the process by which it is being enacted, and the role played by Southern-based disabled people's organisations (DPOs), and Non Government Organisations (NGOs). The article will also consider some of the difficulties that are foreseen in implementing the substance of the convention, once it is ratified.

During the past two years, Handicap International has been an active member of the International Disability Caucus – to date, a consortium of over 50 disabled people's organisations and NGOs that are actively engaged in influencing the outcome of the Convention. This article was written during the period when the author was employed as Programme Support Officer at Handicap International UK.

## **DISABILITY AND THE UNITED NATIONS**

It has been estimated that there are approximately 600 million disabled people in the world, constituting approximately 10% of its population, the vast majority of whom live in developing countries. Disabled people are more likely to be unemployed, be less educated, have less access to basic public services, as well as being one of the poorest, marginalised groups within contemporary society. Over the past 30 years or so, disabled people and their democratically elected organisations have been trying to ensure that their basic human rights are upheld and maintained.

The United Nations (UN) has played a key role in securing the rights of disabled people during the post-war era. 1982-1993 was designated as the United Nations Decade of Disabled Persons, which began to highlight the fact that disabled people were full citizens within society, and began to raise the political profile of disability. The 1980s also saw the beginning of the international disability rights movement, with the founding of Disabled Peoples' International (DPI), which was spawned out of a Rehabilitation International conference held in Winnipeg, Canada in 1982. DPI is a human rights umbrella organisation managed and run by disabled people. The birth of DPI was indeed a watershed in international disability politics, since from that time there has been no moral legitimacy for able-bodied people to speak on behalf of disabled people.

1993 witnessed the adoption by the UN General Assembly of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. This comprises of 22 rules which emphasise the principles of the social model of disability. However, unlike a formal UN Treaty or Convention, the Standard Rules are not legally binding. Consequently, there is only a moral duty upon countries who are members of the United Nations to adhere to and honour the principles enshrined in the Standard Rules.

### **The History and Process of the Convention**

Notwithstanding the fact that disability has existed since time immemorial, it has increasingly been recognised by UN agencies and many countries that disability is fundamentally a human rights issue. Disabled people and their allies have for many years been advocating that a formal convention that addresses disability rights should be developed. Consequently, in 2001 the General Assembly of the United Nations passed resolution 56/168 to establish an Ad Hoc Committee which would investigate the need for a convention, taking into account existing human rights instruments.

The first meeting of the Ad Hoc Committee took place in New York in August, 2002, where the need and rationale for a convention was initially discussed. All Governments who are members of the UN have sent delegates to each of the Ad Hoc Committees and it is their responsibility to undertake the formal negotiations of the treaty. To date, all meetings have taken place in New York.

The second session of the Ad Hoc Committee was convened in June, 2003. At this meeting, it was formally decided that there was indeed a need for a convention. A Working Group was established to prepare a draft text for the convention, which would provide the basis for future negotiations. The Working Group consisted of representatives from 27 governments, 12 NGOs and 1 representative from a human rights institution. It can be seen that from the very beginning, that civil society institutions, including disabled people's organisations, have been involved in the process.

The third and fourth sessions of the Ad Hoc Committee were convened in May/June and September, 2004. During these meetings, the draft prepared by the Working Group was debated, and amendments were also proposed. Interestingly, due to its highly controversial nature, a definition of disability was not discussed.

At the fifth and sixth sessions of the Committee, which took place in January and August 2005, delegates undertook a further review of the text drafted during the previous two meetings. This constituted the second reading of the convention.

On 13 April 2005, Ambassador Don MacKay (New Zealand's Permanent Representative to the United Nations) was elected Chair of the Committee, succeeding Ambassador Luis Gallegos Chiriboga. Ambassador MacKay chaired the Working Group which met in January 2004, and acted as Facilitator at the 4th and 5th Sessions.

The Secretariat of the Ad Hoc Committee is provided by the Department of Economic and Social Affairs (DESA). It maintains a website where all the official documents and proceedings of the Ad Hoc Committee can be found. <http://www.un.org/esa/socdev/enable/rights/adhoccom.htm>

At the end of the sixth session, the second reading of the draft Convention was concluded. It was decided that Ambassador Don MacKay, as Chair of the Ad Hoc Committee, would prepare the next draft of the Convention (called "chair text"), taking into account the respective views of country delegations as well as civil society institutions.

