

“Let the World Know”

Report of a Seminar on Human Rights and Disability

Held at Almåsa Conference Centre, Stockholm,
Sweden

November 5-9, 2000

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Preface and Acknowledgements

This report presents the outcome of an international seminar on human rights and disability, held 5-9 November 2000, at Almåsa Conference Centre, Stockholm, Sweden. The purpose of the seminar was to draft guidelines for more effective identification and reporting of violations and abuse of the human rights of persons with disabilities.

The seminar was funded by the International Disability Foundation and co-funded by Olof Palme International Centre and Swedish Committee for Rehabilitation. The office of the UN Special Rapporteur on Disability organised the seminar and the Special Rapporteur chaired the meeting.

Six major international disability organisations were represented. In addition, 20 experts in disability and/or human rights were individually selected. Dr. Marcia Rioux, Canada, accepted to serve as the rapporteur of the meeting and has compiled this report.

The main outcome of the seminar is a number of guidelines to establish a structure and to develop competence for collecting data and for reporting human rights violations and abuse against persons with disabilities to the UN human rights system. These guidelines concern national governments, the UN system in the human rights area and both national and international disability organisations. I am convinced that the implementation of these proposals means the creation of an effective system for exposure of existing infringements of the human rights and persons with disabilities.

A short version of the report has been distributed to media and is available at the office of the UN Special Rapporteur on Disability.

I want to thank the funders, the seminar rapporteur, the participants and all other involved for their active contribution to the strengthening of human rights protection in the disability field, which will be possible through the seminar.

I sincerely hope that all concerned will consider these recommendations for implementation.

Stockholm, January 2001

Bengt Lindqvist
UN Special Rapporteur on Disability

“LET THE WORLD KNOW”, REPORT OF A SEMINAR ON HUMAN RIGHTS AND DISABILITY HELD AT ALMÅSA, SWEDEN NOVEMBER 5-9, 2000

This seminar is a vital step towards the full recognition and realization of the human rights of all persons with disabilities... We know that persons with disabilities frequently live in deplorable conditions, and face physical and social barriers, which prevent their integration and full participation in the community. As a result, millions of adults and children throughout the world are segregated, deprived of virtually all their rights, and sometimes lead wretched and marginalized lives. This is completely unacceptable.

The Universal Declaration of Human Rights refers specifically to the rights of persons with disabilities. Article 1 declares that all human beings are born free and equal in dignity and rights. There is a joint responsibility at the national and international level to ensure these rights are translated into concrete action.

Despite the adoption of the UN General Assembly of the World Programme of Action concerning Disabled People, and the adoption in 1993 of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, it is clear that a great deal needs to be done. I know that that is the main reason you are meeting this week. I feel it is time to look afresh at this issue and to identify ways of stepping up our joint efforts to secure the full range of human rights for persons with disabilities.

Let me add some questions to your agenda:

- *How can persons with disabilities themselves speak up for their rights and make human rights a tool in their continuous struggle for dignity, equality and justice?*
- *How can we ensure that the rights proclaimed in international norms and legislation are translated into real improvements in the lives of persons with disabilities?*

Mary Robinson, UN High Commissioner for Human Rights,
Video Message to the International Seminar on Human Rights
and Disability, Almåsa Conference Centre, Stockholm
Sweden, Nov. 2000¹

¹ The full text of Mary Robinson's remarks is available at the Office of the UN Special Rapporteur on Disability.

I Introduction

With those challenges, a video of Mary Robinson, United Nations High Commissioner for Human Rights opened an International Seminar on Human Rights and Disability, convened by Dr. Bengt Lindqvist, the United Nations Special Rapporteur on Disability. The meeting was held from November 5th – 9th, 2000 at Almåsa Conference Centre, Stockholm, Sweden.

Twenty-seven experts in human rights law and policy and disability rights law and policy attended the meeting. Six of the 27 participants who attended the meeting were appointed by the International Non-government Organizations (INGOs)² that constitute the UN Panel of Experts. The other 21 participants attended in their individual capacity at the invitation of Dr. Lindqvist. The twenty-seven experts were from 16 countries. In addition, there were seven observers and guests. Mr. Brian Burdekin attended as the special representative of Mary Robinson³. Ms. Akiko Ito of the United Nations (New York) programme on disability, Division for Social Policy and Development also participated in the seminar⁴. The list of participants (including Dr. Lindqvist, observers, assistants and interpreters and accompanying persons) is attached as Annex C. The International Disability Foundation funded the meeting with additional support from the Olof Palme International Center and the Swedish Committee for Rehabilitation.

Dr. Bengt Lindqvist, UN Special Rapporteur on Disability, chaired the Seminar. The Rapporteur of the seminar was Dr. Marcia Rioux of Canada. There were five working groups and they were facilitated by Dr. Richard Light (U.K.), Mr. Ragnar Aðalsteinsson (Iceland), Mr. Eric Rosenthal (U.S.), Ms. Mary O'Hagan (New Zealand) and Ms. Anuradha Mohit (India). The facilitators were supported by a secretariat from Sweden that included: Susanne Berg, Anne Froden, Erica Olsson, Erik Staaf, and Annica Akerberg.

The purpose of the Seminar was to develop guidelines supporting disability NGOs in their work to identify and report human rights infringements and abuses. This report represents the results of this seminar, incorporating the views of those who attended.

² The phrases 'International Non-governmental Organization' (INGO) and 'Disabled Persons Organizations' (DPO) have been included throughout this material. In the interest of clarity, it should be noted that when we refer to INGO we refer to organizations representative of persons with disabilities, parents and advocates that act on the international level. In particular, we have in mind the six INGOs with Consultative Status in ECOSOC (UN Economic and Social Council). The six INGOs are Inclusion International, Disabled Peoples' International, Rehabilitation International, World Blind Union, World Federation of the Deaf, World Network of Users and Survivors of Psychiatry. The phrase 'DPO' has been used to refer to *all* representative organizations of persons with disabilities, parents and advocates, from the largest international organization to the small group meeting in a living room in someone's home.

³ The text of Mr. Burdekin's address is available at the office of the UN Special Rapporteur on Disability.

⁴ The text of Ms. Ito's background on *Human Rights of Persons with Disabilities and the United Nations*, prepared by the Division for Social Policy and Development of the United Nations Secretariat is available at the office of the UN Special Rapporteur on Disability.

Annex D provides a simplified description of the United Nations (UN) structure by way of a diagram for those who are not familiar with the structure and role of UN agencies and bodies.

II Background to the Seminar

There has been an increasing international recognition that disability is a human rights issue. There is also recognition that disability and disability-related exclusion and marginalization is a concern for the UN human rights bodies.

The World Programme of Action concerning Persons with Disabilities, adopted by the UN in 1982, recognized the responsibility within the UN system of addressing the human rights of persons with disabilities, in the following (and other) recommendation:

Organizations and bodies involved in the United Nations system responsible for the preparation and administration of international agreements, covenants and other instruments that might have a direct or indirect impact on persons with disabilities should ensure that such instruments fully take into account the situation of persons who are disabled. (para. 164)

In August 1984, the Sub-Commission on Prevention of Discrimination and Protection of Minorities appointed a Special Rapporteur, Mr. Leandro Despouy, to conduct a comprehensive study on the relationship between human rights and disability. In his report (1993), Mr. Despouy made it clear that disability is a human rights concern, in which the UN monitoring bodies should be involved. Included among his recommendations was the following:

After the Decade has ended, the question of human rights and disability should be kept on the agendas of the General Assembly, the Economic and Social Council, the Commission on Human Rights and the Sub-Commission as an item of constant concern and on-going attention.

The Committee on Economic, Social and Cultural Rights in 1994 assumed the responsibility for disability rights by issuing a General Comment No. 5, in which the Committee makes an analysis of disability as a human rights issue. The General Comment states:

The Covenant does not refer explicitly to persons with disabilities. Nevertheless, the Universal Declaration of Human Rights recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant. In addition, in so far as special treatment is necessary,

States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability. Moreover, the requirement contained in article 2 of the Covenant that the rights 'enunciated ¼ will be exercised without discrimination of any kind' based on certain specified grounds 'or other status' clearly applies to discrimination on the grounds of disability.

At the 54th session of the UN Commission on Human Rights in March/April 1998 the Commission adopted resolution 1998/31, in which the Commission made a series of statements and recommendations for future development in this area. Resolution 1998/31 was a principal breakthrough and a general recognition of the UN responsibility for human rights and persons with disabilities. Therefore, expectations were high that finally things would start to develop. However, in the two years following the adoption of the Commission resolution, there was little follow-up. This was a major concern when the Commission on Human Rights again discussed human rights and disability at its 56th session in April 2000. As a result of the discussion the Commission adopted another resolution (2000/51), which incorporated and expanded the recommendations of Resolution 1998/31.

In the first operative paragraph the Commission recognizes the UN Standard Rules as an evaluative instrument to be used to assess the degree of compliance with human rights standards concerning persons with disabilities.

[The Commission] recognizes that any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities. (para. 1, Resolution 2000/51)

Further, the Commission encourages all the treaty bodies to monitor the compliance of States with their commitments in order to ensure full enjoyment of rights by persons with disabilities. Governments are urged to cover fully the question of human rights of persons with disabilities, when reporting under the relevant United Nations human rights instruments.

[The Commission] invites all the human rights treaty monitoring bodies to respond positively to its invitation to monitor the compliance of States with their commitments under the relevant human rights instruments in order to ensure full enjoyment of those rights by persons with disabilities, and urges Governments to cover fully the question of the human rights of persons with disabilities in complying with reporting obligations under the relevant United Nations human rights. (para. 11, Resolution 2000/51)

In addition, the following operative new paragraph was added which reflects the recognition of the urgent need for action.

[The Commission] *invites the High Commissioner for Human Rights, in cooperation with the Special Rapporteur on Disability, to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities and solicit input and proposals from interested parties, including particularly the panel of experts.* (para. 30, Resolution 2000/51)

It is this framework that provided the impetus for the UN Special Rapporteur on Disability to hold the *Stockholm Seminar on Human Rights and Disability* appropriately titled *Let the World Know*. It is an opportune time to develop the capacity and competence of all parties concerned to ensure that the occurring violations of the human rights of persons with disabilities start to reach the appropriate entities within the UN system and governments and political parties around the world. Disability leaders recognize the need to find an effective mechanism to communicate their experiences to the human rights monitoring bodies. Human rights experts recognize their need to learn more about how various

obstacles prevent persons with disabilities from exercising their rights and freedoms and make it difficult for them to participate fully in the activities of their societies. (Standard Rules, para 15)

The Special Rapporteur, supported by the Office of the High Commissioner for Human Rights, recognizes that persons with disabilities have human rights and are subjects of law. Therefore, persons with disabilities enjoy all the rights set forth in international human rights instruments, as well as some specific rights. These rights must be respected. The international and national communities have the obligation to do what is necessary to enable persons with disabilities to effectively enjoy all their human rights on an equal footing with persons without disabilities.

III Timing of the Seminar: An Opportune Moment

It is within this context that this international seminar was held. Three factors made it a particularly favourable time to begin a concentrated effort to profile the infringements of human rights of persons with disabilities:

- The recent recognition in theory and law of disability as a rights issue;
- The recent promulgation of policies in many countries directed at strengthening the rights of persons with disabilities and eliminating discrimination at the national level; and
- The increasing organization of the disability rights movement worldwide.

In light of these three factors, this seminar provided a unique opportunity to design an effective way of reporting human rights infringements against persons with disabilities as well as to design guidelines for the reporting of such abuses.

The systematic collection of data provides evidence, for the United Nations and state governments, of the need for further attention directed towards eliminating these abuses and provides information to support the struggle of persons with disabilities to justice, equality, self-determination, dignity and worth in their societies. It also provides a way of exposing the various forms of discrimination and violence to which persons with disabilities around the world continue to be exposed.

IV Purpose of the International Seminar: From Rhetoric to Reality

The express purpose of the Seminar was to draft guidelines for identifying and reporting human rights infringements against persons with disabilities. The following were identified as specific objectives and expected results of the Seminar:

- To provide a forum to exchange knowledge and expertise and to dialogue on the integration of disability-related issues into the human rights process;
- To develop a substantive methodology for relating obstacles to participation, neglect, abuse and other forms of discrimination to legal provisions of existing UN human rights Instruments⁵; and
- To design a process for follow-up and for collection and analysis of information and within this to develop and support a reporting capacity within disability NGO's.

V Organization of the Seminar

The Seminar used as its starting point for the work, the Universal Declaration of Human Rights and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Recognition was given to the six main binding human rights instruments: the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social and Cultural Rights; the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment; the Convention on the Elimination of

⁵ Two avenues are currently being pursued in international efforts related to human rights and disability. One is to make use of the already existing general instruments for persons with disabilities and the other is to pursue a specific convention on disability. Seminar participants agreed that these two approaches do not preclude each other. The express purpose of this seminar was to provide mechanisms for using current International instruments and mechanisms for bringing disability in the mainstream of rights concerns. The second prong was not addressed at this seminar.

All Forms of Racial Discrimination; the Convention on the Elimination of All Forms of Discrimination Against Women; and the Convention on the Rights of the Child⁶.

The mode of operation of the Seminar was to provide as much time as possible for discussion, thereby precluding the presentation of papers during the actual seminar. However, seven pre-conference papers were prepared and sent in advance to all participants. These were important as part of the background for the discussions and are attached in Annex E.

To enable the Seminar participants to develop **guidelines for collecting information** that would give real effect to human right instruments, the work was organized around the following approaches to documentation.

- documenting individual reports of infringements⁷
- documenting of legal cases/jurisprudence⁸
- documenting of media⁹
- documenting of policy, services and practices¹⁰
- documenting of legislation¹¹

Further to developing guidelines within each approach for the information to be collected criteria and methodology were proposed for the **collection of the information** including:

⁶ A paper presented to the Seminar by Miriam Tebourbi, *Ensuring Human Rights for Persons with Disabilities*, in which she gives a brief overview of the six instruments. This paper is available at the office of the UN Special Rapporteur on Disability. Another particularly useful reference is Theresa Degener and Yolan Koster-Dresse (eds.), *Human Rights and Persons with disabilities: Essays and Relevant Human Rights Instruments*, Mass., US: Kluwer Academic Publishers (1995).

⁷ Included in this approach was what constitutes an infringement of a human right; a method of reporting that enables comparability of data collected; how to guarantee privacy and confidentiality to the individual reporting; and methods of ensuring the credibility of reported infringements.

⁸ Included in this approach was a methodology for documenting legal cases that would be consistent and comparable across jurisdictions recognizing such factors as: type of legislation, level of court, and so on. Cases that were considered included (a) those in which courts made no finding with respect to rights (discrimination by court interpretation of law), and (b) those in which courts found directly on the infringement of human rights (e.g. anti-discrimination cases or equality cases).

⁹ Included in this approach was how to document infringements of human rights in the media and by the media including media reporting in a manner that is an infringement of human rights and media reporting of infringements of human rights

¹⁰ Included in this approach was the documentation of policies, services and practices that are contrary to the Universal Declaration – either by omission or commission. Mechanisms for consistency across jurisdictions was considered as was a methodology for those who are documenting infringements to recognize which right has been infringed.

¹¹ Included in this approach was the documenting of legislation at various levels of government. Attention was paid to legislation that directly contravenes human rights, legislation that supports human rights and legislation that is silent but in its silence infringes rights.

- setting guidelines for the practical frameworks for reporting, and how to ensure that the information is systematic when collected.
- determining how the collection of information could happen following the expert seminar; and
- providing guidance on how to use the data and its interpretation most effectively, taking into account that there are a number of different audiences for the results of the Seminar.

The diversity of knowledge and expertise of the participants in both methodology and content related to infringements of human rights provided a cross-fertilization of ideas. It was agreed, by the participants, that the guidelines had to be on the one hand coherent, consistent, reliable and valid, and on the other hand, concrete, practical, straightforward, and educative. Effective monitoring and advocacy to enforce international human rights covenants ultimately depends on action at the local and national level by persons with disabilities and their allies. In most countries of the world, advocacy organizations are limited by a lack of recognition, funding, and political support.

It was also clear that whatever was developed had to be understandable and useable by those in the disability community worldwide and by the human rights and legal communities. Whatever guidelines were designed also had to be a bridge between the knowledge bases and the two interests.

There was not time within the framework of the Seminar to consider how the various approaches and different suggestions for structures and procedures could be coordinated and developed into one entity. This report, however, does attempt to synthesize the five perspectives and, hopefully, provides a coherence that enables further refinement and field-testing of the instruments and the proposed directions.

VI General Directions for Mainstreaming the Human Right of Persons with Disabilities

The Seminar participants agreed on the importance of mainstreaming the human rights of persons with disabilities throughout the UN system, especially human rights bodies and mechanisms.

They noted that the Special Rapporteur on Disability of the Commission for Social Development, Dr. Bengt Lindqvist, and the panel of experts appointed to monitor the Standard Rules, have managed to achieve meaningful progress putting forward the issue of disability,

They recalled that NGOs with consultative status of the ECOSOC have direct access to UN organs and bodies.

