

# **Update on the UN Convention on the Rights of People with Disabilities**

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## **Introduction**

Over the past few years, the National Council on Disability (NCD) has released several documents and reports related to the development of a UN Convention on the rights of people with disabilities. This briefing paper describes recent developments regarding the drafting of the convention document, and includes a discussion of the 3<sup>rd</sup> Session of the Ad Hoc Committee by a panel of consumers and experts.

## **Recent Developments**

In June 2003, the Ad Hoc Committee established a Working Group composed of representatives from 27 governments, 12 non-governmental organizations (NGOs) and one national human rights institution to prepare and present a draft treaty text that would be the basis for negotiations of a comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. For additional information on the establishment of the Working Group, please see the NCD website for the document, UN Disability Convention – Topics at a Glance: History of the Process ([http://www.ncd.gov/newsroom/publications/2003/history\\_process.htm](http://www.ncd.gov/newsroom/publications/2003/history_process.htm)).

The Working Group convened January 5 - 16, 2004 to prepare the draft text drawing from a wide variety of governmental and civil society contributions. During this drafting process the Working Group focused on the draft text of the Chairman of the Ad Hoc Committee (Luis Gallegos, Ecuador), the Bangkok draft text, and the Mexican draft text.

The text prepared did not represent the views of any specific delegation to the Working Group, but instead represented the work of the Group as a whole. It should also be noted that the method of work was unusual for a General Assembly body, in that NGO members enjoyed the same rights of participation as representatives of Member States. The draft included 25 proposed articles on topics concerning the promotion of positive attitudes to persons with disabilities; statistics and data collection; equality and non-discrimination; right to life; equal recognition before the law; liberty and security; freedom from cruel, inhuman or degrading treatment; freedom from violence and abuse; freedom of expression; respect for privacy; independent living; children with disabilities; education; participation in political and public life; accessibility; personal mobility; right to health and rehabilitation; right to work; social security; and participation in cultural

life. The 25<sup>th</sup> article addressed monitoring, but did not include draft text relating to monitoring at the international level, and included only minimal text relevant to the creation of a national monitoring framework.

The draft prepared by the Working Group was used at the Third Ad Hoc Committee Meeting, which took place May 24 to June 4, 2004. A first reading of the proposed draft text during the meeting addressed Articles 1-24, international cooperation, and the preamble. In addition, discussions included a new article on women with disabilities, proposed during the meeting by the Republic of Korea. Consideration of the title, structure, sections of the preamble, definitions and monitoring were deferred until the 4<sup>th</sup> session of the Ad Hoc Meeting scheduled to take place from August 23 to September 4, 2004. Although there was agreement that the implementation of the convention would be a national responsibility, discussions also addressed additional implementation mechanisms such as international cooperation.

The discussions of the Ad Hoc Committee during the Third Meeting were held in open plenary, which facilitated the participation of accredited NGOs. Towards the end of the meeting the Committee considered the utility of proceeding on the last day with a second reading of the draft text and proposed amendments in “informals.” These “informals” would be facilitated by different Member States, and would be “open” to enable the participation of NGOs. Despite strong support from a number of delegations, Member States could not reach agreement on whether NGOs should be permitted to participate in such meetings, and the final day was instead completed in formal plenary.

### **Panel Discussion**

NCD invited a panel of consumers and experts to participate in a discussion regarding the Third Ad Hoc Committee Meeting. The moderator for the discussion was Kathleen Martinez, NCD Board Member and NCD liaison to its International Watch Advisory Committee, who posed four questions to each panel member. Panel members included Sheikha Hissa, the Special Rapporteur on Disability at the United Nations; Charlotte McClain, South African Human Rights Commission; Celia Brown, National Association for Rights Protection and Advocacy; and Janet Lord, Landmine Survivors Network. The panelists’ responses are provided below in their entirety.

### **Kathleen Martinez: What were some of the main points of discussion in the Third Ad Hoc Committee Meeting?**

#### Sheikha Hissa

The purpose of the Third Ad Hoc Committee Meeting, which took place in New York from 23 May to 4 June, 2004, was to discuss the draft of the *Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*.

In that respect, therefore, all the Articles of the Convention were discussed to a greater or larger extent. Some took far more time than anticipated, some were more contentious, and others went quite smoothly with almost unanimous agreement on all changes.

Whatever the case, the discussions were always rich and reflected the international community's commitment to the rights of people with disabilities and the serious efforts being made by all to come up with the best possible document.

All articles of the Convention were discussed at the Third Ad Hoc Meeting. However, it was agreed to defer the following articles to the Fourth Ad Hoc meeting, which will take place in August 2004: Article 1, Purpose; Article 2, General Principles; Article 3, Definitions; Article 4, General Obligations; and Article 25, Monitoring. Additionally, the need for an article to cover International Cooperation had almost unanimous support.