In October 2005, this chair text was posted on the United Nations ENABLE web site <http://www.un.org/esa/socdev/enable/index.html> with a covering letter of 20 pages.

The "chair text" comprises of 34 articles, which cover a wide range of issues. These include education, health and rehabilitation, the right to life, statistics and data collection, equality and non-discrimination, respect for privacy, the home and the family, and monitoring. This is far from an exhaustive list, but it gives a good indication of what areas are covered.

It was also decided that two further Ad Hoc Committee meetings be held during January and August 2006 - probably for three weeks each. The next two meetings will determine the precise wording of each of the Articles and the structure of the convention, which will form the final text of the Convention.

## **THE ROLE OF CIVIL SOCIETY INSTITUTIONS**

One of the perhaps unique characteristics within the process of drafting and negotiating the convention has been the active involvement of civil society institutions. Generally speaking, the United Nations has not critically engaged with NGOs when drafting other human rights instruments.

In order to maximise their impact, DPOs and NGOs have established the International Disability Caucus (IDC). This is a consortium of approximately 50 organisations that provides critical input into the convention process, providing detailed comments on the draft articles, and making comments on key issues. The objective of the IDC is to speak with a “united voice” at Ad Hoc Committee meetings. Within the IDC is acknowledged that disabled people’s organisations are in a position of leadership.

This role is of critical importance, because many country delegations do not have any members who have a disability. In fact, during the first three ad hoc meetings, there were very few disabled people represented in any of the delegations. As a result, disability was perceived primarily as a medical issue. However, as the convention process has matured, more countries have recognised the necessity of disabled people being within country delegations, either as government representatives or as special advisers.

At the first Ad Hoc Meeting, DPOs were given the right to make statements during formal sessions of the Committee, which again highlights the importance attributed by the UN and country delegations of the expertise and knowledge they bring to this process.

During the second Ad Hoc Committee meeting it was agreed that UN accredited NGOs and DPOs could attend any public meetings of the Committee and make statements within the plenary sessions, when required. In addition, the IDC negotiated very hard to be members of the Working Group, which was responsible for producing the first draft of the convention. The IDC decided that seven of the 12 seats allocated for the NGOs should be given to each of the seven members of the International Disability Alliance and that the remaining five would be allocated on a regional basis. This was of vital importance because it ensured that the views and opinions of disabled people were taken into account at the very early stages of the process.

Stefan Tromel, former Director of the European Disability Forum, considers that the input of the IDC has been of critical importance in ensuring that any Convention, in ensuring that once signed and ratified, it will genuinely be an effective instrument in ensuring that Governments are held to account in upholding disabled rights. Without the critical engagement of the experience and expertise within the IDC, the UN will not achieve its desired ultimate goal.

Despite the significant progress that the IDC has made during the past two years, it is fully recognised that there is still much more that can be done. One of the challenges has been to ensure that there is sufficient representation from southern-based NGOs and DPOs. The vast majority of DPOs involved in the Convention are based in western countries, despite the fact that two-thirds of disabled people live in the developing world. One of the major obstacles that prevents their active involvement is the cost of travelling to New York. At the sixth Ad Hoc Committee meeting, an initiative, spearheaded by the Inter America Institute on Disability and Handicap International, called Project South, was launched to enable more disabled people from developing countries to attend future Ad Hoc Committee meetings. Some of the larger Northern-based NGOs have already agreed to fund more participants with disabilities from the South.

Luis Fernando Astorga Gatrens, Executive Director of the Inter-American Institute on Disability, strongly advocates for more participation from people with disabilities from the South (1). While acknowledging that many of the issues encountered by disabled people are similar in northern and southern-based countries, he considers that they are perhaps more extreme in the South - especially in regard to social exclusion, poverty and hunger. In addition, he considers that it is vital to increase southern participation in the convention process, in order that civil society institutions based in developing countries should have the opportunity to influence the agenda at subsequent Ad Hoc Committee meetings.

According to Tina Minkowita, from the World Network of Users and Survivors of Psychiatry, and a member of the Working Group that produced the first draft, who assessed the impact of the IDC upon the convention, "States have a far greater understanding of disability as a human rights issue. Civil society, particularly DPOs have had an extensive and wide-ranging impact on substantive discussions. Also, during the first session, many country delegations had a very medical understanding of disability. However, as the process has progressed, a lot of the delegations have brought in a human rights approach and have really begun to understand disability issues" (2).