Drawing on the provisions of paragraph 30 of the Commission on Human Rights Resolution 2000/51¹² on Human Rights and Disability, the Seminar agreed that:

- Human Rights Treaty monitoring bodies must be encouraged to review and amend their existing guidelines to ensure that the rights of persons with disabilities which fall within the scope of individual treaties are fully taken up by the respective treaty bodies in their work.
- The Committee on Economic, Social and Cultural Rights should be encouraged to continue and strengthen its efforts to ensure that States parties report on the measures they have taken in response to the Committee's General Comment No 5 on the rights of persons with disabilities, to include disability issues in its dialogue with States parties, and to ensure that States parties respect and ensure the human rights of persons with disabilities as required by the Covenant.
- Organizations of persons with disabilities, family members and/or advocates should consider taking advantage of the opportunities for formal participation in UN activities by applying for consultative status with the ECOSOC¹³. The United Nations could encourage this by ensuring that disability groups are aware of the advantages of such status and the procedure for applying for status, and assisting them to apply. The criteria used and the procedure should take account of the special difficulties that DPOs may have in accessing international fora and the need to ensure that representative organizations of persons with disabilities, parents and advocates are granted consultative status.
- The Special Rapporteur on disability, together with the High Commissioner for Human Rights, and the Department for Economic and Social Affairs should examine ways to strengthen the existing website on Human Rights and Disability, as well as ensuring the widest possible dissemination of *all* relevant documents and information in *accessible formats*.
- The efforts made at the international level towards ensuring Human Rights of persons with disabilities should be maintained. In that regard, and in view of the termination of the Special Rapporteur's mandate in 2002, it was suggested that the Commission on Human Rights should appoint, at its 58th session (2002), a Special Rapporteur for Human Rights and Disability in relation to the human rights of persons with disabilities, with a mandate similar to existing Special

¹² [The Commission] invites the High Commissioner for Human Rights, in cooperation with the Special Rapporteur on Disability, to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities and solicit input and proposals from interested parties, including particularly the panel of experts. (para. 30, Resolution 2000/51)

¹³ International non-governmental organizations (INGOs) that have consultative status with ECOSOC can directly access the various treaty monitoring committees. In order to provide information to the treaty monitoring bodies these INGOs could either contribute to the reports submitted by their own national government, or submit their own reports containing information they want to reach the Committees.

Rapporteurs¹⁴ of the Commission to examine *inter alia*, the effective enjoyment of Civil, Political, Economic, Social and Cultural Rights of persons with disabilities, in order to maintain momentum¹⁵.

- UN agencies and bodies, such as WHO, UNESCO and UNICEF, should be encouraged to pay particular attention to the issue of disability in their activities as well as in their programmes.
- The Office of the High Commissioner for Human Rights (OHCHR) should include issues of disability and human rights as an integral part of all its work, and in particular, should consider ways of integrating the question of disability in the design of its technical assistance programmes.
- UNESCO should include issues of disability and human rights in the series of activities it is conducting as part of the International Decade for Human Rights Education.

VII Developing an Overall Structure for Reporting Violations of the Human Rights of Persons with Disabilities

This reporting structure has been prepared primarily to support the work of DPOs, international, regional, or national in having available material on human rights infringements of persons with disabilities. The Seminar accepts that its efforts are weakened by the inability to provide financial resources for DPOs to enable them to build effective human rights reporting mechanisms. Nonetheless, many DPOs are already working in this area. This material will, hopefully, provide some initial practical advice to them, as well as encourage other DPOs to develop further work on disability as a human rights issue. The recommendations and the methods of documentation are not, however, confined to strategies that suggest the work has to be carried out by the DPOs. An effort of this scale and importance requires multi-disciplinary teams and supporters. It requires that alliances be effected between interested parties and those with disabilities.

Different sections of the disabled community will necessarily build systems to get information from their members and supporters in ways that account for their *particular*

¹⁴ A list of UN Special Rapporteurs and the current thematic mechanisms and country mechanisms is available at the office of the UN Special Rapporteur on Disability..

¹⁵ The following safeguards are recommended in the event of an appointing of a Special Rapporteur on Human Rights and Disability:

- That the sponsors of any resolution to establish a Special Rapporteur consult with representative disability groups on the proposed mandate of such a procedure
- that the Chair of the Commission on Human Rights consult with representative disability groups in the selection of any Special Rapporteur to be appointed by the Commission;
- that the appointment of a Special Rapporteur of the Commission on Human Rights not impede the development of a convention on the rights of persons with disabilities or be used as a reason for not proceeding with this project.

circumstances. For example, people who are locked in institutions may need very different ways of telling the wider world about the abuse they endure; the Deaf community needs to know that there are coordinators who are Deaf themselves or who are efficient sign-language interpreters and persons with disabilities in isolated rural communities must be aware of, and able to take advantage of, the systems that DPOs create.

Different DPOs will be interested in using one approach rather than another for documenting purposes. And hopefully, there will be other bodies, such as law societies or other rights-seeking organizations that might use the information here to incorporate disability into their on-going reporting efforts.

It is impossible to provide information about how *every* DPO or section of the disabled community can build an *effective* human rights reporting network. Much will depend on the resources that are available to them and the amount of preparatory work that representative INGOs have already done.

In some cases, international representative organizations have already done a great deal of work in the area of the human rights of persons with disabilities. Where individual DPOs are part of an international organization that has undertaken human rights work, much information and experience will already be available. The challenge is for every INGO to identify a DPO that is able to receive information about human rights abuses and forward it to the international human rights agencies.

VIII Understanding What Amounts to an Infringement of Human Rights

Although the international disability community has spoken of disability as a human rights issue for at least two-decades, not all persons with disabilities view discrimination and abuse in terms of international human rights instruments. For some people, discrimination and abuse have become normalized, everyday occurrences that are part of their lives as persons with disabilities.

It is also important to note, however, that there is a danger in describing *every* act of differential or unfavourable treatment as an infringement of a human right. Apart from the fact that this is simply inaccurate, it raises the risk that there will be a backlash against supporting efforts to strengthen human rights. Wherever possible, we would suggest, as a guideline, that persons with disabilities only speak of human rights when such rights are contained in an international human rights instrument (for example, the Universal Declaration of Human Rights and the six main UN Human Rights treaties).

IX Building a System for Dealing with Infringements of Human Rights

Recognizing that there are many forms and ways of infringing the human rights of persons with disabilities and that no single mechanism or instrument is likely to be powerful enough to deal with all the types of infringement, the Seminar worked on the issue from five distinct perspectives. In each of these the participants struggled with both structure and content to enable information to be collected and ultimately collated to provide an overall picture of how human rights and disability intersect. The limited time frame of the Seminar did not enable participants to deal with the way in which these various methodologies for documenting human rights infringements would interface with one another. The proposed methodologies do, however, enable some order to be imposed in getting the process started at several different levels and of providing ideas for people to plan the next steps.

A number of questions arose in developing the guidelines to document infringements of human rights; such questions as: how will people with disabilities be involved? how will the work be systematized? what are the ways of encouraging people to participate? what will be the strategic mechanisms for documenting infringements of human rights?

Involvement of persons with disabilities in the work

Obviously any instrument, whether very simple or very complicated must be tried out or field-tested with the people who will be using it. An instrument is not perfect if it is not used or if it means nothing to those who are supposed to be the beneficiaries of the work. Persons with disabilities have to be involved at every level of the design, development, data collection, collating and reporting of material and the action that results. They are central to whatever process is developed.

Systematizing on-going work and initiating reporting on an international scale

The Seminar investigated ways to encourage the on-going work and to initiate the work in organizations and countries where it has not yet begun. It constitutes a major action to create international cooperation amongst disability rights organizations, governments, and the UN to move forward in the area of disability that has been neglected in the field of human rights.

Ways of encouraging persons with disabilities to participate

The participation at this seminar of the six international organizations of persons with disabilities, constituting the UN Panel of Experts, is an indication that they acknowledged their major role in activating their member associations and in supporting the Seminar initiative. The consensus is that there will need to be a significant training component to ensure the reporting and use of the information.

A second and equally important element was to ensure that the instruments developed were in user-friendly formats and in alternative formats so that all persons with disabilities can participate. The instruments must also take into account that persons with disabilities come from different cultural backgrounds and have different levels of understanding, reading and writing skills.

Mechanisms for documenting the infringements of human rights

Participants at the Seminar provided a number of mechanisms for documenting and reporting infringements of human rights. This is important to meet the challenge that the Office of the High Commissioner for Human Rights gave to the Seminar: "...to find a way to ensure that the rights proclaimed in international norms and legislation are translated into real improvements in the lives of persons with disabilities". Together these mechanisms provide a well-rounded holistic picture of the systemic and multi-faceted nature of infringements.

Each of these mechanisms has strengths in itself as well as the potential to generate some part of the overall knowledge needed. They do not rely in their entirety on persons with disabilities and their organizations, but in addition, propose using existing resources and finding support among those who are natural allies in human rights work. The coherence of information that can be collected through these various approaches is a key issue. More detail is provided in the individual working group reports (chapter X). Below is a brief summary of the proposals.

To document **individual cases** of an infringement of a human right is important to ensure that, as a minimum, gross abuses are reported to the UN immediately. The impact of even one individual case of an infringement of a human right, being reported internationally, can be significant, as has been shown in the case of women, refugees, immigrants and others. Equally important is that the information can be gathered to paint a picture of how profound the infringement of the human rights of persons with disabilities is. It is also important to make visible the unawareness and, even more seriously, the cover-up of abuses of persons with disabilities.

As a methodology, the idea of a Human Rights Specialist in individual organizations, who is provided with support and charged with the responsibility for obtaining evidence of individual abuse, was investigated. A Specialist was proposed who would be located both at the INGO level and at the national level where there are national cross-disability organizations of persons with disabilities. The reporting of individual cases would be carried through a national organization to an international alliance, which would collate the information. A Human Rights Specialist, as proposed, would guarantee that the documentation and reporting would be done to ensure credibility, privacy, and confidentiality of the information. It would be owned by persons with disabilities and contain an element of support for individuals.

To document **legal cases and jurisprudence**, the Seminar proposed creating and maintaining a global database on the Internet. The database would consist of court cases and administrative decisions related to disability and human rights. It would be a compilation of both international and national case law using international standards to address either disability rights or interpretations of general or disability-specific rights guarantees. In addition, it was proposed that a guide to legal literature about human rights should complement the global database. The issue of who would create the database, both nationally and internationally, was discussed. It was decided that the most logical place for such a database to be housed nationally, would be with ministries of justice. Alternatives were proposed in the event that this was not feasible or not taken up by national ministries of justice. In particular the idea was raised of using the resources of law associations, law schools, DPOs, anti-discrimination or human rights bodies or other statutory bodies. The global database, to which national governments would upload their data, should be at the Office of the High Commissioner for Human Rights.

The establishment of a Disability Rights Media Watch (DRMW) was proposed to document human rights infringements in and by the **media**. This is envisioned as a body that would develop uniform criteria to monitor the media throughout the world. The work would include media reports violating human rights in language and in presentation as well as stories about the infringements of human rights of persons with disabilities. The DRMW would be responsible for compiling, verifying, and analyzing the information collected and for developing and distributing reports based on the material. The information would be maintained in an international database coordinated by the Disability Rights Media Watch. Collaboration with media watches on other issues would enable an exchange of information and strategies for action. It could also provide the avenue for the collection and verification of the data. The importance of the involvement of DPOs and INGOs was stressed as fundamental to the effectiveness of the DRMW.

Discussion of documenting **legislation** led to a proposal to use existing national legal information systems as sites for the national compilation of data and to coordinate data across nations. The types of organizations that were highlighted as having the capacity and competence to carry out this work included: university departments and law schools, research or social policy agencies, and human rights organizations. The INGOs or many national DPOs, who already have within their mandate to do policy and legislative reviews, were pointed out as being in a very strong position to document their work and make it available in a uniform manner.

The importance of systematically documenting legislation was also underlined. While legislation may protect human rights, it may also be used in a way that creates inequality or exclusion. Legislation may be silent and, by its silence, result in the infringement of a right. All of these aspects were taken into account. It was pointed out that many countries have not yet recognized that the treatment of persons with disabilities falls within the area of exercising human rights. These are the cases where the media watch, the individual case reporting and the legislative review will need to be highly interactive.

A proposal for a comprehensive multi-dimensional reporting manual was presented as the most appropriate tool for documenting infringements in **programmes, services and practices**. Such a manual would be useful in directing attention to issues of particular concern. It would also provide an opportunity to look at a single type of programme or service or practice from all perspectives and to document the way in which the combination of law, policy, practice and social attitudes cumulatively impact on human rights. It is proposed as an effective tool for an issue-by-issue approach to documenting cases of infringement of rights. Recognition was also given to its importance in assisting DPOs wanting to prepare shadow reports to an official government report submitted to the UN under one of its treaties. It could also assist governments in assessing their effectiveness in meeting their human rights and citizenship rights guarantees.

Shared elements

What all of the five proposals have in common is a structure and central collection point for information and for encouraging reporting and follow-up action. This is crucial to the effective reporting of infringements in any area. While the strategies are different and logically have to be, they each have that component as a basis for cohesive, accurate, timely and current information. Strong recognition was given to the possibility of retribution against individuals reporting the infringement of human rights and the need to protect individuals from any repercussions because they reported a case of abuse. This would be one of the tasks of those collecting the reports and collating the information.

Each of the five workshop reports recognized that all data collection instruments had to be informative as well as providing a tool for data collection. The workshops recommended that particular examples should be provided in the data collection instruments. There should also be a clear, uncomplicated guide to international norms and standards as well as clear statements of the source (e.g. the International Covenant on Economic, Social and Cultural Rights or the International Covenant on Civil and Political Rights), and an indication of the specific rights (for example, the right to education, the right to work, the right to be free from torture and so on).

Following up the proposals

The proposals by the workshops were made as an initial draft and the need for further development was recognized. One of the ways put forward for this to occur was to use the proposals with activist groups, either those engaged in a reporting exercise under one of the UN human rights treaties, or those undertaking an assessment of national law and practice in relation to the enjoyment of human rights. It was also suggested that it would be necessary to use the proposals in some regions with less knowledge of rights and without the experience of reporting rights abuses. Development of the proposals may also need to be supplemented by further reference to the existing guidelines and observations of the treaty bodies.

Together these proposals provide a broad, encompassing methodology to monitor the infringements of human rights. Each one will provide in itself important data and together

they bring the acts of discrimination and of human rights abuses fully into the domain of international standards, by which we judge how well nations are doing in ensuring human rights. They will provide the evidence that is seen everyday throughout the world of the outright denial of equality, dignity and justice for persons with disabilities. They will document the intended and unintended infringements of rights and the individual and systemic denial of rights. These proposals will create a basis for assessing how well the international community is meeting its own standards.

X Making it work: Developing Instruments for Documenting Infringements of Human Rights: The Five Working Groups Report

Each of the five working groups of the seminar had a mandate to explore one of the five approaches to documenting infringements of human rights. The working group reports have been organized under four general headings for consistency because time did not permit the five working groups to coordinate their reports.

Throughout the following material, particular examples are used to illustrate how to document human rights infringements and in the explanation of why particular information or procedures are important. They are also used in the explanatory notes about processes recommended for the collection of the information. The Seminar has tried to provide a broad range of examples overall and not to limit them only to one particular type of disability. It is important to note, however, that these are only examples with the sole intent to make the material more useable for the reader. Other examples could be substituted and there was no intention to favour one type of human rights abuse or the type of abuse faced by one group or disability over another. Any DPO may find it useful to substitute examples of human rights infringements that are easier for their organization to identify with. As follow-up documents are developed, more examples can be provided or others substituted.

The instruments outlined are not fully fleshed out but they do provide a general overview of structure and methodology for documenting infringements of the human rights of persons with disabilities. There has been an attempt to make the instruments both educative and informative. In some cases, this is clearer than in others. Further refinement of the instruments will be needed.

A. Documenting Individual Cases¹⁶

1. *The Context of Reporting Individual Cases of Infringement of Human Rights*

Persons with disabilities, wherever they live and whatever their particular impairment, regularly face human rights abuses¹⁷. Some persons with disabilities may say, quite reasonably: ‘having my human rights abused is a daily event. Why should I bother to report it?’ The question is all the more relevant when there may be little that can be done to quickly stop the abuse happening again.

We would offer three answers:

- The lack of knowledge about the extent to which the human rights of individual persons with disabilities are infringed makes it difficult to win public support for the defense of those rights¹⁸.
- The more information that is made available about individual human rights abuses against persons with disabilities, the harder it is for governments to claim that their citizen’s human rights are respected.
- Perhaps most importantly, even if the majority of individual cases of human rights abuse will never come to the notice of the international human rights community, there are ways of ensuring that *gross abuses are reported to the UN immediately*.

2. *Structures for Effective Reporting: The Role of a Human Rights Specialist*

¹⁶ Systematic reporting of human rights abuses committed against persons with disabilities is not well developed. Even so, a project in the UK, which contains 1,200 separate reports of abuse inflicted on more than 2,000,000 persons with disabilities, has shown that abuse is 1½ times more likely to end as a result of the victim’s death, rather than as a result of legal action. (Source: *Human Rights Project*, administered by Disability Awareness in Action (DAA). *DAA can be contacted at the following address: 11 Belgrave Road, London SW1V 1RB, United Kingdom. Telephone: + 44 (0)20 7834 0477 E-mail: research@daa.org.uk*

¹⁷ Although the international human rights instruments refer to ‘states’, Article 2 of the *International Covenant on Civil and Political Rights* makes it clear that states have a responsibility to promote the rights of *all* of its citizens, even if it is not involved in the abuse itself. “Each State Party to the present Covenant undertakes to respect and to ensure all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, *without distinction of any kind...* [emphasis added]” (*Article 2 International Covenant on Civil and Political Rights*).

¹⁸ DPOs in some regions of the world will find it difficult to bring human rights abuses to the international community. Although it is not intended to replace the work of other DPOs, the UK-based human rights network: Disability Awareness in Action is currently running a project to record information about human rights abuses of persons with disabilities. The information kept by DAA remains the ‘property’ of the DPO concerned, but DAA can ensure that information about abuse is formally recorded and passed to the international disability and human rights communities, as well as providing periodic reports describing the abuses they have recorded.