The major issues that generated a great deal of discussion and differing views were the following:

- The inclusion of a specific article dealing with women. It was generally the view of NGOs and most delegations of developing countries that an article on women is needed in the Convention in the same way that there is an article on children. The reason for that being that both groups require special attention, have special needs and need to be responded to in a specific way. It has also been documented, especially in developing countries and in more conservative societies and communities where women, who suffer discrimination, women with disabilities end up suffering double the discrimination, as well as exclusion and at times ostracism by their community. To date there has been no agreement on adding an article dealing specifically with women.
- Article 9 on equality before the law also generated energetic discussion particularly the segment dealing with the right of people with disability to manage and take full responsibility of their financial affairs and legal affairs.
- Article 6 on data collection and statistics brought out the point, particularly from developing countries, of the need to ensure that data and statistics on people with disabilities are not misused. The purpose of data collection and statistics is to help decision/policy makers make informed decisions and set appropriate policies for the benefit of people with disabilities.
- Article 21 on the right to health and rehabilitation. It was agreed almost unanimously that this Article should be split into two; one dealing with Rehabilitation & Habilitation and the other with Health Care, with the clear understanding that rehabilitation is not strictly a medical issue. The trend towards rethinking rehabilitation as addressing all the needs of people with disabilities, as well as their families and communities should be clearly reflected in the Convention.
- Article 19 on accessibility reflected the wide gap between developing and industrialized countries about the understanding of accessibility. For many developing countries, accessibility means changing the physical environment and has not yet extended to all aspects of life.

#### Charlotte McClain

Some of the main points were establishing separate articles on vulnerable groups within the disability sector. These include but are not limited to children and women. In terms

of the substantive articles there was a lot of discussion on Article 23, Social security and adequate standard of living. Education was also a main point. Another point was the discussion on international cooperation. The issues of mobility, accessibility and universal design all received a considerable amount of time.

#### Celia Brown

The main points of discussion are on individual self-determination and autonomy. Some member states have different opinions when it comes to forced intervention and forced institutionalization. The disability community has strongly stated that people with disabilities have the right to make their own decisions and there should be a prohibition of forced interventions to correct or improve a perceived impairment.

#### Janet Lord

The 3d session of the Ad Hoc Committee marked the first time that a convention text was put before the Ad Hoc Committee for a “first reading.” The vast majority of the session was spent reviewing, article-by-article, a draft convention text consisting of a preamble and 25 articles drafted by the Working Group of the Ad Hoc Committee in January 2004. States as well as NGOs were afforded the opportunity to submit proposed modifications to the Working Group text on nearly every article, with the exception of the articles on definitions and monitoring which were deferred for future discussions.

Just a few highlights from this highly technical and detailed deliberation include:

- Debates around the degree of specificity to be provided by the articles in the convention (some States favor specificity of the type provided in the UN Standard Rules, others favor more generalized obligations and assert that greater specificity will jeopardize universal ratification).
- Whether and how to split the article on health and rehabilitation into two separate articles. The notion of splitting the article received support by many governments as well as NGOs.

How to address specific groups of people with disabilities within the convention: Should there be a separate article on children with disabilities (the Working Group did include a separate article)? Should there be a separate article on women with disabilities (as proposed by South Korea)? Should there be a separate article addressing groups at risk, such as people with disabilities in armed conflict or other emergency situations? Are some of these issues better addressed in an integrated manner throughout the convention?

**Kathleen Martinez: What has been the role of disability oriented non-governmental organizations (NGOs) in the drafting process? To what extent are NGOs being utilized or excluded in drafting the convention?**

#### Sheikha Hissa

NGOs played a great and important role which did not start with the Ad Hoc Committee discussions but from the very inception of the idea of a Convention. They were active contributors to the work of the Working Group and their influence was clear and felt in all the discussions. They were extremely visible and vocal throughout the process and enriched the document considerably. Many government delegations turned to their

national or to the international NGOs for advice and interventions were sometimes drafted by NGO and government representatives together.

#### Charlotte McClain

The NGOs have been very instrumental in providing expert and experimental information on the needs and contextualizing the lives of people with disabilities. In the 3rd session at least 12 NGOs contributed from the floor. They have also been very successful in ensuring that cross disability issues are considered in the development of the Convention. Many of the NGOs are supporting government delegations. However, on the last day of the ad hoc meeting there was an intervention from the representative of the Africa group to review the participation of NGOs in the forthcoming session of the Committee; in my view this exclusion would be unfortunate.

