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Disability-Inclusive Disaster Preparedness and Response: Challenges and Opportunities for Reconstruction in Haiti,

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NGO PARTICIPATION IN HUMAN RIGHTS LAW AND PROCESS: LATEST DEVELOPMENTS IN THE EFFORT TO DEVELOP AN INTERNATIONAL TREATY ON THE RIGHTS OF PEOPLE WITH DISABILITIES

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Convention on the Rights of Persons with Disabilities”**

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I. INTRODUCTION

The human rights of people with disabilities traditionally have been ignored in mainstream international human rights theory and practice and in the work of international institutions.¹ Today, however, a small but rapidly growing transnational advocacy network of disability activists is emerging to challenge this neglect around the effort to develop an international convention on the rights of people with disabilities.

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1. For an extensive study of this and other issues pertaining to the rationale for an international convention on the human rights of persons with disabilities, See NAT'L COUNCIL ON DISABILITY, A WHITE PAPER: UNDERSTANDING THE ROLE OF AN INTERNATIONAL CONVENTION ON THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES 41-43, 58 (2002).

The inclusion of this panel topic in the program for the International Law Weekend is significant for two reasons. First, it should be noted that disability as a topic historically has been marginalized in the study and practice of international law and in the international human rights law field in particular. In fact, disability has remained largely invisible—one need only look at the leading texts on international human rights law to discover this invisibility,² though the convention drafting process we are focusing on today represents an important step toward integrating disability into the mainstream of international human rights law.

Second, in general, disability has not been regarded as a human rights issue. Rather, disabled people, instead of being seen as claimants of their own rights, are regarded instead as objects of pity, people whose lives need fixing or who are in need of help in the most paternalistic sense.³ This has had very disturbing consequences, with serious and systemic violations across the full spectrum of human rights, going unnoticed, unreported, and unaddressed. Mainstream human rights groups have not integrated disability in their work, although Human Rights Watch and Amnesty International have publicly acknowledged their historical neglect and have committed to addressing this gap through undertaking reporting on human rights violations against people with disabilities.⁴ Treaty bodies have not integrated disability into their monitoring process in any ongoing and consistent fashion—notwithstanding some particularly good work by the Committee on Economic, Social and Cultural Rights in General Comment 5.⁵

This panel is significant for a second reason. As the program title suggests, international law is in a period of crisis, and indeed, the need for more human rights standard setting is being called into question even by scholars and practitioners in the international human rights field. The Geneva-based International Council on Human Rights Policy has a forthcoming study which is looking precisely at the question of whether the focus of the human rights movement should be in a new standard setting or whether primary attention should be directed toward implementation of existing standards.⁶ This is of both

2. As an example, one of the leading textbooks in the international human rights law field, contains no index entry for “disability,” “people with disabilities” or similar terms, in contrast to multiple entries for other minority groups. See HENRY STEINER & PHILIP ALSTON, *INTERNATIONAL HUMAN RIGHTS IN CONTEXT* (2d ed. 2000).

3. For more on traditional models of disability, see GARETH WILLIAMS, *Theorizing Disability*, in *DISABILITY STUDIES* 123 (Gary L. Albrecht, et al. eds., Sage Publications 2001).

4. See, e.g., Statement of Kenneth Roth, *Summit on Human Rights and Disability*, National Council on Disability, Washington, D.C., Apr. 8, 2002 (transcript on file at the National Council on Disability).

5. *Persons with Disabilities*, ICESCR Comm’n., General Comment 5, 11th Sess., U.N. Doc. E/1995/22 (1994).

6. For more information on this project, see the website of the International Council on Human Rights Policy, <http://www.ichrp.org> (last visited Mar. 16, 2004).

practical and theoretical consequence for those of us working in the area of disability rights.

I will begin my presentation by reviewing where we are in terms of NGO participation to develop a convention on the human rights of people with disabilities. I will then draw some conclusions about modalities of NGO participation and their implications both for international law and for the success of the treaty process in general. I will then, time permitting, review some of the key issues on convention content that are likely to come under consideration in the months ahead.

II. NGO PARTICIPATION IN THE PROCESS TO DEVELOP AN INTERNATIONAL CONVENTION ON THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES—WHERE WE ARE

The Mexican initiative which launched the process to develop a new convention on the rights of people with disabilities, introduced two years ago before the UN General Assembly,⁷ came as a surprise to the NGO community and, in particular, those working on issues relating to the rights of people with disabilities. While the surprise was welcomed, much work needed to be done in order to mobilize the disability community from around the world and to bring it together in some coordinated way to participate meaningfully in the process and ensure its success.

The international disability community has historically been disparate and divided, working only in the informal sense within the UN system. The NGO focal point on disability within the UN system has been the International Disability Alliance (otherwise referred to as IDA), a loose federation of seven international disabled people's organizations: Disabled Peoples' International, Rehabilitation International, the World Network of Users and Survivors of Psychiatry, the World Blind Union, Inclusion International, the Deaf Blind Federation, and the World Federation of the Deaf. Together, IDA has followed disability issues within the UN system, has participated in the monitoring of the non-binding UN Standard Rules on the Equalization of Opportunities for People with Disabilities,⁸ and served as that instrument's Panel of Experts, as appointed by the UN Special Rapporteur on Disability. This group has not worked closely with mainstream human rights organizations.