Many INGOs have issues and concerns particular to their organization and membership. In addition, it has become very clear to us, during the course of our deliberations that the international human rights community is more likely to act quickly and decisively where the disability community is able to speak with a united voice.

Many of the INGOS have already undertaken substantial work on disability as a human rights issue. We encourage these INGOs to build effective structures to ensure that individual members have direct access to a human rights specialist within the INGOs to enable the reporting of individual cases of rights abuses or infringements. It is important to build equally effective structures at the national level.

The Seminar recognized that there has to be an individual within the organization who is charged with responsibility for obtaining evidence of individual abuse. This individual must be afforded substantial support in order to undertake their duties in an appropriate way. Particularly, the Seminar recommends that the individual worker be the *only person* who is able to identify the victim of abuse (please refer to our comments concerning confidentiality, below).

Where individuals are provided with the opportunity to report abuse, it is *vital* that the DPO/INGO concerned has prearranged and clearly understood procedures for:

- confirming the accuracy of allegations made;
- offering support and counselling services for traumatized complainants who request or require it;
- referring cases to the appropriate investigative or prosecutorial agencies, where the complainant freely consents to this;
- making alternative accommodation and/or personal assistance available, where this would prevent further abuse; and
- ensuring that there are staff available to ‘listen’ to the victim where necessary.

3. Procedural Issues

Protecting victims of abuse

In many countries, personal information, and the uses to which it can be put, is strictly controlled by domestic law. INGOs/DPOs must ensure that their human rights reporting mechanisms comply with local law.

It is essential to ensure complete confidentiality to protect those affected by abuse (whether informants or victims). Any material that might be used to identify the complainant or victim of abuse must be kept secure from unauthorised access.

We consider that the safety of the complainant and/or victim of abuse is of paramount concern. Where there is any risk to the complainant or victim, INGOs/DPOs must ensure their protection, particularly from retribution or punishment.

Protecting INGO/DPO Staff

Individuals working to collect evidence of human rights abuse must not, themselves, be put at unacceptable risk. INGO/DPOs must be particularly alive to the risk that their human rights specialist's determination to obtain evidence adversely affects their ability to assess personal risk.

Further, INGO/DPOs must be aware that the graphic and horrific nature of the evidence obtained by human rights specialists may, over time, induce stress and/or depression. DPOs are encouraged to pay particular attention to the welfare of individuals involved in the collection and documentation of human rights abuse.

4. Types of information that need to be collected and recorded Information recorded by the local coordinator

The INGO/DPO human rights specialist has a difficult task in respecting the confidentiality of the complainant while getting enough information to show that the complaint is genuine.

- **Contact information**

The INGO/DPO human rights specialist will need to record the complainant's personal details, including his or her:

- ▶ Name
- ▶ Address
- ▶ Telephone number

We recommend, as a standard procedure, that, if it is necessary for the complainant to be contacted again, it should only be the coordinator that does this. The coordinator must NOT forward these personal details to anyone else, including regional or national DPOs.

If other people try to contact the complainant, without knowing their situation, it is possible that they will inadvertently put the complainant or victim at risk (for example, where the complaint is about treatment in an institution and the only contact details for the complainant is the institution itself).

- **Details of the abuse**

It is important that the INGO/DPO human rights specialist obtains as much information about the circumstances of the abuse as possible.

This would include such information as:

- ▶▶ Who is the victim?
- ▶▶ What is the nature of the complaint?
 - Where did it take place
 - Describe what happened on the particular occasion or happens on a regular basis?
 - What is the infringed right?
- ▶▶ What is the impact on the individual?
 - Does it affect the individual's performance in general daily activity?
 - Does it intimidate the individual?
- ▶▶ Why does the complaint occur? What are the circumstances?
 - Is it a response to individual behaviour?
 - Is it the usual method of treating people or part of a policy?
 - Is it a common treatment practice?
 - Is it generally considered to be in the best interest of the individual or for his or her own good?
 - Is it accepted behaviour in the environment in which the individual lives?

An Example of Details Needed

Simply writing: *'the complainant is tied to their bed'* is of little help.

Other information that should be included (whenever possible) would include (but is not limited to):

- **How** the person is tied down – is it by force, with several attendants holding them down? Are they restrained with straps, handcuffs, ropes? Are they tied down most of the day, or only if they do particular things?
- **Who** is restraining the victim – is it nursing/care staff or other people? Can individuals involved in the abuse be individually identified?
- **How long** has the victim been restrained - has the victim been enduring this abuse for years or has it started more recently?
- **What** are the results of being restrained – are physical or mental injuries caused? Has the victim required medical treatment for injuries sustained whilst restrained or, if such attention should have been provided, has it been refused?

Information recorded by the INGOs/DPOs

With the sole exception of cases requiring immediate and urgent action, there is no necessity for anyone, save the individual human rights specialist receiving the complaint, being able to identify the complainant and/or victim.

However, all further information should be provided to the INGO or DPO that has taken responsibility for coordinating the collection and dissemination of abuse reports. The INGO/DPO must, nevertheless, treat all information with the utmost care.

Whilst statistical information concerning human rights abuses is valuable, we have been persuaded that individual cases can often have far greater impact – both on the international human rights bodies and the media. As a result, it is clear how vital it is to obtain comprehensive information concerning the abuse and the surrounding circumstances.

Photographic/video evidence of the abuse or resulting injuries may be particularly effective in combating or publicizing human rights abuse. However, where the victim concerned does not have the opportunity to consent to photographic or video evidence being obtained, we believe that investigators must recognize that their use raises particular and heightened ethical issues. In particular, inappropriate use of photographic or video material may render it indistinct from unhealthy voyeurism.

B. Documenting Legal Cases/Jurisprudence

1. The Context of Documenting Legal Cases Related to Disability and Human Rights

Court decisions and associated jurisprudence related to disability is already available in most countries in court reports or administrative tribunal reports. In some countries there are already established national databases. Cross-nationally and even within countries, similar fact cases may have very different legal reasoning and cases may be won or lost in one case on a technicality and in another by appeal to the rights of an individual. Different legal structures and court systems may provide more or less access to arguments based on international human rights principles or by appealing to international norms and standards to which a country is signatory. It is clear that monitoring legal cases and related jurisprudence can provide guidance in clarifying how the treatment of persons with disabilities infringes their human rights. A cross-national database would provide a method of understanding how law both creates inequality and redresses inequality and discrimination.

2. Structures/Authority for Effective Reporting: A Global Database on the Internet

The establishment of a global database accessible on the Internet covering court cases and administrative decisions about the human rights and fundamental rights of persons with disabilities is proposed as an effective approach for reporting. This would involve the preparation of a compilation of important international and national case law that uses

international standards to advance disability rights at the national level or national cases that provide progressive interpretation of general or disability-specific rights guarantees.

The database should be supplemented by registration of legal literature about the same subject. Where relevant information is already available on other websites belonging to NGOs, the UN, or other institutions, links should be provided. A search list for the website could be developed and made available for this purpose. It would be necessary to update this list from time to time to take account of relevant developments in this area.

The High Commissioner for Human Rights could provide the stimulus for this initiative by inviting all governments to co-operate with her in establishing a reporting system that covers decisions and legal literature about human rights/ fundamental rights of persons with disabilities. The invitation could refer to relevant background material including the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and the Resolution 2000/51 of the High Commission on Human Rights. Such an invitation by The High Commissioner's would need to emphasise, in accordance with Standard Rule 18, the role to be played by NGOs in the monitoring of the system. The High Commissioner could also invite donor states to consider funding this project.

It is important to stress that the responsibility for reporting logically lie with government and in particular the national Ministry of Justice of each country. In federal states it would be both the Ministry of Justice at the federal and at the state level which would be in the best position for reporting of cases under their jurisdictions. In a self-governing territory in which a local government has its own jurisdiction, the local Ministry of Justice would be best positioned to report cases about the human rights of persons with disabilities.

The reporting would need to be take place within a short time limit after a decision had been brought down to ensure that it was kept up to date and was useful. The Ministry of Justice could abstract each case in English using a standardized reporting format and then forward the abstract to a global database in Geneva under the office of the High Commissioner for Human Rights.

3. Procedural Issues

Alternatives to Ministries of Justice for data-collection

Relying solely on Ministries of Justice to provide the data for a database of this kind and scope may not be possible as it may not be feasible for some Ministries of Justice to collect decisions and report about human rights cases in an adequate or comprehensive manner. That does not diminish the need for a database. It does suggest, however, the need for a monitoring body that might play one of two roles. In the case where a Ministry of Justice is collecting and reporting the data, the main role of the monitoring body would be to ensure that the Ministry is meeting its responsibilities in a timely and comprehensive manner. However, in circumstances where the Ministry of Justice does

not undertake the reporting, the monitoring body or an appropriate representative of the body may wish to undertake the task of providing the information. In these circumstances the monitoring body should seek to open a dialogue with the Ministry of Justice in the hope that it could eventually take on the role.

Monitoring body

The envisioned monitoring body would ideally consist of a comprehensive group of representatives from legal institutions and organisations with a special interest in human rights and disability. We suggest that the initiative for *establishing* the monitoring body should be taken primarily by the national organisation of disability organisations in conjunction, as appropriate, with the following bodies:

- National or Federal Bar Association
- Human Rights Commissions or Human Right Centres
- Ombudsman or other similar statutory authority

Members of the monitoring body should include representatives of the national organisation of organisations of persons with disabilities and, as appropriate, representatives from the National Disability Council, the Courts, the Bar Association, the Ombudsman, Human Rights Commission, Human Rights Centres, Faculties of Law, Administrative Tribunals, Parliamentary Commissions and individual experts.

If a country does not have a national organisation of disability organisations, then a broad representation of organisations of persons with disabilities could be substituted on the monitoring body. They could include representatives from organizations of people with visual impairments, mobility impairments, intellectual disabilities, Deaf and hearing impairments as well as other groups of persons with disabilities with chronic diseases, hereditary diseases, leprosy and so on.

If it does not prove possible to establish a monitoring body fully along the lines outlined above, then one or a group of the institutions or organisations of persons with disabilities could be approached to undertake the data collection or monitoring role.

All members of the monitoring body would, on their own, collect court cases and other relevant material and present such information at the meetings to ensure that all relevant court cases and administrative decisions are compiled and included in the reports to the international database.

4. Information to be Collected and Recorded

Many countries have already established a national database containing their courts decisions and related jurisprudence. Building on this, and supplementing it with the proposed High Commissioner for Human Rights recommendation, would ensure that all Ministries of Justice have a national database in which relevant court cases and administrative decisions could be registered in the language in which they are written. The decisions should be accessible in this database in full text and with exactly the same

content as the decision when the court, administrative tribunal, Ombudsman or other authority made the decision. The responsibility to produce the English abstract of the case could be either the Ministry of Justice or some other competent authority, but in either case, should contain the following elements:

- Names of the parties in the case
- Name and address of the court or other decision-making authority
- Registration numbers of the case, date and year of the decision, so that the case always can be identified without any doubt.
- Rules from international conventions, declarations or other instruments, which are applied or discussed in the case.
- National rules or laws that are applied or discussed in the case.
- The abstract shall give a short description of the facts, ruling and outcome of the case.

C. Documenting the Media

1. The context of documenting human rights infringements by and in the media

The media is a key tool in the making of public opinion throughout the world. It has a powerful influence on the way disability is perceived and the attitudes of the public towards persons with disabilities. It is not possible to speak of a monolithic view of disability in the media but the majority of the world press, whether the large dailies from the western nations or local papers in small developing countries, tend to portray persons with disabilities as less than full citizens. Often there is an image of pity, charity and incapacity surrounding stories of persons with disabilities. When they are portrayed otherwise, it is sometimes the image of superhero or saint. Both of these represent disability in an unrealistic light and mask the recognition of the infringements of human rights that are taking place. In one case they present disability as an undesirable and intolerable burden, citizens who do not contribute to their society. In the other, people are presented as successful against all odds implying that the individual has overcome their particular impairment and achieved beyond all expectation. This fails to recognize the significance of societal discrimination, environment and attitude in disabling people.

The press can infringe human rights in what it reports and in how it reports – the language, the tone, the story are all sites of discrimination. But so also are the types of stories carried. Stories that present the elimination of disability as a high priority in society cannot be overlooked in a human rights framework. There is therefore a need to develop an assertive media strategy in order to influence media and as a tool in documenting the infringement of the human rights of persons with disabilities in the media.

2. Structure for effective reporting: A Disability Rights Media Watch (DRMW)

Recognizing the effectiveness of already existing media watches in other areas of human rights, the Seminar put forward the idea of the establishment of a clearinghouse to monitor the media and its reporting related to disability. The goal of the Disability Rights Media Watch (DRMW) would be to provide a networking service to DPOs at all levels in matters related to media, information and communication concerning the human rights status of persons with disabilities.

Its functions would be:

- to develop a uniform criterion, from international norms and standards, by which to judge media reporting from a human rights perspective
- to collect information in the media on disability issues
- to advise concerned DPOs on matters in the media related to them
- to distribute information through the network to DPOs on all levels, other NGOs, government agencies, INGOs, UN bodies and media organizations.
- to support training programs for DPOs on how to respond to media violations and how to use media as a tool for social change.

The DRMW would develop and maintain an international database on human rights and disability and specifically would collect, validate and analyse complaints relating to infringements of human rights in the media, based on uniform criterion it would develop for that purpose.

3. Procedural Issues: Optional Mechanisms

There were several optional structures suggested for the DRMW. It was clear that the preferred option was to create a new independent body, either a stand-alone body or one housed within an existing DPO or INGO, to carry out the functions. Recognizing that this might not be economically or politically feasible to establish in the short term, however, did not in any way diminish the importance the workshop attached to the development of a database and the need for reporting as soon as possible. They therefore recommended, as a second option, negotiating with currently operating media watches and media monitoring organizations to build into their work the functions they foresaw for DRMW. This has benefits because organizations have a great deal of experience in this type of work which would highlight issues relating to disability and the convergence of disability with other human rights issues.

Structures for the Disability Rights Media Watch (DRMW)

Option 1: A new independent body

Established specifically to carry out the functions of providing a networking service for DPOs to report human rights infringements in a uniform and systematic manner and to monitor and impact media activity relating to disability.

Board of Directors

- 6 international DPOs (more than 50% of the board)
- other INGOs

Managing or Executive Director

- reporting to the Board

The Board could determine such issues as whether the DRMW is placed in a current DPO/IDPO or is to be structured as a freestanding body. That discussion would involve such issues as:

- ensuring that no single DPO have control over DRMW
- establishing procedures so that all DPO`s have access to the work of DRMW
- locating in a major city with accessible technology and information suitable for establishment

Option 2: Using existing organizational structures

DRMW will build on already existing structures and organizations that are doing similar work and on which the disability rights issues in media could be affiliated and incorporated. In this option, there may be a need to give additional attention to how the training roles for disability organizations would be carried out.

4. Information to be Collected and Recorded

There are already a number of international bodies that carry out media watches. Their expertise would be solicited to provide guidance for the collection and collation of useful data. It was recognized, however, that the effectiveness of any instrument would be impacted by its capacity to gain the cooperation and enthusiasm of the disability grass-roots to collect data and to realize the impact of information at the international, national, regional, and local levels. There were, therefore, recommendations directed specifically to the form of the instrument that would be made available to DPOs as a uniform tool for data collection.

It was proposed that there be a general introduction to the instrument used for data collection that would do the following:

- Explain the purpose of collecting and reporting what is in the media, in particular, that the data will be used to look for trends of reporting that infringe on the rights of persons with disabilities in the media;
- Point out the different forms of publications where reporting or infringement is to be tracked, such as, newspapers, magazines, advertisement, TV Programs, radio shows, Internet, movies, books, short stories;

- Explain briefly and clearly the concept of human rights, with specific examples, and also clarify the difference between media reporting on a violation and the media as a perpetrator of infringements;
- Make clear the importance of valid and true information and lay out methodology to verify the information being collected;
- Explain that all information sent in will be verified in some way; and
- Point out that anonymous reporting is acceptable, yet will also require some kind of verification.

The information to be recorded by the individual or group submitting a report would include information of the following nature:

- Contact information
 - ▶▶ Name
 - ▶▶ Address
 - ▶▶ Telephone number
- If unable to reveal those details, is there other information that provides the information to enable the details to be verified?
- Information about the infringement/violation being reported
 - ▶▶ What are the details of the violation? If possible list international media disability standards set up by DRMW.
 - ▶▶ Is there a copy of the reported material?
 - if yes, please attach;
 - if no, where/when and how was the material published and how can DRMW obtain it?
- The context of the media involved:
 - ▶▶ What is the context of the media article – refer for example to the situational/cultural/religious/political circumstances?
 - ▶▶ Describe the media that published the material with reference to geographic cover, circulation number, owner, political/religious, persons responsible for material.
- Information about the reporting and individual reaction to the infringement
 - ▶▶ Can you propose appropriate action to be taken
 - ▶▶ Have you already taken any action, please describe?

Reported infringements would be subjected to an analysis by the DRMW to ensure their validity and to provide a reporting format that would be useable in collating the information and developing the databank. This would be instructed by the knowledge and experience of other media watch organizations. However, such questions as the following provide a suggestion of what that process would involve:

- Is it a rights violation as set out by DRMW in list/international media disability standards? Is it a disability related violation?
- Type of violation: categorize based on list/international media disability standards set out by DRMW
- Type of violation? Categorize based on list/international media disability standards set out by DRMW.
- Can the violation be verified?

- Where did the violation occur?
- In what type of media – magazine, newspaper, TV, radio et cetera – did the violation occur?
- Was the media the perpetrator of the violation?
- Was the media the messenger?