In addition to the participation of NGOs it is also important to point out that National Human Rights Institutions have for the first time in the history of developing conventions been accorded recognition as national human rights institutions and contributed to the process of developing the Convention.

#### Celia Brown

The disability oriented non-governmental organizations had a role in being a part of a working group made up of disability non-governmental organizations and member states drafting the convention. Their working group came together to draft a text of the convention in January 2004. The Chairman of the Ad Hoc Committee requested the participation of the disability non-governmental organizations and select member states to work together on a draft text of the convention for the Third Ad Hoc Committee meeting.

#### Janet Lord

NGOs generally, and organizations concerned with the human rights of people with disabilities specifically, have played very active roles in the Ad Hoc Committee process to date. The majority of NGOs actively participating in the process are either disabled peoples' organizations or organizations with strong disability rights programming. At the outset of the process, NGOs lobbied hard to secure access to the process. Decisions taken by the Ad Hoc Committee during its first year of operation relating to NGO participation were generally favorable, though subject to the broad discretion of the Chair of the Ad Hoc Committee. In practice, the Chair (Ambassador Gallegos from Ecuador) has given great latitude to NGOs in facilitating their participation (e.g., he has been very generous in not imposing strict time limits on NGO oral interventions, always ensures that NGOs have the chance to speak in plenary on every issue, has been very open in meeting regularly with NGOs).

Subsequent meetings of the Ad Hoc Committee and its Working Group have continued to build on NGO participation in the process. NGOs continue, in increasing numbers, to serve as delegates on Member State delegations to the Ad Hoc Committee, thereby achieving the highest level of access, including participation in closed or informal sessions where non-delegation NGO representatives are excluded. In addition, those

NGOs who are not represented on government delegations continue to wield influence in various ways, giving oral interventions on the floor of the Ad Hoc Committee, organizing briefings on various issues for governmental and other participants, issuing written statements and position papers, and “working the corridors” to influence government positions. The high watermark of NGO participation in the process thus far was the representation of 12 NGOs on the Working Group (along with 27 governments and 1 national human rights institution) during the January 2004 session. No differentiation was made at all between governments and NGOs during the course of the Working Group. Some countries, however, continue to press for a reversion to more closed, informal sessions where NGOs would not be allowed to participate, even as observers without the right to speak. While a number of states favor continued participation at high levels (Mexico, EU, Canada, New Zealand), the opposition among a few (some African countries, some Asian countries) can serve to block consensus and therefore may still result in a roll back of NGO participation. For that reason, NGOs are closely monitoring the situation and preparing lobbying strategies.

**Kathleen Martinez: What are your views regarding the involvement of the U.S. in the treaty drafting process?**

Sheikha Hissa

The type of involvement seems the same as the US's involvement in all other rights treaties of this kind, very reserved. In fact the US delegation was more vocal at the 2<sup>nd</sup> Ad Hoc meeting, however, in the last one I did not feel the presence of a US delegation in any meaningful way.

Charlotte McClain

The U.S. delegation in the first and second session raised some objections around the development of the Convention. Since then the U.S has not participated actively in either the working group or the last 3<sup>rd</sup> ad hoc session. I think this is a concern because I do believe that there are lessons learned from domestic legislation that we could learn from. There are also some best practices that reside in the U.S. that could have been instrumental. Some of these would include mainstreaming people with disabilities, accessibility and providing the relevant services. Fortunately, there has been a strong U.S. NGO lobby and they have shared some very useful information with delegates.

Celia Brown

The US has already announced that they will not be a party to the treaty. However, the US delegation held an outreach session to discuss the treaty at the Third Ad Hoc Committee.

Janet Lord

The United States has taken what can only be described as an altogether extraordinary position in relation to its participation in the Ad Hoc Committee process, namely, a stance which American officials at the Ad Hoc Committee have repeatedly characterized as one of “neutrality.” Contrary to its typical role with respect to multilateral treaty negotiations - one of active engagement regardless of support for or opposition to the

process in question - the United States has indicated that it has no plans to sign or indeed ratify any resulting convention. At the same time, it will not oppose the convention and believes that it may indeed be useful for other countries without a comprehensive disability legislative framework such as that provided under US laws. Accordingly, the US has indicated that it would like to provide technical assistance to the process in terms of sharing from the US experience. This is the role played by US officials in the Working Group which was, by and large, constructive. Given the stance of the United States in opposing some of the major treaties of the last ten years, the position taken in relation to this particular convention must be seen as something of a success in that the US will not play the role of the spoiler as the rest of the world attempts to construct a useful piece of international law for the rest of the community of states. What remains very disappointing, however, is the complete absence of members of the American disability community on the US delegation. Even given the position of neutrality, there is no rational basis for this continued exclusion. It is indeed an embarrassment to the American people and an affront to the American disability community.