There have been major challenges to coordination given the fact that the IDA has worked largely as an isolated entity and on a separate track from

7. For a copy of the UN General Assembly Resolution creating the Ad Hoc Committee, see Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, 3rd Comm., 56th Sess., Agenda Item 119(b), U.N. Doc. A/C 3/56/L.67/Rev.1 (2001).

8. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, U.N., 85th Plen. Mtg., ¶ 1, Part IV, U.N. Doc A/Res/48/96 (1993).

mainstream human rights organizations and indeed other groups whose participation is thought necessary to achieve success in a human right standard setting process. It was not at all clear that a broad, cross-disability NGO grouping could be formed at all, much less achieve the level of coordination and consensus necessary to push a process to develop an international treaty forward. However, having said that, during the first two sessions of the Ad Hoc Committee, some major and unprecedented successes were achieved:

- NGOs lobbied hard for access to and meaningful participation in the first session of the Ad Hoc Committee in July-August 2002. They succeeded in winning a decision on access for ECOSOC accredited groups as well as a separate process for non-ECOSOC accredited groups.⁹ The modalities of participation were also quite generous—fears that the process would be restrictive because it was a UN General Assembly Ad Hoc Committee (as opposed to a process convened under a UN structure more favorable to NGOs) turned out to be unfounded.¹⁰ NGOs enjoyed generous rights of participation as observers, with the right to submit written statements as well as to make oral interventions, a right that was supported by the Chair of the Ad Hoc Committee, Ambassador Gallegos from Ecuador.
- NGOs produced joint statements and provided a daily Disability Negotiations Bulletin¹¹ which formed the political messaging and NGO information platform for the process. At one point during the first week of the first Ad Hoc Committee Session when negotiations threatened to break down, a strongly worded open letter to delegates in the Bulletin was acknowledged by government delegates to have had significant impact in turning things around. This was a positive meeting, although no definitive decision was made to pursue a treaty.

During the second Ad Hoc Committee session, these forms of participation continued, with disabled activists from both the developed and developing countries participating in far greater numbers than the previous year.

9. See *Accreditation and Participation of Non-governmental Organizations in the Ad Hoc Committee to Consider Proposals for a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities*, U.N.G.A. Res. A/RES/56/510, available at <http://www.un.org/esa/socdev/enable/rights/adhocngo82e.htm> (last visited Mar. 16, 2004).

10. See *Decision on the Modalities of the Participation of Accredited Non-Governmental Organizations in the Ad Hoc Committee to Consider Proposals for a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities*, Aug. 2, 2002, available at <http://www.un.org/esa/socdev/enable/rights/adhocdecision2.htm> (last visited Mar. 16, 2004).

11. See <http://www.worldenable.net/rights/adhoc2meet.htm>.

- NGOs worked hard to broaden participation, bringing disability activists from around the world to New York. Landmine Survivors Network partnered with Disabled Peoples International to train disabled activists from all regions of the world to participate in the two week Ad Hoc meeting. This significantly broadened participation by NGOs from the developing world. All in all, there were hundreds of NGOs registered to participate. Within one day of the commencement of the session, the Ad Hoc Committee made the decision to move ahead to develop a convention, and the attention shifted to the process by which a convention would be elaborated. The rest of the two week period was a long and difficult negotiation regarding the structure of a working group which would be tasked with developing a negotiating text for the third session of the Ad Hoc Committee. NGOs were divided on many aspects of these issues, as were governments. In the end, NGOs successfully lobbied for seats for 12 NGO participants on the Working Group. Furthermore, these participants would be selected by NGOs themselves. The seven IDA groups plus five regional representatives were selected. Procedures for participation in the Working Group will be in accordance with procedures already established for NGO participation in the Ad Hoc Committee. This entire scenario is totally unprecedented in international human rights standards setting process, even more inclusive than the Rights of the Child Convention process, which represented a high mark of NGO participation in the human rights sphere.
- I have just returned from a regional meeting in which the NGO representative from West Asia—Adnan Al Aboudy, who is the Director of Landmine Survivors Network's Jordan Network - convened a broad consultation of experts and advocates from his region in order to develop a regional contribution to the Working Group meeting in January.¹²

12. For the report of the meeting, see Landmine Survivors Network, *Expert Dialogue and Arab Regional Consultation: Amman, Jordan Issues Related to the Drafting of an International Convention on the Human Rights of People with Disabilities* (Oct. 20-21, 2003), available at www.landminesurvivors.org (last visited Mar. 16, 2004).