Finally, a methodology for follow-up to the collection, validation and reporting of information would be developed so that that information could be used to ensure action is taken either in individual cases, where appropriate or in cases of systemic infringement of the human rights of persons with disabilities.

D. Documenting legislation

1. The context of documenting human rights infringements in legislation

Legislation is, not infrequently, found to be a source of systemic discrimination experienced by persons with disabilities. These infringements of human rights may be an intended or unintended consequence of legislation that is grounded in a traditional notion of disability as a condition that results from an individual's impairment. Recognizing disability as a consequence of the structural conditions in society that limit the options and abilities of the individual within his or her environment, brings into the open the infringements of human rights that may be masked by interpretations of disability as an individual pathology¹⁹.

The importance of the use of international norms by the disability NGOs themselves was recognized to be the starting point for developing documentation of the infringement of the human rights of persons with disabilities in legislation. The “demystification of international human rights law” within the disability community and the “demystification of disability” within the human rights community were agreed to be essential if both communities are to work together to give concrete meaning to the human rights of persons with disabilities.

¹⁹ Disability Legislation may be categorized into four models: Biological-Medical Model, Functional Rehabilitation Model, Social/Environmental Model and Human Rights Model. In the Bio-Medical Model, attention is directed to delineation or listing of what physical, intellectual or sensory impairments an individual has for the person to be included within the legislation. The Functional Rehabilitation model takes the functional approach and emphasizes action or activities that an individual can perform. The social/environmental model addresses the structural conditions in society that limit the options of individuals with disabilities. In this third model, the focus of limitation has shifted from the individual to society. The Human Rights Model is premised on the recognition of a set of fundamental human rights to which all persons are entitled rather than focusing on disability either from an individual deficit or an environmental perspective. By addressing the rights of all people the definition is found in the breach of the rights rather than the delineation of characteristics of the person. See the draft report on the interregional seminar and symposium on international norms and standards relating to disability (organized by the University of Hong Kong and the Equal Opportunities Commission of Hong Kong SAR in cooperation with the United Nations Hong Kong 1999)

The process outlined, here, focuses on developing a prototype for a set of guidelines to provide a tool for disability NGOs and individual disability rights advocates to use international norms and standards to evaluate the effectiveness of the laws of their countries. It proposes that legislation relating to disability be analyzed in the context of the various interpretations of disability as social phenomena.

2. Structures for Effective Reporting: Options

There are a number of potentially useful ways of collecting the documentation with regard to legislation. It is recommended that these existing structures be investigated as sites for national compilation of data and to coordinate the efforts across nations. It may be possible to use one or more of the following:

- The vice chancellors and heads of departments of universities, law departments, and research or social policy organisations could be involved in generating information on human rights issues of persons with disabilities.
- Research projects and dissertations could be suggested in the area of human rights of persons with disabilities. In this activity the students of law can play a vital role.
- Distance education and universities can be approached to start diploma certificate courses in the area of human rights of persons with disabilities.
- Distance education universities may undertake projects for developing manuals and guides for NGOs and activists in using the human rights instruments and in developing national and international mechanisms for redressing legislation that is infringing the human rights of persons with disabilities.
- International NGOs in the field of disability can actively collect data on laws policies, programs which are compatible with human rights instruments and which are in violation of human rights instruments. The INGOs can identify national organisations, which have the capacity to undertake such a project. INGOs can generate resources for a human rights project so that the national organisations are properly supported.

3. Procedural Issues

Recognition was given to issues that might hinder the use of international norms in redressing infringements of the human rights of persons with disabilities in legislation.

First, the use of international norms and standards require some basic knowledge in international law. This includes basic knowledge such as that countries have obligations to implement the norms in international legal instruments (such as conventions or covenants) once they have ratified the instruments. It is also useful to be aware that the legally binding norms or instruments that a country has ratified may be used as the guidelines for domestic legislation or development of policies and programmes of the government, as can non-legally binding instruments. In many cases, the innovative and

diverse use of the international norms and standards (both legal and non-legal instruments) has not been fully explored by disability NGOs and advocates.

Second, the level and extent of the knowledge on issues concerning human rights vary in different parts of the world. In some parts of the world, especially in under-resourced countries, disability issues are not yet seen as falling within the parameters of human rights. While there may be recognition that there is some element of human rights that would have meaning for those with disabilities it is not seen as pertaining to all issues or to be commensurate with the human rights of non-persons with disabilities. This may also be the case in terms of the experience and capacity of NGOs at international, national or local levels. Among other groups who have also been marginalized, there have been in recent years a number of national or even sub-national NGOs that have been able to advocate their issues directly at the international level using international human rights instruments²⁰. It may be instructive for disability NGOs to affiliate with or liaise with some of these groups to build capacity in using international norms and standards to recognize, document and address systemic human rights infringements.

4. Information to be collected and recorded

The discussion about information to be collected and recorded was limited to an illustration of the use of international human rights instruments as guidelines to evaluate domestic disability legislation.

The scope of what needs to be documented is quite extensive. In some instances the infringements of the human rights of persons with disabilities occur as a result of an existing legal provision that limits the exercise of human rights, for example legal prohibitions against some persons with disabilities voting, immigrating, or marrying. In others it is the absence of special legislative provision to meet the particular needs of a specific class of persons with disabilities; for example, many contract laws do not recognize persons with intellectual disabilities as competent parties to contracts. This results in the violation of their economic rights. Similarly, in many procedural laws, both civil and criminal, there are no provisions to provide for particular needs of people who have sensory or speech disabilities. This violates the right to equality before the courts and tribunals and the right to equal protection of the law. The infringement may be by omission or commission. On the other hand, there are laws that clearly are designed to overcome historic and current infringements of rights, for example affirmative action, employment equity and legislated quotas for participation.

The information that needs to be recorded by the individual or the group that is making a report would include information of the following nature:

- Contact information
 - ▶▶ Country
 - ▶▶ Legislation
 - ▶▶ Article of legislation

²⁰ See UN report on *Declaration of the Rights of the Indigenous People*

- ▶▶ Particular circumstances of the infringement of human rights
 - ▶▶ Right that is infringed by the legislation
- Type of law
 - ▶▶ Is it a Constitutional provision?
 - ▶▶ Is it a provision of criminal law?
 - ▶▶ Is it a provision of civil law?
 - ▶▶ Is it a provision of administrative law?
 - ▶▶ Is it a law that provides special provision for discrimination and the protection of human rights?
- In each of these cases, further questions will lead to knowledge about whether it is systemic discrimination and infringement of human rights or whether it is a case of intended and particularized discrimination. In each case three general questions have to be addressed:
 - ▶▶ Does the law (or Constitution) protect and ensure the right for persons with disabilities?
 - ▶▶ Does the law (or Constitution) directly and explicitly infringe the right for persons with disabilities?
 - ▶▶ Is the law (or Constitution) silent and in its silence infringe the right of persons with disabilities?
- Such particular information as the following might be sought:
 - ▶▶ Does the Constitution guarantee the right without discrimination? If so, do these provisions refer specifically to persons with a disability, or have they been interpreted to as guaranteeing information against discrimination on the ground of discrimination?
 - ▶▶ Do laws requiring compulsory services, e.g. education for all legislation, apply to children with a disability or does the law exempt children with disabilities from the compulsory category of service.
 - ▶▶ Are there opportunities for persons with disabilities to exercise general legislated rights or to participate in universal policy initiatives, e.g. are polling booths accessible and information available in multiple formats?
 - ▶▶ Are there supports and services that enable the participation of persons with disabilities in legislation establishing government-apportioned services, facilities and accommodation and employment?
 - ▶▶ Are there factors particular to disability, such as low income, underdevelopment of language skills, limited education etc. that *de facto* exclude persons with disabilities from participating in legislated activities and exercising their human rights?
 - ▶▶ Does the manner of delivering a service, facility, accommodation or employment *de facto* limit participation?

Two examples follow that are illustrative of the way a piece of legislation could be documented and the type of information to be collected:

An Example of Details Needed: The Right to Work

Article 6 of the International Covenant on Economic, Social and Cultural Rights requires every country to ensure "the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses and accepts."

This means that persons with disabilities, with the necessary skills and qualifications, have the right to work in an area of their own choice, like all other citizens.

- Does the constitution in your country:
 - protect and ensure the right to work for persons with disabilities?
 - contravene the right to work for persons with disabilities?
 - is the constitution of your country silent and in its silence infringing the right to work of persons with disabilities?

Please quote relevant provisions from the constitution of your country.

- Are there laws or regulations of your country that:
 - protect and ensure the right to work for persons with disabilities?
 - contravene the right to work for persons with disabilities?
 - is the constitution of your country silent and in its silence infringing the right to work of persons with disabilities?

Please provide relevant examples from the laws and regulations of your country.

- Are there governmental or administrative orders in your country that:
 - protect and ensure the right to work for persons with disabilities?
 - contravene the right to work for persons with disabilities?
 - is the constitution of your country silent and in its silence infringing the right to work of persons with disabilities?

Please provide relevant examples from government or administrative orders of your country.

If you have a constitution, laws or regulation and/or governmental or administrative orders protecting and ensuring the right to work for persons with disabilities give examples of their implementation or lack of implementation.

If possible, provide a copy of relevant documents or give as many relevant details as possible.

An Example of Detail Needed: The Right to Vote and Be Elected

Article 25 of the International Covenant on Civil and Political Rights requires every country to ensure "the right of everyone to take part in the conduct of public affairs, directly or through freely chosen representatives; to vote and be elected at periodic elections by universal suffrage; and to have access, on general terms of equality, to public service in his/her country."

This means that a disabled person has a right to cast a vote and contest an election for any public office. This also means that the accessibility needs of persons with disabilities are taken into account in the design of polling stations, ballot papers and machines.

- Does the constitution in your country:
 - protect and ensure the right to vote for persons with disabilities?
 - contravene the right to vote for persons with disabilities?
 - is the constitution of your country silent and in its silence infringing the right to vote of persons with disabilities?

Please quote relevant provisions from the constitution of your country.

- Are there laws or regulations of your country that:
 - protect and ensure the right to work for persons with disabilities?
 - contravene the right to work for persons with disabilities?
 - is the constitution of your country silent and in its silence infringing the right to work of persons with disabilities?

Please provide relevant examples from the laws and regulations of your country.

- Are there governmental or administrative orders of your country that:
 - protect and ensure the right to work for persons with disabilities?
 - contravene the right to work for persons with disabilities?
 - is the constitution of your country silent and in its silence infringing the right to work of persons with disabilities?

Please provide relevant examples from government or administrative orders of your country.

If you have a constitution, laws or regulation and/or governmental or administrative orders protecting and ensuring the right to vote and to be elected for persons with disabilities, give examples of their implementation or lack of implementation.

If possible, provide a copy of relevant documents or give as many relevant details as possible.

E. Documenting Programmes, Services and Practices

1. The context of documenting human rights infringements in the adoption and implementation of programmes, services and practices

The enormous range of possible issues complicates attempting to find a uniform mechanism for documenting infringements of the human rights of persons with disabilities in areas of services and practices. In developing a methodology for documenting human rights violations in the implementation of services, programmes and practices, consideration was given to the benefits of a comprehensive manual which would aid NGOs, treaty bodies, governments and others in assessing whether particular human rights guarantees had been observed in relation to persons with disabilities.

This may be an area where the most effective way of documenting would be to find a consensus on a specific issue that cuts across geographic boundaries and governmental politics and to track that issue. Issues, such as institutionalisation, inclusive education or voting practices might be practices/services that could be documented in this way.

2. Structures for Effective Reporting: The Role of a Comprehensive, Multi-dimensional Reporting Manual

The idea of a comprehensive manual of reporting was put forward as a methodology for the collection of information and effective monitoring. A manual of type proposed here inevitably includes the various approaches to documentation that are included in other sections of this report, so duplicates those reports in a number of ways. However, because it proposes an issue-by-issue approach to documenting the infringement of human rights in programmes, services and practices, it has to be designed in this way to be comprehensive.

A manual would assist disability rights advocates as well as general human rights advocacy organizations to conduct effective human rights documentation and advocacy for the rights of persons with disabilities at the local and national level. A manual would also assist international human rights oversight bodies to monitor and enforce international human rights.

A comprehensive multi-dimensional manual could then be of use to those audiences in the following ways:

- Assisting NGOs who wished to prepare a shadow report to an official government report submitted to the United Nations under one of the treaties (in particular the International Covenant on Economic, Social and Cultural Rights, but not only that treaty).
- Providing a framework for NGO analysis of implementation of the rights in question at the national level, even when a reporting exercise was not going on.
- Assisting governments in writing their UN reports or in assessing their policies and practices in the field of education for consistency with human rights guarantees. Finally, it might be of assistance to human rights treaty bodies in educating them as to the issues that they should be raising with State's parties and requiring States to include in their reports.

3. Procedural Issues

A prototype of what might be included in such a reporting or monitoring manual was prepared as a guideline for creating an instrument of this nature. The right to education was chosen as a sample draft of an entry that might appear in such a manual²¹.

²¹ This draws on other manuals that have been prepared under some of the United Nations human rights conventions, for example *Assessing the Status of Women: A Guide to Reporting under the Convention on the Elimination of All Forms of Discrimination Against Women* (Commonwealth Secretariat and International Women's Rights Action Watch, 2nd ed., 1996).

Any instrument of this nature would need to be refined: to ensure that it was reliable; to test that it is applicable to disability; and to bring it in line with other methodologies that have been proposed in other types of documentation. It would be particularly important to work with DPOs to ensure that it is easy to understand and can be administered within the context of their existing activities. As with any of the data collection tools, it has to resonate with those who will use it. A comprehensive tool requires a significant depth of expertise and the resources in people and time if it is going to be used and thereby provide the data for reporting and collating human rights infringements.

4. Information to be collected and recorded: prototype of a manual

The reporting manual should be designed with three sections for each individual right. For example, in the case of the right to education it might include:

- an introductory section referring to the principal guarantees of the right to education without discrimination in the general international human rights instruments;
- a brief statement of the extent of the obligation of the State, not merely to refrain from positive infringements of the right to education on the basis of equality, but also the obligation of the State to take positive measures to ensure the realization of that right and to prevent its violation by others; and
- a list of questions seeking information which would enable an assessment to be made of whether a government is fulfilling its obligations to respect and ensure the right of persons with disabilities to education on the basis of equality. The list set out below does not purport to be exhaustive, nor will every question necessary be relevant to every country.

The following categories of issues and questions are relevant to whether a State is fulfilling its obligations to ensure to all persons the right to education at the primary and secondary level:

- law and policy (general)
- choice and availability of different types of policies, services and practices
- barriers to accessibility
- portrayal of persons with disabilities in the service or practice environment
- budgetary and planning matters
- training and materials for employees and service users
- organizational governance
- employee training and compliance

Each of these generates specific information to be collected. By way of example, a prototype of inclusive education is provided below.

Examples of Information to be Documented: Inclusive Education

<i>Law and policy – general</i>	
<ol style="list-style-type: none"> 1. Does the Constitution or national legislation guarantee the right of education for all without discrimination? If so, do these provisions refer specifically to persons with a disability, or have they been interpreted as guaranteeing protection against discrimination on the ground of disability? 2. Do laws requiring compulsory schooling apply to children with a disability or does the law exempt children with disabilities from the requirement of compulsory attendance? If the law does mandate compulsory education for all children, is the law observed in the case of children with disabilities? Is the position different for boys and girls? 3. Are the views of persons with disabilities and their families taken into account: <ol style="list-style-type: none"> (i) in the development of education policy by governments; and (ii) the design and implementation of educational programmes? 4. When major educational reforms are undertaken, how are organizations of persons with disabilities and the views of persons with disabilities represented in the policy-making and the process of reform? 	<ol style="list-style-type: none"> 5. Are the government and educational authorities committed to the promotion of diversity in schools as a contributing force for change, in order to support the social integration of all children and the realization of their human rights? 6. Do educational opportunities for children with disabilities “facilitate the child’s active participation in the community” as required by Article 23 of the CRC? <ul style="list-style-type: none"> • Are there opportunities for fully integrated education in the same schools and programs as all other children? • Are there adequate supports in mainstream schools to ensure that children with disabilities receive the appropriate services and education they need? • Are these supports and services provided in a manner that assures that education enables the child to achieve the fullest possible social integration? 7. When the government prepares plans for submission to international agencies for funding, how does it ensure that any such plan fully includes the right of persons with disabilities to education without discrimination?
<i>Budgetary and planning matters</i>	
<ol style="list-style-type: none"> 1. What percentage of the national (educational) budget is spent on ensuring that children with disabilities are given access to education? 2. What sums are allocated specifically for the provision of special education facilities, such as schools for the deaf and other groups? What percentage of the overall education budget do these represent? 3. Do budgets allocated by governments or education ministries to schools contain a specific allocation to finance modifications to school buildings or other aspects of its operation to ensure accessibility for 	<ol style="list-style-type: none"> 4. Is special central funding available in order to undertake major modifications to school buildings or facilities to ensure accessibility for all members of the school community? 5. Does the government or education ministry make available to schools or parents funding to permit the employment of additional teacher's aides or personal assistants in order to facilitate a child's participation in school activities?