**Kathleen Martinez: What do you think will be the major points of discussion at the Fourth Ad Hoc Committee meeting in August?**

Sheikha Hissa

Naturally the issues deferred from the last Ad Hoc Meeting will be the major points of discussion at the next Ad Hoc meeting. In particular, I believe that Article 25, Monitoring, will be one of the most extensively discussed. The issue in front of us is whether there should be a new monitoring mechanism, person, or committee created for this Convention or whether existing mechanisms and bodies can be used to monitor implementation. The other issue is whether implementation will be at the international level or whether it will be left to countries to monitor nationally the implementation of the Convention. In the end, I believe the decision will be up to the United Nations as they will be ultimately responsible both administratively and financially for the monitoring.

Another issue that will be further discussed is that of International Cooperation. A clear understanding should be reflected in the Convention that International Cooperation is not only about aid and financial support—which are important—but about the exchange of information, expertise, ideas and experiences as well, and that the flow is not always North-South, but South-North as well and South-South. There are many innovative and inventive experiences and success stories achieved with little resources by countries of the South that are worth transmitting to the rest of the world.

Charlotte McClain

I think the issue of monitoring both at a national and international level will be discussed. There are various initiatives taking place between sessions to develop some thinking on monitoring. The issue of a definition of disability has yet to be discussed. The next meeting will also have to apply its mind to the role of NGOs given the concerns raised in the 3rd session—namely will they be able to participate in the informals. The title, the preamble and structure are outstanding issues and probably will be discussed at the next session.

Celia Brown

I think the major points will be self-determination and autonomy, legal safeguards with some member states supporting forced medical intervention and forced institutionalization with appropriate legal procedures. Also I think there will be discussion on Advance Directives, a way of supported decision making for people with disabilities

Janet Lord

While the agenda for the fourth Ad Hoc Committee meeting is not yet out in its specific detail, the report generated by the Ad Hoc Committee at the third session outlined the following topics that would be the subject of discussion at the next session: (i) Convention title; (ii) Convention structure; (iii) parts of the Preamble requiring further discussion; (iv) definitions (Article 3 of the Working Group text); and (v) Monitoring. It is also likely that a further review or “second reading” of the articles discussed at the third Ad Hoc Committee meeting will take place.

Of these, the structure of the convention and monitoring are likely to be central to the discussions at the next session. The structure of the convention is still at issue given the position taken by the European Union. The proposals put forward by the European Union at the third session of the Ad Hoc Committee require, in part, some structural changes to the Working Group text. Among these, several provisions were proposed to be moved up front in the treaty structure (participation and accessibility) to reflect their overall implications. Other changes put forward by the EU (most notably changes in relation to Article 4 on general obligations) signify a shift in approach to that taken in the draft Working Group text. The EU position is reflective of a narrower, non-discrimination approach to the convention that resembles treaties negotiated earlier in time, namely, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Elimination of All Forms of Racial Discrimination. The vast majority of States spoke out against changes that would fundamentally alter the structure and content of the convention, in effect favoring a comprehensive convention along the lines of the Convention on the Rights of the Child. It remains to be seen how the Ad Hoc Committee will be able to resolve the divide between the EU and those States favoring a broader, more comprehensive convention.

Monitoring is the other topic of central importance and likely to generate considerable debate among States. One dimension of the discussion will revolve around Working Group draft Article 25 which is the only provision on monitoring, but relates only to monitoring at the national level. The other, much more contentious side of the discussions, concerns international monitoring. Some States favor the establishment of a fairly standard treaty monitoring body to oversee the international monitoring of the convention. Other States have indicated their reluctance to see the creation of another treaty body, especially given discussions currently underway in the UN human rights system concerning the need to streamline and make more efficient the existing treaty monitoring body system. The process to develop a convention on the rights of people with disabilities is caught in the cross-fire of this on-going debate. The outcome of an

expert meeting convened by the Office of the High Commissioner for Human Rights in Geneva in July will review options for the establishment of a monitoring mechanism and will no doubt figure prominently in discussions at the Ad Hoc Committee in August.

**Future developments**

The Fourth Ad Hoc Committee meeting, which will convene from August 23 to September 4, 2004 will consider the proposed revisions and amendments to the draft text. A draft of the proposed revisions and amendments is available as Annex II: Compilation of the revisions and amendments made by the members of the Ad Hoc Committee to the draft text (<http://www.un.org/esa/socdev/enable/rights/ahc3modfinal.htm>)

The Chairman of the Ad Hoc Committee, Luis Gallegos (Ecuador) said he hoped to have the Convention ready for signature by September 2005.

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