III. NGO POSITIONING IN RELATION TO SUBSTANTIVE ISSUES CONCERNING THE ELABORATION OF A CONVENTION

The main focus during the first two meetings of the Ad Hoc Committee mandated to consider proposals for the elaboration of an international convention on the rights of persons with disabilities has been to convince governments of the need for a specialized convention on the human rights of people with disabilities. The central objective of NGO lobbying, therefore, has been to set forth a clear rationale for the treaty, addressing, for example, the point that absent a specialized convention, disability will not be successfully integrated into the UN human rights system, the international human rights movement, or the work of other important actors such as development organizations.

Now that we do indeed have a process to develop a convention, NGOs engaged in the process are starting to articulate more concrete positions on the content of a convention.¹³ Regional meetings, engaging both governments as well as non-governmental actors, are likewise engaging in more substantive elaboration of what the content and structure of a new convention might include.

As I mentioned earlier, I just returned from a meeting in Jordan—a Roundtable Expert Dialogue and Regional Consultation on Issues related to the Drafting of an International Convention. The purpose of this meeting was to examine some of the key substantive issues at this early stage of the negotiation process. Hosted by Landmine Survivors Network in cooperation with the Jordanian National Disability Council, the meeting brought together some 50 disability activists—people with disabilities who represent some of the NGO leadership within the Middle East. This group, several of whom attended the second session of the Ad Hoc Committee this past June, participated in a human rights training session for two days, the outcome of which was an NGO statement of issues relating to the content and structure of a new convention. This training session was followed by a two-day consultation and roundtable dialogue which included NGO activists, as well as governmental participants from around the region, representatives from both the UN Department for Economic and Social Affairs (which serves as the Secretariat for the Ad Hoc process) and the Office of the High Commissioner for Human Rights, the Special Rapporteur on Disability, representatives from Amnesty International and Human Rights Watch, and leaders from disability and development organizations, such as Action on Disability and Development in the United Kingdom. The two events marked the first time that the region had brought together groups from disability, human rights and development communities for

13. For copies of NGO position paper contributions relating to the content of a proposed convention, see <http://www.un.org/esa/socdev/enable/rights/adhocdocs.htm> (last visited Mar. 16, 2004).

the common purpose of pursuing a dialogue on strengthening the content of human rights law to make effective the enjoyment of human rights by people with disabilities. This meeting looked at the following issues:

- *Core guiding principles and objectives to support the elaboration of an international convention on the rights of people with disabilities.* There is as yet no consensus on the precise objectives and core principles that form the foundation for the convention. What is interesting from a legal standpoint is that some emerging positions on this issue support the elaboration of sections in the operative part of the convention setting forth the objectives—the purpose for the convention—as well as a section on guiding principles. This mirrors the approach we see particularly in international environmental agreements and indeed other framework conventions developed in the last ten years. The content of disability guiding principles—such as participation, non-discrimination, autonomy, international co-operation—will be highly significant not only in terms of the development of more precise substantive obligations in the civil, political, economic, social and cultural realm, but also in terms of providing a basis for the interpretation and progressive development of the convention by a treaty monitoring body, treaty bodies of other principal human rights conventions, and indeed by international tribunals.
- *The elaboration of an implementation system in a new convention.* Major questions which will be the focus of the negotiations in the years ahead will be:
 - i) What is the relationship between the UN Standard Rules and its voluntary monitoring system and a new system of implementation?
 - ii) What will be the role of the UN Special Rapporteur on Disability and a new convention?
 - iii) What will be the impact on the development of a monitoring system in a new convention of the current effort to reform the human rights treaty bodies? On this last point, Australia has come out strongly opposed to a new treaty monitoring body, and in fact has continued to argue that the human rights of people with disabilities could best be addressed not in a specialized convention, but in a protocol to an existing human rights convention. This approach makes little sense as a practical or theoretical matter, and the NGO community has rejected any attempt to annex and further marginalize disability rights within the human rights law system generally.

- *The integration of disability and development in a new convention.* Attention was focused not on the inclusion of the right to development in a new convention as a few have suggested, but rather how barriers to implementation by developing countries in particular might successfully be addressed within the context of an implementation system. One concept to consider is the incorporation of supporting measures of implementation akin to the kind of provisions we have seen successfully incorporated into international environmental law agreements, such as a provision to support public education and awareness-raising through training. Such measures are understood within the disability content and the UN Standard Rules as a precondition to the equalization of opportunities for people with disabilities. Other examples of supporting measures would include information gathering, information exchange, and the formation of technical advocacy bodies that might support, for example, the elaboration of guidelines and technical assistance on accessibility standards. The issue of development is likely to be contentious and yet it need not be a huge barrier to success of the future negotiations if understood in the context of measures to support implementation.

IV. CONCLUSION

For the momentum generated by the United Nations General Assembly to be productively maintained and utilized, the process by which the convention on the rights of persons with disabilities is developed must continue to be inclusive of people with disabilities, including the most marginalized groups. The current effort is notable for its generous rights of participation among NGOs, particularly in view of the decision to give 12 seats on the Working Group that will formulate a negotiating text to NGO representatives, and represents a further progressive development in international law-making.