<p>all students, staff and other members of the school community?</p>	
<p><i>Choice and availability of different types of education</i></p>	
<ol style="list-style-type: none"> 1. Does existing law and policy require that inclusive education be available to all children with a disability where they wish to have such education? • Does existing law and policy ensure that special education is available to deaf children and other children who need special education? 2. Are parents able to choose the type of education they consider most appropriate for their children? 	<ol style="list-style-type: none"> 3. What information is provided to parents to ensure that they are aware of the full range of options that may be available for their child? <ul style="list-style-type: none"> • Is inclusive education an option for those who wish to make that choice? • What procedures are there to ensure that a child has the opportunity to express his or her views on the type of education he or she wishes to have, and what weight is given to the child's views? 4. Do all children with disabilities have access to the type of education they wish to undertake within a reasonable distance from their homes?
<p><i>Barriers to accessibility</i></p>	
<ol style="list-style-type: none"> 1. Do children with disabilities face particular difficulties in getting to and from school? What financial or other measures has the government taken to ensure that children can get to school without difficulties? 2. Do children with disabilities face difficulties in getting their education in their native minority language? 3. Are sign language using children (e.g., deaf children) prevented from receiving their education in sign language? Do teachers prevent or discourage the use of sign language in schools? 4. What impact do school-related expenses have on the ability of children with disabilities to attend school? How does this affect girls particularly? 	<ol style="list-style-type: none"> 5. What financial or other measures have the government or schools taken to ensure that such expenses do not amount to a barrier to attendance at school? What impact have they had, especially so far as ensuring that girls are not inhibited from school attendance? 6. What physical and other barriers are there to access to school buildings and other facilities? 7. What monitoring procedures are in place to ensure that schools and their facilities are accessible? 8. Does the education ministry have a programme with a definite timetable for removing barriers to accessibility in schools? 9. What requirements are there to ensure that new schools or new school facilities are designed and constructed so that they are fully accessible to all children? Are these requirements observed?
<p><i>Portrayal of persons with disabilities in the school environment</i></p>	
<ol style="list-style-type: none"> 1. Does the government or the education ministry have a stated commitment to the reflection of diversity in curricula, textbooks and other materials? • Are persons with disabilities 	<ol style="list-style-type: none"> • What efforts have been made to review textbooks and teaching materials to ensure the adequate inclusion of persons with disabilities and issues that are of particular concern to persons with disabilities? 2. How many teachers with disabilities teach

<p>portrayed in textbooks or other materials used in schools? Are these images positive or do they reflect negative stereotypes?</p>	<p>in schools?</p> <ul style="list-style-type: none"> • What barriers are there to students with disabilities who may wish to become teachers? <p>What measures have been taken to increase the number of persons with disabilities undertaking teacher training?</p>
<p><i>Inclusion of all children in the full range of school activities</i></p>	
<p>1. Are children with disabilities included in school sporting activities and all other school activities (such as school excursions, etc)?</p>	<p>2. Are students with disabilities given the full benefit of careers counseling and training opportunities organized through the schools, or are they encouraged to think of themselves as qualified only for a limited number of professions?</p>
<p><i>Curriculum and materials</i></p>	
<p>1. Are library materials and other teaching materials available in accessible formats, and is the same material available at the same time to all students? Is any effort made to ensure that they are or can readily be made available in accessible formats?</p>	<p>2. What steps have been taken to ensure that curricula are designed and delivered in a manner that ensures equal access to the curriculum for all students?</p> <p>3. What arrangements are made in order to ensure that students with disabilities are able to take examinations under conditions that guarantee them substantive equality?</p>
<p><i>School governance</i></p> <p>1. Are parents of children with disabilities represented on the board and other governing bodies?</p> <p>2. Are persons with disabilities or representatives of organizations of persons with disabilities included among community representatives on schools boards and councils?</p> <p>3. Are special provisions made to ensure students with disabilities are represented on student councils.</p>	
<p><i>Teacher training and competencies</i></p>	
<p>1. Do teacher training programmes in teachers' colleges and universities include persons with disabilities themselves?</p> <p>2. Do teacher training programmes in teachers' colleges and universities include developing competence in teaching children with disability?</p> <p>3. Are practicing teachers encouraged or required to undertake training in relation to disability issues as part of their further education activities?</p>	<p>4. Are teachers and students made aware of the different communication needs of different students and given appropriate opportunities to develop their skills in this regard?</p> <p>5. What particular difficulties do girls with disabilities face in schools? What steps have been taken to address these issues?</p> <p>6. What measures have been taken to ensure that all students fully understand disability issues and that some do not ostracize or make fun of fellow students with</p>

	disabilities?
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XI Additional General Recommendations to Strengthen the Use of International Instruments on Human Rights for Persons with Disabilities

The following are recommended initiatives that could be taken or supported by the Office of the High Commissioner for Human Rights. They have been grouped into six categories to provide coherence and to make clear the holistic approach that is being proposed. They are general recommendations supplementary to recommendations made within the reports of the five focus areas of documentation.

Integration of disability issues into the work of UN human rights treaty bodies

- Organizing a meeting between representatives of the individual treaty bodies and disability groups in order to discuss the relevance of disability issues and measures that would lead to the better inclusion of disability issues in the work of the treaty bodies.
- Organizing a meeting with all the members of one committee and disability groups for an in-depth discussion of issues that arise particularly under that treaty—perhaps in conjunction with NGO or other efforts to assist the committee in developing a general comment or recommendation on one or more violations of the rights of persons with disabilities.
- Organizing a meeting between the ‘special procedures’ of the Commission on Human Rights (thematic and country mechanisms of the Commission) and disability groups in order to discuss the relevance of disability issues and measures that would lead to the better inclusion of disability issues in the work of the treaty bodies.
- Organizing a meeting of national human rights institutions at which disability issues are a central part of the agenda.

Increased representation of persons with disabilities on UN human rights bodies and as holders of special mandates

- Exploring what steps can be taken to promote better representation of persons with disabilities as members of treaty bodies or as Special Rapporteurs of the Commission on Human Rights or the holders of other positions under the procedures of the Commission, as well as staff of the Office of the High Commissioner.

Steps to raise awareness of disability as a rights issue

- Organizing a series of judicial colloquia in which the relevance of international human rights standards – both general and disability-specific – to domestic litigation could be explored with judges, advocates and others.

Proposed studies to document infringements and support the enforcement of the rights of persons with disabilities

- Preparing a detailed study that compares the rights guaranteed in the Standard Rules and other disability-specific instruments to those contained in the general human rights instruments.
- Preparing a study of the extent to which each of the treaty bodies and special procedures has addressed disability issues in their work under reporting mechanisms, complaints procedures and other ways.
- Preparing, in collaboration with regional organizations such as the Council of Europe, the Organization of American States or academic institutions, detailed studies of individual rights and how they have been interpreted or could be interpreted in ways that would advance the human rights of persons with disabilities.
- Coordinating the data collection to develop “shadow” reports for the reporting requirements for the Convention on the Rights of the Child, the Covenant on Economic, Social and Cultural Rights and other relevant international human rights instruments.
- Promoting and supporting “shadow reporting” by disability advocacy organizations around the world and disseminate beyond the human rights monitoring bodies to which they are directed.
- Prepare an analysis of the way fundamental human rights issues are currently left out of existing treaty monitoring and also the priorities for action established by grassroots organizations to bring about rights enforcement.

Training for capacity building

- Organizing training workshops for disability and human rights advocates on how to use the UN human rights procedures more effectively.
- Providing support for the preparation of a manual guide to the use of international and regional human rights mechanisms to advance the human rights of persons with disabilities. Developing a “cataloging resource” specifically on (1) how to use the human rights mechanisms (2) how to use international norms and standards and (3) who/which organizations to contact for further information

- Encouraging and advising national organizations of persons with disabilities to increase awareness amongst individual persons with disabilities and their family members of the fact that the human rights' declared and acknowledged in all UN Human Rights instruments apply to everybody, without exception.
- Developing and sponsoring workshops on the documentation of human rights monitoring.

Funding

- Approaching donor agencies for support in setting up human rights committees in national organisations, for the purposes of undertaking research projects and training for capacity building of NGOs in the area of human rights.
- Approaching donor agencies to organise para-legal training for master trainers in the area of human rights so that resource persons for conducting training courses at the national level and local level are prepared.
- Encouraging law commissions to undertake the review of existing laws with the view to suggest improvements for making laws compatible with human rights instruments.
- Encouraging donor agencies, for example, development co-operation organisations, to consider the policy of co-operation to the extent that human rights issues become a necessary activity in their partner organisations along the lines of gender issues.
- Organizing foreign assistance programs to increase funding for disability rights advocacy around the world, placing a priority on providing funds to establish advocacy organizations in countries in which advocacy organizations are least developed.

XII Concluding Remarks: From little acorns great oaks grow

As Dr. Bengt Lindqvist reminded the participants at the opening of the Seminar, there is a real chance now to bring the infringement of the human rights of persons with disabilities to the world stage. The doors of the human rights system are open and there are no barriers to using the international human rights norms and standards for persons with disabilities. The world is waiting for a response from the disability field.

Anuradha Mohit reflected the thoughts of many of the participants in recognizing the need for the work:

There has been a need for an instrument for a long time. We have had no way for the individual to raise an abuse of his or her rights internationally.

Joshua Malinga ended the Seminar by recognizing that the participants, including the six international non-government organizations, that make up the UN Panel of Experts left 'united as a voice' in having made a strong start in having guidelines and a strategy for exposing human rights abuses at all levels. He said:

This seminar...injects a new spirit to go forward with our work, to expose violations of human rights of our people throughout the world. It has provided us with new knowledge, new ideas, and new plans to do the work.

The many recommendations and ideas from this Seminar do provide a direction for moving forward. When Dr. Lindqvist planted an oak tree at Almåsa in Sweden, in recognition of the work of the seminar, he reminded us that it is from little acorns that great oaks grow. The roots of justice are secured in honouring the human rights of persons with disabilities.

Annex A

C. List of Participants (including observers, secretaries etc)

Annex B

D. Seven pre-conference papers were prepared for the Seminar. They are attached.

- Pre-paper 1:** *The Seminar: background, purpose and organization*
(Marcia Rioux)
- Pre-paper 2:** *Recording human rights abuses against persons with disabilities: practical issues revealed by the Disability Awareness in Action Human Rights Project* (Richard Light)
- Pre-paper 3:** *Bioethics and disability* (Rachel Hurst)
- Pre-paper 4:** *International human rights protections for institutionalised persons with disabilities: an agenda for international action* (Eric Rosenthal)
- Pre-paper 5:** *Disability rights and human rights: plunging into the 'mainstream'?*
(Andrew Byrnes)
- Pre-paper 6:** *Promotion and enforcement of the rights of persons with disabilities: a South African perspective – some ideas on the process of getting the violations* (Jerry Nkeli)
- Pre-paper 7:** *Preliminary ideas and procedures for ensuring systematic international collection of information* (Anuradha Mohit and S. K. Rungta)

**Let the world know - International seminar on human rights and disability
5-9 November 2000, at Almåsa Conference Center, Stockholm, Sweden**

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<p>Let the world know - International seminar on human rights and disability 5-9 November 2000, at Almåsa Conference Center, Stockholm, Sweden</p>

Pre-paper 1.

The seminar – background, purpose and organization
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I Background

There has been an increasing international recognition that disability is a human rights issue. There is also recognition that disability and disability-related exclusion and marginalization is a concern for the UN human rights bodies.

The World Programme of Action concerning Disabled Persons, adopted by the U.N. in 1982, recognized the responsibility within the U.N. system of addressing the human rights of people with disabilities, in the following recommendations:

Organizations and bodies involved in the United Nations system responsible for the preparation and administration of international agreements, covenants and other instruments that might have a direct or indirect impact on disabled people should ensure that such instruments fully take into account the situation of persons who are disabled. (para. 164)

Particular conditions may exist which inhibit the ability of disabled persons to exercise the human rights and freedoms recognized as universal to all mankind. Consideration should be given, by the United Nation Commission on Human Rights, to such conditions. (para. 166)

Incidents of gross violation of basic human rights, including torture, can be a cause of mental and physical disability. The Commission on Human Rights should give consideration, inter alia, to such violations for the purpose of taking ameliorative action. (para. 168)

In August 1984, the Sub-Commission on Prevention of Discrimination and Protection of Minorities appointed a Special Rapporteur, Mr. Leandro Despouy, to conduct a comprehensive study on the relationship between human rights and disability. In his report (1993), Mr. Despouy made it clear that disability is a human rights concern, in which the UN monitoring bodies should be involved. Included among his recommendations were the following:

After the Decade has ended, the question of human rights and disability should be kept on the agendas of the General Assembly, the Economic and Social Council, the Commission on Human Rights and the Sub-Commission as an item of constant concern and ongoing attention.

The UN Committee monitoring the Covenant on Economic, Social and Cultural Rights should assume the supervisory task in the disability field. The Committee should receive a special mandate for this purpose.

The Committee on Economic, Social and Cultural Rights in 1994 assumed this responsibility by issuing a General Comment No. 5, in which the Committee makes an interesting analysis of disability as a human rights issue. The General Comment states:

The Covenant does not refer explicitly to persons with disabilities. Nevertheless, the Universal Declaration of Human Rights recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant. In addition, in so far as special treatment is necessary, States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability. Moreover, the requirement contained in article 2 of the Covenant that the rights 'enunciated ¶ will be exercised without discrimination of any kind' based on certain specified grounds 'or other status' clearly applies to discrimination on the grounds of disability.

At the 54th session of the UN Commission on Human Rights in March/April 1998 the Commission adopted resolution 1998/31, in which the Commission made a series of statements and recommendations for the future development in this area. Resolution 98/31 was a principal breakthrough and a general recognition of the UN responsibility for human rights and disabled persons. Therefore, expectations were high that finally things would start to develop. However, in the two years following the adoption of the Commission resolution, there was little follow-up to the expectations raised. This was a major concern when the Commission on Human Rights again discussed human rights and disability at its 56th session in April this year. As a result of the discussion the Commission adopted another resolution (2000/51), which incorporated the recommendations of Resolution 98/31.

In the first operative paragraph the Commission recognizes the UN Standard Rules as an evaluative instrument to be used to assess the degree of compliance with human rights standards concerning disabled people:

[The Commission] *Recognizes that any violation of the fundamental principle of equality or any discrimination or other negative differential*

treatment of persons with disabilities inconsistent with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities. (para. 1)

Further, it encourages NGOs in the disability field to provide relevant information to the Committee on Economic, Social and Cultural Rights and to the Office of the High Commissioner for Human Rights (para. 7). NGOs are advised to avail themselves of the technical assistance of the Office of the High Commissioner to assist them to function effectively in the human rights sphere (para. 8). In the resolution the Commission encourages all the treaty bodies to monitor the compliance of States with their commitments in order to ensure full enjoyment of rights by persons with disabilities. Governments should cover fully the question of human rights of persons with disabilities, when reporting under the relevant United Nations human rights instruments. In paragraph 11 the Commission:

Invites all the human rights treaty monitoring bodies to respond positively to its invitation to monitor the compliance of States with their commitments under the relevant human rights instruments in order to ensure full enjoyment of those rights by persons with disabilities, and urges Governments to cover fully the question of the human rights of persons with disabilities in complying with reporting obligations under the relevant United Nations human rights.

In addition, the following operative new paragraph was added which reflects the recognition of the on-going lack of action. The operative paragraph 30 of this resolution has the following wording:

[The Commission] *“Invites the High Commissioner for Human Rights, in cooperation with the Special Rapporteur on Disability, to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities and solicit input and proposals from interested parties, including particularly the panel of experts;”* [para. 30]

This readiness within the UN Commission on Human Rights to include the disability dimension into monitoring the general treaties on human rights seems to have come without anticipation to those concerned, despite the history of action described above. There appears to be a lack of knowledge and expertise both in the human rights administration, among governments and among international disability organisations to use this opportunity effectively.

Evidently there is a need for mutual learning. Disability leaders need to find an effective mechanism to communicate their experiences to the human rights monitoring bodies. Human rights experts need to learn more about how various ‘*obstacles prevent persons with disabilities from exercising their rights and freedoms and make it difficult for them to participate fully in the activities of their societies*’ (Standard Rules, para 15).

It is this framework that has provided the impetus for holding the Stockholm Seminar. It is an opportune time to develop the capacity and competence of all parties concerned to ensure that the occurring violations of the human rights of disabled persons start to reach the appropriate entities within the UN system and governments and political parties around the world.

II. Purpose

The purpose of the expert meeting is to draft guidelines for identifying and reporting human rights violations and abuses against disabled people. The following have been identified as specific objectives and expected results of the meeting:

- To provide a forum to exchange knowledge and expertise and to dialogue on the integration of disability-related issues into the human rights process
- To develop a substantive methodology for relating obstacles to participation, neglect, abuse and other forms of discrimination to legal provisions of existing UN human rights Instruments
- To design a process for follow-up and for collection and analysis of information; and within this to develop and support a reporting capacity within disability NGO's

III Organization of the Seminar

Three factors make it a particularly favourable time to begin a concentrated effort to profile the infringements of human rights of people with disabilities:

- The recent recognition in theory and law disability as a rights issue;
- The recent promulgation of policies in many countries directed at strengthening the rights of people with disabilities and eliminating discrimination at the national level; and
- The increasing organization of the disability rights movement worldwide.

In light of these three factors, this meeting provides a unique opportunity to carry out an analysis of the most effective ways of reporting human rights abuses and violations against disabled people and of designing a mechanism for the reporting of such abuses.

The systematic collection of such data would provide evidence for the United Nations and state governments of the need for further attention directed towards eliminating these abuses and would provide information to support the struggle of disabled people to justice, equality, self-determination, dignity and worth in their societies. It would also provide a way of exposing the various forms of discrimination and violence to which disabled people around the world continue to be exposed.

The seminar will use, as a basis for its work, the Universal Declaration of Human Rights and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Both these documents will be available for participants at the seminar.