However, there is concern that states, particularly those within the European Union, have repeatedly emphasised that the process is not about creating new rights but to ensure that there is equal access to existing rights. Also, some of the draft articles, in effect those regarding the protection of children, still remain discriminatory.

Another example of the way in which civil society has actively engaged in and made a significant contribution to the Convention has been the reflection paper on inclusive development, written by a Task Group of the International Disability and Development Consortium. The Disability and Development Consortium is a global consortium of non-governmental organisations supporting disability and development work in more than 100 countries around the world. Its aim is to promote the rights of persons with disabilities through effective collaboration and sharing of information and expertise. This paper was presented at the 5<sup>th</sup> session of the Ad Hoc Committee, held during January 2005.

The paper argues that the Convention will only become truly effective in upholding the rights of disabled people, if an inclusive approach to disability and development is adopted. Inclusive development, in essence, has two fundamental elements. First, it recognises that disabled people are actively engaged in the development process. Secondly, development institutions “must be taken into account and be assessed in accordance with their impact on the lives of persons with disabilities, and consistent with the promotion and protection of internationally recognised human rights.”

It also argues that, given that over 75% of disabled people live in developing countries, unless disability issues are mainstreamed, and the principles of inclusive development are adopted, then the eradication of poverty, and the achievement of the Millennium Development Goals will not be achieved. The paper therefore states, “The eradication of poverty will not – indeed cannot – be achieved without mainstreaming disability issues in all development policies and ensuring that persons with disabilities engage in the planning, design, implementation and evaluation of development programmes” (3).

The paper makes a number of recommendations, which seek to strengthen the ability of the Convention in promoting disability rights. One key recommendation is the need to ensure that a separate Article regarding international cooperation is drafted and included. International cooperation is perceived to be of paramount importance for the effective implementation of the Convention. Furthermore, it must be exercised in a manner that respects the participation and representation of disabled people, and that furthers development goals – particularly at the community level.

It is also of the utmost importance that adequate monitoring instruments are developed to ensure that signatory states fulfil their obligations. Any monitoring mechanisms that are

developed must address the different levels of implementation – national, regional and international. Furthermore, as is the case for all other articles of the convention, it is essential that these are grounded within a human rights framework and are linked to other development instruments such as Poverty Reduction Strategy Papers (PRSPs).

## **CONCLUSION**

The events that have taken place in New York over the last three years are arguably of immense historical importance in the field of disability politics. Once the convention has been signed and ratified by the Member States of the United Nations, disabled people and their democratically elected representative organisations will have an internationally recognised legally binding instrument by which to hold their governments to account in terms of enforcing disability rights. Such a convention will become a milestone in ensuring that disabled people are recognised as full and active citizens in the society in which they live.

Notwithstanding this vision for the future, there is still a long way to go before it is fully realised, with many challenges and difficulties ahead. If the Convention is to be effective, then adequate and robust monitoring mechanisms must be developed. At the present moment there is little consensus regarding what precise monitoring mechanisms should be put in place. Furthermore, there is widespread debate regarding which body should have responsibility and authority for supervising the monitoring process. Historically, such mechanisms for other human rights treaties and conventions have proved to be woefully inadequate.

Another challenge is ensuring that there is the political will amongst member States to sign and ratify the Convention, once the negotiation process has been completed.

Finally, what is most encouraging is that the current negotiation process for the Convention leaves a lasting legacy for the manner in which civil society institutions actively engage with the United Nations in negotiating the substance of international instruments. Ambassador MacKay, at the end of the session, stated that the spirit of the process to date is possibly unique within the UN, for there is a genuine desire of all parties involved to work towards a common, shared goal, to achieve something of significant importance.

Given that the passage of the Convention has the potential to become an historic milestone in securing disability rights, it is vital that all civil society institutions, especially DPOs in the

South, continue to be actively involved in the ongoing debates and negotiations of the Convention process. Only this will ensure that the Convention, once it is finally ratified, genuinely enhances the rights of disabled people, thereby ensuring that disabled people enjoy the fruits of full citizenship, alongside their able-bodied counterparts, in the society in which they live.

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