The work will be organized around the following forms of documentation and small groups will be asked to develop guidelines for enabling a coherence of information to be collected ensuring that there is consistency and compatibility across the areas when the various reporting takes place. In the workshops we will first consider content and then process. The five areas of documentation around which the workshops will be organized are:

1. documenting individual reports of infringements

In this area, seminar participants will look at what constitutes an infringement of a human right; a method of reporting that enables comparability of data collected; how to guarantee privacy and confidentiality to the individual reporting; and methods of ensuring the credibility of reported infringements. They will review and assess current on-going methods of reporting of infringement of rights in disability and in the cases of other marginalized groups (women, refugees, etc.)

2. documenting of legal cases/jurisprudence:

In this area, seminar participants will determine a methodology for documenting legal cases that is consistent and comparable across jurisdictions recognizing such factors as: type of legislation, level of court and so on. Cases to be considered will include:

- i. cases where courts made no finding with respect to rights (discrimination by court interpretation of law) (e.g. “justifiable” homicide; exclusion from schools; substitute consent; best interests cases)
- ii. cases where court found directly on the infringement of human rights (e.g. anti-discrimination cases or equality cases)

3. documenting of media (a media watch);

Seminar participants in this area, will be asked to consider how to document infringements of human rights in the media and by the media including:

- i. media reporting in a manner that is an infringement of human rights
- ii. media reporting of infringements of human rights

4. documenting of policy, services and practices

Seminar participants will be asked to consider ways of documenting policies, services and practices that are contrary to the Universal Declaration – either by omission or commission. The Standard Rules will provide guidance in this area. Mechanisms for consistency across jurisdictions will need to be considered as well as determining a methodology for those who are documenting infringements to recognize which right has been infringed.

5. **documenting of legislation** that is contrary to the Universal Declaration, both state and national (or federal). In this area, participants will be asked to look for a methodology to document legislation at various levels of government. Attention will need to be paid to legislation that directly contravenes human rights, legislation that supports human rights and legislation that is silent but in its silence infringes rights.

Further to developing guidelines for the information to be collected, each of the groups will be asked to develop criteria and methodology for the **collection of the information** including:

- setting guidelines for the practical frameworks for reporting, and how to ensure that the information is systematic when collected.
- determining how the collection of information could happen following the expert meeting; and
- providing guidance on how to use the data and its interpretation most effectively, taking into account that there are a number of different audiences for the results of the seminar.

The diversity of expertise of the participants in both methodology and content of understanding infringements of human rights should provide a cross-fertilization of ideas that will enable the purpose of the seminar to be met.

**Let the world know - International seminar on human rights and disability
5-9 November 2000, at Almåsa Conference Center, Stockholm, Sweden**

Pre-paper 2.

**Recording human rights abuses against disabled people: practical
issues revealed by the Disability Awareness in Action *Human
Rights Project***



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Introduction

I have been asked to provide a brief summary of practical issues that have been revealed by the Human Rights Project²² that Disability Awareness in Action [DAA] has operated for the past 18-months. The Human Rights Project [HRP] currently comprises 1,200 separate reports of abuse against 2,000,000 disabled people. Perhaps the most sobering fact revealed by the HRP is that abuse was 1½ times more likely to end as a result of the victim's death, than as a result of legal intervention.

The DAA Human Rights project is a pragmatic, if modest, attempt to ensure that disabled people's organisations, human rights agencies, national and supranational governmental organisations have access to authoritative data concerning abuse of disabled people's human rights.

The finite resources available, in combination with the significant methodological issues thrown up, have conspired to delay the wide scale dissemination of Project data. However, it is our fervent hope that this meeting will serve to increase awareness of the Project and our need to build active partnerships with sister organisations, precisely because the HRP is intended to be a resource available to all agencies engaged in the promotion of our human rights.

²² The Human Rights Project has been made possible with the generous support of Comic Relief.

Background to DPI Europe's Human Rights Network Project

In 1992, Disabled Peoples' International World Conference resolved to institute a centralised compilation of evidence demonstrating the human rights violations experienced by disabled people. A feasibility study, to examine implications for member organisations and individuals, was undertaken and, in 1997, DPI Europe obtained funding from the European Union for a 3-year project to include the participation of DPI organisations in 5 member states.

The DPI Europe project formulated guidance on the Universal Declaration of Human Rights – with particular regard to disability – and proposed strategies for the collection of information concerning violations. Most of those involved in establishing the project were lawyers, whose work formed the basis for formal training of a network of volunteer co-ordinators, in each of the participating states, regarding the collection of evidence from both individuals and material in the public domain. Following the *Amnesty International* model, the volunteers are independent of, though accountable to, representative organisations of disabled people and work under strict guidelines of confidentiality and anonymity. The evidence collected is submitted to the centralised database, maintained and managed by Disability Awareness in Action [DAA].

Methodological barriers

Defining abuse

The circumstances that will, or will not, comprise human rights abuse is often both contested and technically complex. Complexity *can* be compounded by the fallibility of the forensic process of evidence collection, particularly from a victim who has paid a high emotional cost for the abuse.

Despite these complexities and practical difficulties, few if any NGOs could afford to allocate day-to-day data collection and administration of a human rights project to legally qualified staff, experienced in obtaining and weighing evidence. It is, therefore, unavoidable that the reliability of data obtained could be questioned requiring, in my opinion, that the NGO takes all reasonable steps to ensure that project staff are both adequately trained and supervised.

State as 'principal'

No attempt has been [nor can be] made in the DAA HRP to establish state culpability for reported abuses, except where such responsibility is evident from the circumstances of the case. This has important implications for recording abuses of international legal duties that tend to be *addressed to nation states*.

DAA endorse an approach that acknowledges responsibility for omission as well as commission. We certainly see little ethical difference between committing human rights abuse as a principal or accessory or, indeed, closing one's eyes to evidence of ongoing or systemic abuse.

The numbers game

Any attempt to report international human rights abuse is subject to an inescapable paradox - evidence of abuse is hardest to uncover in the most repressive states, with the inevitable result that the highest frequency of abuse is recorded against liberal states.

In those states where gross violations of human rights (GVHR) are endemic, abuse that is confined to disabled people, rather than the wider population, may not be highly prioritised. Put simply, if the entire population lives with the risk of state-sponsored genocide, violations that threaten disabled people's right to education or to found a family may seem unworthy of comment.

Sources of evidence

The source of reports utilised to obtain 'evidence' of human rights abuse have fundamental implications on the reliability – and therefore credibility – of the project. Some of the implications associated with various sources of evidence are mentioned below:

Media

Where media reports comprise a significant source of data, one has to rely:

on the abuse being recognised in the first instance
on the issue being judged of general, rather than merely specialist or minority appeal
on the media having sufficient independence to report incidents objectively or at all
on reliably and systematically accessing published reports, particularly those published in foreign languages.

Individual reports

The ability to obtain primary evidence of abuse from individual complainants offers unparalleled opportunities; it also carries the greatest responsibility.

Where individuals are provided with the opportunity to report abuse, we consider it *vital* that the agency concerned has prearranged and clearly understood procedures for:

verifying the accuracy of allegations made
offering support and counselling services for traumatised complainants that request or require it

referring cases to the appropriate investigative or prosecutorial agencies, where the complainant freely consents to this (it might also be considered appropriate to retain a 'watching brief' on subsequent treatment of the complainant)
making alternative accommodation and/or personal assistance available, where this would prevent further abuse
ensuring that there are staff available to just 'listen' to the victim when they need to talk.

Precisely because of the modest resources available to DAA and the responsibilities outlined above, we have deliberately avoided *encouraging* direct complaints from individual victims.

Other publications

Desk-based research of existing material, including biographies, academic research, crime statistics and reports by other disability NGOs offers another potentially valuable source of data. There are obvious ethical and methodological issues flowing from such secondary research methods, but these are well known to professionals in the relevant disciplines and do not need repetition here.

Should there be a time-limit on the inclusion of historical evidence?

At present, the DAA HRP includes a number of cases that occurred decades ago - including the holocaust and sterilisation programmes - but about which reliable evidence has only recently been available. This issue is a matter of some concern to the DAA Project team, not least because of the central dichotomy that results: despite the historic nature of these cases, the details of them are often not generally known; equally, reporting 'old' cases may serve to diminish the Project's credibility for the wider community.

DAA responded to this difficulty by excluding all reports that related to incidents committed prior to 1990, except where the report concerns:

gross human rights violations
those that affect 'substantial numbers', and
those that have been demonstrably state-sponsored and endemic.

Cases falling into one or more of these categories are classified as 'historic' and are only used to provide background discussion in Project reports.

Confidentiality

I am sure that little needs to be said about protecting the privacy of informants and victims. It should also be noted that in many states, including the UK, personal data and the uses to which it can be put are strictly controlled.

The DAA HRP is registered with the appropriate UK-authorities and operates a strict confidentiality policy. Briefly, we have ensured that:

individuals (whether informants or victims) cannot be identified from the database
hard-copy information which could identify individuals is retained within a secure
environment

restricted access to the HRP information amongst employees.

Which variables are relevant and/or appropriate?

In view of the sometimes negative reactions to medical perspectives, any question that seeks to elicit information concerning the victim's impairment may prompt extremely negative responses from disabled people. Indeed, previous (and unconnected) research projects have been significantly hampered when subjects believed that researchers had adopted a medically-based approach.

The risk of offending victims by seeking information concerning impairment-type must be weighed against the value of identifying relevant trends. For example, the DAA HRP offers some evidence for the 'common-sense' view that people with learning difficulties are at particular risk from enforced sterilisation and medical experimentation, whilst people diagnosed with mental illness risk controversial invasive medical 'treatment'.

Disability-specific issues

In addition to the widely identified constraints on accurate data collection and verification of human rights abuses, projects focusing on the abuse of *disabled people's* human rights are subject to a number of additional barriers:

where abuse is inflicted by people in a 'caring' relationship with the victim, the abuse may be seen as 'normal' or less damaging than the withdrawal of personal care that may result from complaining
even where the victim is willing to report the abuse, when it occurs in a 'closed' institution there may be little opportunity to do so, either as a result of the victims social exclusion, or the deliberate efforts of staff to suppress such allegations
the person abused may not self-identify as a 'disabled person', thereby preventing their reporting an abuse 'relating to' disability
the nature of the impairment itself may make it difficult or impossible for the victim to complain
the nature of the impairment may lead to any complaint being dismissed as unfounded and simply prompted by the impairment *i.e.* 'mischief associated with interference in the cognitive process'
in view of the common reliance on family members, rather than state-funded personal assistants, there are likely to be strong disincentives to making public an abuse that might have disastrous effects on the family – a price that they may be unwilling to pay.

In conclusion

A paper of such modest proportions cannot hope to do justice to the numerous practical issues revealed by the DAA Human Rights Project, but it is my hope that it offers a glimpse of the risks and opportunities provided by investigating this still neglected area.

Perhaps the single most important issue upon which we should conclude is to emphasise the emotional cost for staff-members engaged in this sort of work. It is comforting to assume, in our ignorance, that it is only 'minor' abuses that are inflicted on disabled people in the third millennium. The frequently graphic accounts and lurid photographs to which investigators are subjected, day in and day out, demand that agencies engaged in the recording of human rights abuse owe a particular and generous duty of care to their staff.

**Let the world know - International seminar on human rights and disability
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**Pre-paper 3.
Bioethics and disability**

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As the UNESCO Declaration on the Human Genome and Human Rights and the European Convention on Human Rights state, the first principle of bioethics must be one of human rights – the rights not only of those already living but also of the prospective human being. The UNESCO Declaration says (Article 2):

‘Everyone has a right to respect for their dignity and for their human rights regardless of their genetic characteristics. That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.’

Despite these international principles, it has become increasingly clear that advances in genetics are producing serious threats, both pragmatic and attitudinal, to the very existence, uniqueness and diversity of disabled people. To make matters worse, these threats are hidden by a virtuous mask of the objectives of cure, enhancement and alleviation of suffering.

The myths, fears and stereotypes around disability and our quality of life dominate decision-making and disabled people are predominantly left out of the debate. In seeing disability merely as a biological commodity, our inherent humanity is lost. In setting objectives of scientific advance that only focus on cure, our potential elimination is sanctified. By ignoring the current understanding of disability as the interaction between a discriminatory and disadvantaging society and a person with impairments, the expenditure on cures far outweighs expenditure on services to support inclusion for disabled individuals. Above all, the threat of eugenic practices further isolates us and ignores the tremendous contribution that disabled people bring to society.

Just like everyone else, disabled people want scientific advances that alleviate pain and help us to participate more fully in our communities. What we question are scientific advances that ignore our intrinsic humanity, that see us

merely as a bunch of impaired genes that are only of any use if they can be enhanced and that regard it as perfectly acceptable to eliminate disabled foetuses because disabled foetuses should not become potential human beings.

Society's attitude to disability is so negative and benefits and services so inadequate that it is not surprising that parents would prefer to have a non-disabled child. The medical profession find many life and death decisions painful and, in the present under-funding of health care, these decisions are often based on cost. However, decisions based on other people's assessment of our quality of life do not uphold our rights, nor do they uphold the rights of parents or families who are put under undue pressure to agree with these assessments.

How can anyone else judge our quality of life? How can quality of life be assessed in just medical or functional terms anyway? Everyone - disabled and non-disabled - relies on relationships, work, friends, community and society as a whole to impact on our quality of life. We all need these external forces to make us feel good about ourselves, to understand what we are as individual human beings, to help us to grow and to contribute. Disabled people need to contribute – not as a rung on someone's ladder to a charitable heaven - but in our own right, with our uniqueness recognised and our diversity celebrated.

Diversity is an essential element of evolution and ecology. Experience has shown that the eradication of any species, be it animal, human or plant, happens at the peril of those remaining. This historical lesson is being completely ignored by geneticists, who go ahead with their discoveries, which they proclaim are only for the benefit of humankind, keeping extremely quiet about the possible outcomes of manipulation of the evolutionary process and therefore of the environment as a whole – not to mention keeping quiet about the enormous profits they make.

Scientists and policy-makers and the general public are fully aware that technological advances must not discriminate on the grounds of race and gender. And yet, disability is seen as a different issue altogether. Despite a growing international awareness of disability as a human rights issue the notion of elimination of our specific diversity is supported and seen as socially acceptable behaviour.

How can society make judgements about what constitutes a good life or what personal characteristics are necessary? Do we really want a society that says you can only contribute if you are young, beautiful, athletic and intelligent. Do we want to be responsible now for making even greater divides between those who are deemed to 'have' (a quality of life) and those who are seen as the 'have nots' –creating an even greater divide between the rich and the poor?

Some things are being achieved to counteract these negative attitudes. Undoubtedly the introduction of non-discrimination legislation in a few

countries of the world is having a positive impact. As governments legislate to ensure that the environment becomes more accessible to disabled people, that information is made available in alternate formats, that education becomes inclusive and employment supported, disabled people become familiar citizens and discrimination is lessened. Unfortunately, none of these non-discrimination laws specifically cover genetic discrimination.

On the down side, countries where there are no legal or ethical frameworks for the protection of individuals are being used as a ready pool for conducting genetic research. An example is China, where research is being conducted on illiterate Chinese people who do not have the luxury of free choice – just as they had no choice over mandatory sterilisation for individuals with genetically linked diseases.

In the last few years, disabled people have come together to discuss bio-ethical issues and the following strategies have been agreed as the very least that should be done to ensure rights and dignity to disabled people:

Future advances and practices must be based on the furtherance of human rights, fundamental freedoms and human dignity, recognising, in particular, the potential rights of the unborn child who may exhibit the difference of disability

- Ethical principles must be based on honesty and integrity and should be formulated in consultation with all responsible stakeholders, including and in particular, disabled people and their organisations.
- Prior, free and fully informed consent of the person concerned must be obtained before any testing or diagnosis. If the person is not in a position to consent, authorisation should be obtained in the manner prescribed by human rights law and guided by the person's best interest. And their best interest must be judged without negative assumptions on quality of life or from the perspective of other interested parties.
- Information given to parents and families must be fully comprehensive, non-discriminatory and without pressure.
- Strategies should be put in place to ensure that the disabled child has an advocate at all stages in the decision-making process.
- Decisions should not be made using arbitrary quality of life assessments, nor should cost factors be used as criteria.
- Disability advocates should be part of all medical training and awareness raising of assessments of potential.

Bio-ethics should be the debate on how genetic and medical advances can be used for the benefit of society. Disabled people are not being given full and equal access to this debate and decisions that are being made seriously threaten our future and humanity. Our exclusion makes it easier for people like Peter Singer, a world-renowned Professor of ethics at Princeton University (USA) to claim that: there is more value in the life of an intelligent monkey than a seriously disabled child' and for many other clinicians and ethicists to say that it is immoral knowingly to give birth to a disabled child. We must be at the forefront of the debate to uphold our human rights to life, dignity and freedom.

**Let the world know - International seminar on human rights and disability
5-9 November 2000, at Almåsa Conference Center, Stockholm, Sweden**

Pre-paper 4.

**International Human Rights Protections
for
Institutionalized People with Disabilities:
An Agenda for International Action
by**

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Introduction

This paper describes the widespread pattern of human rights violations against institutionalized people with disabilities and proposes action to improve rights enforcement under international human rights conventions, such as the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social, and Cultural Rights (ICESCR), and the Convention on the Rights of the Child (CRC). While the adoption of a specialized international human rights convention on the rights of people with disabilities may be able to improve on existing protections, there is also an urgent need for new strategies to make better use of protections under existing international human rights conventions.

The observations and recommendations in this report derive from seven years of work by Mental Disability Rights International (MDRI). MDRI has investigated conditions in sixteen countries on three continents, and we have published reports on the treatment of children and adults with disabilities in Uruguay (1985), Hungary (1987), Russia (1999), and Mexico (2000).²³ MDRI has presented these reports to the UN Human Rights Committee, the Inter-American Commission of Human Rights and the European Committee for the Prevention of Torture, resulting in international attention to human rights violations by the United States, Mexico, and Hungary. We have pressured

²³Copies of these reports are available at this conference. Information about ordering MDRI reports is available on the web at www.MDRI.org.

countries to bring about reform by publicizing abuses through the international press, and we have collaborated closely with grassroots activists to bring about sustainable change in their own countries. MDRI has been invited by governments, service providers, international development organizations, and UN agencies - such as WHO and UNICEF - to provide technical assistance on legal and service system reform.

I. Pattern of Abuses and the Human Rights Challenge

A. Summary of MDRI's Worldwide Findings

Since 1993, MDRI has documented living conditions in psychiatric hospitals, orphanages, nursing homes, specialized institutions for people with developmental or physical disabilities, as well as prisons and jails in sixteen countries,²⁴ primarily in Central and Eastern Europe and Latin America. The patterns of abuse MDRI has found in these diverse regions are, in many ways, strikingly similar. People with mental and physical disabilities are commonly detained in closed, segregated institutions -- out of public view and often in remote parts of a country far from population centers. People may remain in these custodial facilities for life, living cut off from family, friends, and community. In some cases, they are detained without any legal process to protect against arbitrary detention. Even when legal procedures for civil commitment exist, they are often circumvented or ignored. For example, people with mental disabilities are often placed under the "guardianship" of a mental health administrator and then "voluntarily" committed to an institution. Many people are declared mentally incompetent without legal representation or due process protections, and placement under guardianship functionally strips them of any legal right to make the most basic decisions about their own lives.

Large numbers of people are improperly detained in institutions because of the lack of community-based services and support systems. In many of the countries MDRI has visited, authorities report that *the majority* of people could live in the community if appropriate services were available. A small percentage of institution populations are made up of individuals who present a danger to themselves or others or who are in need of treatment that can only be provided in an institution. Many people without disabilities are placed in institutions because they are marginalized in society and have no community support network, but they become increasingly socially isolated and acquire mental disabilities by living in an institution. This is particularly true for large numbers of children placed in orphanages or residential schools.

Behind the closed doors of institutions, people are subject to inhuman and degrading treatment. In Mexico, Hungary, Armenia, and Kosovo, MDRI found people

²⁴MDRI has observed conditions in institutions in the following countries: Argentina, Armenia, Azerbaijan, Costa Rica, the Czech Republic, Hong Kong, Hungary, Kosovo/Yugoslavia, Lithuania, Macedonia, Mexico, Romania, Russia, Slovakia, Ukraine, and Uruguay.

detained in squalid conditions -- in some cases left naked, covered in their own feces. People are routinely strapped to benches, beds, or wheelchairs -- largely due to the lack of staff to provide basic care. In Uruguay, MDRI found electro-convulsive therapy (ECT) used on people with mental retardation as a form of behavior control. In Uruguay, Hungary, and Romania, overdose, poly-pharmacy, and the failure to monitor side effects of medications expose hundreds of people to unnecessary and life-threatening dangers. In some institutions, people are literally left to starve or freeze to death. In Armenia, for example, MDRI visited an institution that reported an annual mortality rate of 30%.

Women are particularly vulnerable to abuse within institutions. Women subject to sexual abuse are commonly misdiagnosed with major mental health disorders, institutionalized, and then re-traumatized through the coercive treatment they receive in institutions. Within institutions, women are particularly vulnerable to sexual abuse by staff or other patients. Non-consensual sterilization, forced abortions, and the arbitrary denial of parental rights are common.

In the United States, MDRI is working with activists fighting aversive behavior modification procedures that cause pain, degradation, as well as physical and psychological damage. Aversive procedures include the use of electric shock, physical restraints or isolation, white noise at 95 decibels, slapping, pinching, putting ammonia capsules to the nose or squirting lemon juice, vinegar or hot pepper in the mouth.²⁵ These procedures induce extreme levels of suffering and meet the classic definition of inhuman and degrading treatment -- yet they are now permitted by US federal law and in some US states.

B. Human rights oversight and enforcement

Despite this widespread problem of discrimination and abuse, international human rights oversight and enforcement bodies rarely hold countries accountable for the treatment of people with disabilities in psychiatric institutions, orphanages, or other such institutions. Mainstream, non-governmental human rights groups, have rarely demanded enforcement of the rights of institutionalized people with disabilities. Concerned citizens do their best, within their own countries, to protest against abuse and to demand more appropriate services. Yet such groups rarely receive international funding or support, and they are left to struggle in isolation.

Human rights oversight and enforcement mechanisms to protect the rights of people with mental disabilities are limited or non-existent within most of the countries MDRI has investigated. Where legal protections for people with mental disabilities are established, as in Hungary, they are of little value without the establishment of enforcement mechanisms. These programs must reach out to the community to identify people in need of assistance, and they must document patterns of abuse that can be remedied through legal reform and policy changes. Active efforts are also needed to

²⁵Nancy R. Weiss, *THE APPLICATION OF AVERSIVE PROCEDURES TO INDIVIDUALS WITH DISABILITIES: A CALL TO ACTION* (1999).

ensure the inclusion of people with disabilities in human rights monitoring and policy-making. Training programs must also be established for grassroots NGOs made up of consumers or family members to expose them to the policy options that are available and to mechanisms within their own countries for bringing about legal or policy reform.

Internationally recognized human rights for people with mental disabilities will remain an empty promise until advocacy groups receive the support they need to act on the national level to document abuses, bring them to public attention, work through their own domestic court systems, and ultimately appeal to the international community for support. In order to bring attention to the violation of human rights in institutions, the Special Rapporteur and this Expert Committee should develop a strategy to promote disability rights advocacy groups worldwide.

C. Rights in Institutions and the Community

Human rights in institutions cannot be examined in isolation from conditions in the community. A large number of people are improperly detained in institutions because of inadequate community-based services. Barriers to community integration -- including the lack of community based service and support systems, as well discrimination and the lack of legal protections in the community -- can make it difficult or impossible to protect the rights of people in institutions. Any effort to improve services in institutions or in the community will involve competition for limited funding.

Responses to human rights violations in institutions present serious dilemmas. Dangerous conditions in institutions must be immediately remedied. But major repairs to buildings and new investments in staff and services may have the unintended effect of reinforcing outmoded, segregated models of services -- often at the expense of new investments in community-based alternatives. There must be a delicate balance between the funding needed to protect the rights of people within institutions on a temporary basis while new investments are made in the creation of community-based programs.

In the cases when international development programs respond to the concerns of people in psychiatric institutions or orphanages, program planners are often unaware of the potential for people with disabilities to live in the community. People with disabilities and advocacy organizations representing them are rarely consulted in the design and implementation of programs. Very often, disability activists are struggling within their countries to obtain funding for support systems that will permit them to keep people with disabilities out of institutions. Yet these efforts are frequently ignored by international charity programs that direct funds to orphanages or other institutions.

In Romania, Russia, Armenia, and Kosovo, MDRI has found extensive efforts to fix-up institutions - at the expense of community-based alternatives sought by local

activists.⁶ In Romania, following the death of Ceaucescu, the international response to the widely publicized abuses in orphanages was followed by a massive increase in the total orphanage population -- from 80,000 in 1989 to 120,000 in 1996.⁷ While there are now extensive programs to support the community integration of children from Romanian orphanages, family ties broken by placement in the early 1990s are difficult to reestablish, and new resources are needed to make up for the mistakes of earlier years.

Human right standards must be used to hold international development organizations - particularly UN agencies - accountable. As a strategy for reporting is developed, development and assistance programs funded by UN agencies such as WHO, UNICEF, and UNDP should also be monitored for compliance with international disability rights standards.

II New guidelines to the interpretation of human rights conventions

International covenants provide important protections for institutionalized people with disabilities, but these covenants have been under-utilized to monitor state practice and hold countries accountable for abuses against people with disabilities. One of the limitations of existing conventions is that they have no specific provisions relating to the concerns of institutionalized people with disabilities. Appendix A of this report examines the generally disappointing jurisprudence in the European system of human rights with regard to institutionalized people with disabilities, as well as one important new case from the Inter-American Commission of human rights that may point the way towards a new approach to the interpretation of human rights conventions. In the March 1999 case of *Victor Rosario Congo*, the Inter-American Commission of Human Rights recognized that a UN General Assembly resolution, the *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (the "MI Principles"), can serve as an authoritative interpretation of the American Convention on Human Rights.⁸

⁶See, e.g. Holly Burkhalter and Eric Rosenthal, *The Way to Save Russia's Orphans*, WASHINGTON POST, August 4, 1999; Eric Rosenthal, Elizabeth Bauer, Mary F. Hayden, and Andrea Holley, *Implementing the Right to Community Integration for Children with Disabilities in Russia: A Human Rights Framework for International Action*, 4 HEALTH AND HUMAN RIGHTS 83 (1999).

⁷*Id.* at 89.

⁸Report 29/99, Case 11,427, Ecuador, adopted by the Commission in Sess. 1424, OEA/Ser/L/VII.102 Doc. 36, March 9, 1999, p.8. The Inter-American Commission cited the analysis in Eric Rosenthal and Leonard S. Rubenstein, *International Human Rights Advocacy under the 'Principles for the Protection of Persons with Mental Illness,'* 16 INT'L J. L. & PSYCHIATRY 257 (1993) (describing the use of the MI Principles as a guide to the interpretation of international human rights conventions).

UN General Assembly resolutions can help in the application of convention-based rights by providing detailed guidelines to the requirements of general protections. Following the precedent established by the Inter-American Commission, the convention-based UN Committees that issue General Comments on the conventions could adopt the MI Principles and other disability rights instruments as authoritative interpretations of binding conventions.

The UN Special Rapporteur and this Expert Committee can play a very important role in promoting this new interpretation. The detail that these standards provide would both: (1) clarify governments' responsibilities under international human rights conventions (2) provide the basis for detailed reporting by governments under the mandatory reporting requirements of international human rights conventions and (3) provide a universal standard of assessment that would permit grassroots and international human rights activists to document abuses and hold governments accountable.

Rather than drafting new reporting standards, the Special Rapporteur should build on the human right principles already adopted by the UN General Assembly. There are specific areas in which UN General Assembly resolutions do not provide detailed protections against common practices that violate the rights of institutionalized people with disabilities. The Special Rapporteur and this Expert Committee should propose new international standards with regard to these areas of practice.

III. Increased recognition and enforcement of UN disability rights resolutions

UN General Assembly resolutions on the rights of people with mental and physical disabilities provide important protections for institutionalized people with disabilities. In addition to the MI Principles, the 1971 *Declaration on the Rights of Mentally Retarded Persons* (the MR Declaration) and the 1993 *Standard Rules on Equalization of Opportunities for Persons with Disabilities* (the StRE) are important to the protection of rights of institutionalized people. MDRI has found each of these three instruments very useful in monitoring conditions around the world and in assessing compliance with international human rights conventions. This section analyses some of their strengths and weaknesses and proposes a few of the areas of concern that require the development of stronger international standards.

A. Strengths and weaknesses of UN standards

The 1991 *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (the MI Principles) provide detailed minimum standards for treatment and living conditions in mental health facilities and they establish due process protections regulating commitment or detention in institutions. MDRI has relied on the MI Principles to assess human rights conditions in the mental health systems and mental retardation facilities of sixteen countries, and we have found that the MI Principles provide the detail needed to touch upon the major human rights concerns we have identified, including such widespread practices as: arbitrary commitment to

institutions, coercive treatment and improper medication in institutions, misuse of physical restraints, and deprivation of humane and dignified living conditions.

The MI Principles also broadly establish a right to live, work, and receive treatment in the community or in "the least restrictive environment...appropriate to the patient's health needs and the need to protect the physical safety of others."⁹ This right is of profound importance in countries that detain people in institutions because of the absence of community-based services. Enforcement of this right would require many states to restructure service systems, shifting funds away from the exclusive support of institutions toward the creation of support systems in the community.

The 1971 "Declaration on the Rights of Mentally Retarded Persons" (the MR Declaration) is not as fully developed as the MI Principles, but it provides a number of important rights. The MR Declaration establishes that a person with mental retardation cannot be deprived of the rights due all other citizens except through a process that includes "proper safeguards against every form of abuse." Any such restriction of rights "must be based on an evaluation of the social capability of the mentally retarded person," must be subject to periodic review, and is subject to appeal to higher authorities. While lacking specific due process protections, the MR Declaration prohibits the common practice of declaring a person "mentally incompetent" and appointing a guardian without any legal process. Additional, clearly defined, minimum standards of due process are needed to protect against abuse of the guardianship process - one of the most common forms of discrimination against people with mental retardation MDRI has found around the world.

B. Need for further analysis

A detailed expert analysis is needed to determine exactly which provisions of the MI Principles, the StRE and the MR Declaration would interpret specific articles of international human rights conventions. For example, MI Principle 11(11) sets forth minimum standards for the protection against the improper use of seclusion and physical restraints, which could be recognized as minimum standards to protect against a violation of the protection against "inhuman and degrading treatment" in article 7 of the ICCPR. MI Principles 15 and 16, regulating voluntary and involuntary commitment to psychiatric facilities, could be recognized as a guide to the requirements of article 9 of the ICCPR protecting against arbitrary detention.

A detailed analysis is needed because many of the protections under the MI Principles, the StRE, or the MR Declaration are difficult to link to any one, specific convention based protection. One of the most important emerging principles in international standards is the right to community integration. This principle is recognized in the MI Principles, the StRE, the MR Declaration, and in a number of other international instruments, including the draft Inter-American Convention on the

⁹Principle 9(1).

Elimination of Discrimination Against People with Disabilities.¹⁰ Yet it is not clear whether this right would be directly recognized under the ICCPR or the ICESCR. It could be argued, for example, that it is inherently discriminatory (in violation of ICCPR article 2(1) or ICESCR article 2(2)) to provide mental health services exclusively in a closed, segregated institution for people who are capable of living in the community. To what extent would a country be required to modify existing mental health and social services systems to provide appropriate, community-based services? The Special Rapporteur and this Expert Committee should take a strong stand on the right to community integration and should propose guidelines to the interpretation of convention-based protections against discrimination, referencing the MI Principles and other UN General Assembly standards.

MDRI has found that there are a few major gaps in the MI Principles. While they call generally for enforcement, they do not specify in any detail how human right oversight and enforcement mechanisms should be established. It is also necessary to adopt standards for rights enforcement in the community. Even though human right violations in institutions may be more extreme, abuses in community-based programs can be more difficult to identify because they are diffused through many small programs. Abuses in community programs can feed on public fears and misperceptions of deinstitutionalization and can undermine public support for reform.

The practice of aversive behavior modification programs that may cause extreme levels of suffering or indignity are not clearly prohibited by international human rights standards. There is a need for a protocol defining the aversive procedures that would violate the protection against inhuman and degrading treatment. Appendix B of this report is a standard proposed by TASH, an international disability rights group based in the United States.

IV Need for Support of Independent Advocacy and Monitoring

An international strategy should not rely solely on self-reporting by States, and Special Rapporteur Bengt Linqvist does not have the resources alone to document in detail the abuses that exist in institutions of almost every country of the world. There is no substitute for the locally-based expertise, cultural sensitivity, and fact-finding ability that grassroots organizations and international disability rights NGOs can bring to hold governments - and the international community - accountable. Grassroots disability rights advocacy groups, unfortunately, receive little recognition or support within their own countries or from the international community. In MDRI's experience, groups made up of people with psychiatric or developmental disabilities, as well as groups made up of related family activists, have even fewer resources available to them than do groups made up of people with physical disabilities. The UN Special Rapporteur and this Expert Committee must devise a strategy to approach government foreign assistance agencies, international development organizations, and civil society programs to support, assist, and train grassroots human rights organizations throughout the world.

¹⁰See Rosenthal, Bauer, Hayden and Holley, *supra* note 6, at 89.

Appendix A The Promise and Limitations of Existing International Conventions

While there is an obvious lack of any specialized human right convention to protect people with disabilities, existing UN international human rights conventions provide many protections that apply to institutionalized people with disabilities. International human rights conventions provide the possibility of direct enforcement, public education through mandatory reporting requirements by States Parties, and political pressure to conform with internationally accepted rights protections. International human rights conventions have been seriously underutilized by the disability rights community. Any new effort to build on existing human rights protections must be based on a realistic understanding of their limitations as well as their strengths.

A. Lack of specific protections for people with disabilities

One major limitation on existing human rights conventions is that they do not provide specific references to people with disabilities. Thus, States Parties to these conventions are not required to report on the treatment of people with disabilities in or outside of institutions. The general protections of existing human rights conventions lack the specificity needed to direct the attention of UN oversight agencies, governments, or health and social welfare providers as to their obligations with regard to institutionalized people with disabilities.

General Comments issued by UN convention-based committees should provide the detailed guidance necessary to spell out a country's obligations in a particular area of practice. The General Comments also serve as reporting guidelines under the convention. Unfortunately, the General Comments pertaining to the rights of institutionalized people with disabilities are extremely limited.

Without direct reference to the rights of people with disabilities in the main human rights conventions, most governments and service providers are unaware that issues such as commitment to psychiatric facilities, guardianship, informed consent to treatment, the use of seclusion or physical restraint, the right to privacy or other dignified living conditions are matters subject to the protection of international human rights law. In many countries, the treatment of people in institutions is not regulated by domestic law, and institutional authorities are under the impression that these are matters left entirely to their discretion. Even in countries where domestic laws govern the rights of institutionalized people, the failure of the international community to scrutinize treatment practices in institutions reinforces the widespread perception that treatment practices in institutions are matters of exclusively domestic concern.

B. Jurisprudence in the European and Inter-American systems

The European and American conventions on human rights provide roughly parallel protections. Regional human rights systems in Europe and the Americas have the most effective enforcement mechanisms and present the greatest opportunities for individual and systemic rights enforcement. The European and American courts of human rights can hear cases on the application of human rights to individual circumstances, presenting not only an opportunity for individual enforcement but also for the authoritative interpretation of international human rights protections under general conventions.

1. European System

The European Commission and Court of Human Rights have heard numerous cases on the rights of institutionalized people with disabilities.¹¹ As a result of this process, it has been established that treatment practices within institutions raise fundamental human rights concerns. The European Court has contributed greatly to the interpretation of article 5 of the European Convention of Human Rights (ECHR) protecting the right to liberty and security of the person. The Court has, for example, required States Parties to the ECHR to follow procedures set forth in their own domestic laws and to provide individuals with a right to review by a court or other independent authority.¹²

While the European Court has stated that special scrutiny is required to protect especially vulnerable people in institutions,¹³ the European Court has, in practice, been extremely deferential to institutions when reviewing allegations of inhuman and degrading treatment under article 3 of the ECHR. In the case of *B. v. United Kingdom*, for example, the European Commission found a case inadmissible under article 3 because the facts alleged did not amount to inhuman and degrading treatment.¹⁴ In the case, the applicant, a patient at Broadmoor psychiatric hospital in the United Kingdom, claimed that he was "detained in grossly overcrowded conditions, lacking in adequate sanitary (e.g. toilet and washing) facilities, and in constant atmosphere of violence. He alleged that dormitory beds were only 6-12 inches apart, and there was no privacy and little fresh

¹¹See Lawrence O. Gostin, *Human Rights of Persons with Mental Disabilities: The European Convention of Human Rights*, 23 Int'l J. Law & Psychiatry 125 (2000).

¹²Rosenthal and Rubenstein, *supra* note 8, at 277.

¹³The Court in *Herczegfalvy v. Austria* stated that, "The position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with." Judgment of 24 September 1992, 244 Eur. Ct. H.R. (Ser.A), para. 82, 15 E.H.R.R. 437 (1993).

¹⁴App. No. 6870/75, Second Partial Decision of the Commission as to Admissibility, 10 Dec. & Rep. 37 (Euro. Comm'n H.R. 1977).

air or exercise. The applicant claimed he had received no treatment whatsoever and almost never saw a doctor.”¹⁵ The European Commission noted that:

The physical conditions in Broadmoor Hospital are admittedly unsatisfactory and have been criticized by different official bodies over the number of years. While hospital staff...may do their best to cope with these inadequacies, this does not exclude the possibility that the physical conditions of detention could in themselves give rise to a question under Article 3.

In the case of *B. v. United Kingdom*, the Commission unfortunately determined that the degree of suffering induced by poor conditions did not rise to the level of a violation of the convention. Many other cases have similarly alleged inhuman and degrading treatment in psychiatric institutions in Europe, including the detention of individuals in prolonged physical restraints, but the European Commission and Court of human rights have time and time again found that practices are not sufficiently extreme to constitute a human rights violation.¹⁶

It is significant that the Commission in *B v. United Kingdom* recognizes that conditions in institutions may violate the rights protected under the ECHR *even if* staff “do their best” to assist patients. In many circumstances, abuses against people with mental disabilities are not caused by any intentional infliction of pain and suffering by mental health providers but are the result of inappropriate care due to lack of resources or the administrative convenience of the institution. Unlike “torture,” which is usually understood to be limited to cases where pain is inflicted on purpose,¹⁷ “inhuman and degrading treatment” has no intent requirement.¹⁸

¹⁵Gostin, *supra* note 11, at 151.

¹⁶Gostin, *supra* note 11, at 152. In the case of *A v. United Kingdom*, the Commission did accept a friendly settlement of a claim of inhuman treatment, however, in which it accepted that the requirements of the convention were met by the establishment of minimum standards for institutional conditions, including the provision of clothing, mattresses, portable latrines, and toilet paper, as well as safeguards against the improper use of seclusion and physical restraints.

¹⁷The Convention against torture and Other Cruel, Inhuman or Degrading Treatment or Punishment” defines torture as “any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind....It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.” Article 2(1).

¹⁸See Rosenthal & Rubenstein, *supra* note 8, at 273.

2. Inter-American system

Jurisprudence in the American system of human rights is much more limited with regard to the rights of institutionalized people with mental disabilities, but it presents much greater hope than does the European system. In March 1999, the Inter-American Commission of Human Rights issued its first decision on the rights of a person with a mental disability, *The Case of Victor Rosario Congo*.¹⁹ Mr. Congo, a person with a mental disability, died of "dehydration" in pre-trial detention after he was beaten by a guard, placed in isolation, and denied adequate medical and psychiatric care. The Commission found that Mr. Congo's mental state degenerated as a result of being held in isolation and that holding him in seclusion under these circumstances constituted inhuman and degrading treatment in violation of article 5 of the American Convention. The Commission did not find that Congo was deliberately deprived of food and water but that state authorities failed to take appropriate measures, given his mental health condition, to ensure that he received adequate food and water. The Commission found that Ecuador's failure to provide appropriate care for Mr. Congo violated its duty to protect his life under article 4(1).

The Congo decision is important because the Inter-American Commission made clear that it will adopt "special standards to the determination of whether the provisions of the Convention have been complied with in cases involving persons suffering from mental illness..."²⁰ In addition, the Inter-American Commission recognized the use of the Principles for the Protection of Persons with Mental Illness (MI Principles) as a guide to the interpretation of the American Convention.²¹

[T]he Commission considers that in the present case the guarantees established under article 5 of the American Convention must be interpreted in light of the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care. These principles were adopted by the United Nations General Assembly as a guide to the interpretation in matters of protection of human rights of persons with mental disabilities, which this body regards as a particularly vulnerable group. ²²

¹⁹Report 29/99, Case 11,427, Ecuador, adopted by the Commission in Sess. 1424, OEA/Ser/L/VII.102 Doc. 36, March 9, 1999, p.8 n.7.

²⁰*Id.* at para. 53.

²¹An analysis of the MI Principles as a guide to the requirements of international human rights conventions was first raised in Rosenthal & Rubenstein, *supra* note 8. In *The Case of Victor Rosario Congo*, the Inter-American Commission cited this analysis in para. 54 n.8.

²²*Id.* at para. 54. In a footnote, the Commission added: "The UN Principles for the Protection of Persons with Mental Illness are regarded as the most complete standards for protection of the rights of persons with mental disability at the international level. These Principles serve as a guide to States in the design and/or reform of mental health systems

The recognition of the MI Principles as an authoritative guide to the interpretation of the American Convention is important within the Inter-American system and in the development of international human rights law. The recognition of the MI Principles by the Inter-American Commission constitutes state practice that raises the value of the MI Principles as a matter of customary international law. In the future, human rights bodies are more likely to follow the precedent established by the Inter-American Commission in using the MI Principles as a guide to the interpretation of the American and other conventions. The clear and detailed standards set forth in the MI Principles may help the Inter-American Commission - and possibly the European Court - avoid adverse decisions, such as *B v. United Kingdom*.

The Inter-American Commission is sympathetic to hearing additional cases on the rights of people with mental disabilities. In March 2000, the Commission granted MDRI's request for a hearing on the findings of MDRI's report, *Human Rights & Mental Health: Mexico* (February 2000), which documented a broad pattern of abuses in Mexico's psychiatric facilities. This was the first hearing in this human rights oversight body about the protection of human rights in a mental health system as a whole. As a result of the hearing, the Inter-American Commission raised concerns about human rights in Mexico's psychiatric hospitals in the OAS's annual report on Mexico's human rights record.²³ This hearing demonstrates the value of regional human rights systems as tools for human rights monitoring and public education about the conditions of people with disabilities in closed institutions.

C. Protections for children with disabilities

The jurisprudence in the European human rights system is emblematic of the difficulties of applying general human rights conventions in the context of institutional care, particularly with regard to areas that have traditionally been left to medical discretion or domestic social policy. A contrast to this is Article 23 of the Convention on the Rights of the Child (CRC), which provides important, detailed protections for children with mental and physical disabilities.

The CRC provides a model of the kind of rights an international disability rights convention could provide - or of the kind of rights that could be guaranteed under existing international conventions if they were supplemented with detailed General Comments.

and are of utmost utility in evaluating the practices of existing systems. Mental Health Principle 23 establishes that each State must adopt the legislative, judicial, administrative, educational, and other measures that may be necessary to implement them." *Id.* at fn. 8, citing Rosenthal & Rubenstein, *supra* note 8.

²³Inter-American Commission on Human Rights, Annual Report of the Inter-American Commission on Human Rights 1999 III, paras. 20-22, Doc. 6 rev, OEA/Ser.L.V/II.106 (April 13, 1999). The report is available at www.cidh.oas.org/annualrep/99eng.

Article 23(3) provides that every child with a disability has "effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities...." The CRC provides that services mandated under the convention must be provided "in a manner conducive to the child's achieving the fullest possible social integration and individual development." Throughout the CRC, there are detailed provisions for the protection of the family, recognizing that the family is the "natural environment for the growth and well-being of all its members and...should be afforded the necessary protection and assistance so that it can fully assume its responsibilities in the community."²⁴ It is arguable that to provide the "fullest possible social integration" for the vast majority of children with disabilities, and to protect the right of children to a family, services would themselves have to be provided in a family-like environment in the community and *not* in orphanages or institutions. The CRC unfortunately does not state the logical outcome of the protections it provides, which would require a fundamental alteration of many countries' social care systems. The convention does provide sufficient detail, however, to assess human rights in a social service system as a whole. In addition, it provides guidance to policy-makers, human rights activists, and international development agencies about the need to structure a response to the human rights problem in institutions that would emphasize community-based alternatives.²⁵

Appendix B: TASH Statement on Aversive Procedures

TASH (formerly The Association for Persons with Severe Handicaps) is a US-based, international advocacy association of people with disabilities, their family members, and other advocates and people who work in the disability field. TASH has proposed the following statement that could be adopted by the international community to interpret the requirements of the International Covenant on Civil and Political Rights article 7 protection against inhuman and degrading treatment:

Throughout the world, individuals with disabilities are victim to what is termed "aversive interventions" to control behaviors that are associated with their disabilities. Aversive procedures use painful stimuli in response to behaviors that are deemed unacceptable their caregivers.. All aversive techniques have in common the application of physically or emotionally painful stimuli.

These techniques are inappropriately used, not only to control dangerous behaviors, but also to modify behaviors that are simply idiosyncratic (moaning or twisting one's hair), unusual (tics or rocking) or are inconvenient to caregivers (getting out of one's assigned seat or refusing to perform a task) . When an individual is at imminent risk of hurting him/herself or others, intervention is necessary to assure safety. Such intervention may

²⁴CRC, *preamble*.

²⁵See Rosenthal *et. al.*, *supra* note 8.

include brief physical restraint but should not include aversive procedures. Individuals with disabilities who act in ways that are dangerous deserve at a minimum, the same protections afforded prisoners.

Aversive procedures are often used as part of a systematic program for decreasing certain behaviors. They are used without the consent of the victim and typically, without the informed consent of a guardian. Aversive procedures have some or all of the following characteristics:

- ? Obvious signs of physical pain experienced by the individual;
- ? Potential or actual physical side-effects such as tissue damage, physical illness, severe physical or emotional stress, and/or death;
- ? Dehumanization of the individual;
- ? Significant discomfort on the part of family members, staff or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions;
- ? Obvious repulsion and/or stress on the part of observers who cannot reconcile such extreme procedures with acceptable standard practice;
- ? Rebellion on the part of the victim against being subjected to such procedure;
- ? Permanent or temporary psychological or emotional harm.

The types of aversive procedures used on persons with disabilities include, but are not limited to:

- ? Electric shock applied to the body (e.g. arm, leg, or hand) for the purpose of discouraging the specific behavior it follows by causing pain [not to be confused with electroconvulsive therapy (ECT) used to treat severe depression]
- ? Extremely loud white noise or other auditory stimuli
- ? Forced exercise
- ? Shaving cream to the mouth
- ? Lemon juice, vinegar, or jalapeno pepper to the mouth
- ? Water spray to the face
- ? Placement in a tub of cold water or cold showers
- ? Slapping or pinching with hand or implement
- ? Pulling the hair
- ? Ammonia capsule to the nose
- ? Blindfolding or other forms of visual blocking
- ? Placement in a dark isolated box or other methods of prolonged physical isolation
- ? Ice to the cheeks or chin
- ? Teeth brushed or face washed with caustic solutions

- ? Prolonged restraint through manual or mechanical techniques (e.g. face-down four- or five-point restraint using mechanical tie-downs or several staff applying physical pressure)
- ? Withholding of multiple meals/denial of adequate nutrition

Although it has been believed that such procedures are necessary to control dangerous or disruptive behaviors, it has now been irrefutably proven that a wide range of methods are available which are not only more effective in managing dangerous or disruptive behaviors, but which do not inflict pain on, humiliate, or dehumanize individuals with disabilities. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that will achieve the individual's needs.

**Let the world know - International seminar on human rights and disability
5-9 November 2000, at Almåsa Conference Center, Stockholm, Sweden**

Pre-paper 5.

Disability rights and human rights: plunging into the 'mainstream'?

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a. introduction

There are striking parallels between the position of disability rights issues and advocates and that of women's rights issues and activists 15 years ago, so far the response of the "international human rights mainstream" to those issues is concerned. Existence on the conceptual periphery of that dominant discourse, the general neglect of these issues in the work of the human rights bodies, and the assignment of primary responsibility for these issues to specialised bodies to be dealt with as issues of social development rather than as human rights issues, are common features of both areas.

Yet in the past 15 years, there has been a great deal of progress in moving issues of women's human rights into the human rights mainstream. This change, while still far from achieving what needs to be achieved, has been reflected in frequently articulated commitments to integration of gender in the mainstream, the addition of many issues of gender importance to the agenda of human rights bodies, and the enormously increased involvement of women's human rights activists in the work of the human rights bodies. This paper suggests that the development of strategies similar to those which women's human rights activists deployed in their efforts to bring gender issues more fully into the international human rights discourse may also bear fruit in the attempt to ensure that the disability rights issues receive the attention they deserve.

The purpose of this paper is to sketch some of the ways in which disability rights issues might be moved to a more prominent place on the international human rights agenda. It is written from the perspective of an international human rights lawyer who has been involved in the mainstream and also in the field of women's human rights, but who is not an expert in the field of disability. The underlying assumption of the paper is that greater attention to disability rights issues by human rights bodies may assist in increasing the protection of the human rights of persons with disabilities.

b. the current position

Presently the disability rights and human rights communities at the international level are largely separate. Although there is some overlap, the number of those who are fully conversant with disability rights issues and standards, as well as with general human rights issues is quite small. Much of the activism around disability issues is oriented around disability-specific norms, responsibility for which falls within the mandate of bodies working in the field of social development and humanitarian affairs without a specific human rights focus or mandate. Some of those norms are dated and unsatisfactory in a number of respects, most are embodied in so-called "soft law" instruments such as declarations and bodies of principles, and have weak or non-existence monitoring or enforcement mechanisms.

Nevertheless, while much disability rights activism takes place outside the international human rights frameworks, the separation is by no means a complete one, and there have been efforts to give disability issues a more prominent place on the human rights agenda, to use human rights bodies and their procedures to advance the human rights of persons with disabilities, and to develop new interpretations of existing norms as well as new norms to address violations of the rights of persons with disabilities which are not adequately covered by existing international norms.

There have been some important gains as a result of these efforts. In 1991** the Committee on Economic, Social and Cultural Rights (the body of independent experts established to monitor the implementation of the International Covenant on Economic, Social and Cultural Rights) adopted a general comment on the human rights of persons with disabilities.²⁶ Although some of other the UN human rights treaty bodies have touched on disability issues in their general comments or recommendations, reporting guidelines or concluding observations on State reports,²⁷ this general comment represents the first (and so far only) sustained analysis by one of the UN human rights treaty bodies of the applicability of the general human rights guarantees to persons with disabilities.²⁸ Of particular importance in this general comment is the Committee's definition of discrimination on the ground of disability, which explicitly states that discrimination under the ICESCR includes a failure to afford a person reasonable accommodation. There have also been efforts to utilise the complaints procedures under a number of international human rights treaties to seek redress for violations of the human rights of persons with disabilities. The record here has been mixed. The area where existing human rights standards have proved of some use is that of the right to be free from arbitrary detention, to have any deprivation of liberty carried out in accordance with the provisions of law and subject to review by an independent court, as well as in relation to conditions of detention.

²⁶ See Committee on Economic, Social and Cultural Rights, *General Comment No. 5* (1994), UN Doc HRI/GEN/1/Rev.4, available through www.unhchr.ch.

²⁷ See, e.g., Committee on the Elimination of Discrimination against Women, *General Recommendation 18* (1991), UN Doc HRI/GEN/1/Rev.4, available through www.un.org/womenwatch.

²⁸ See the suggestion in the 1993 report of Special Rapporteur on Human Rights and Disability of the Sub-commission on Prevention of Discrimination and Protection of Minorities, Leandro Despouy, that disability issues be taken up within the human rights framework, in particular by the Committee on Economic, Social and Cultural Rights.

For example, under both the European Convention on Human Rights²⁹ and the American Convention on Human Rights,³⁰ the international supervisory bodies have considered, and in some important cases upheld, claims by persons with mental disabilities or who are mentally ill that their fundamental rights have been violated by the legislative scheme providing for their detention or by the manner or conditions of their detention within that legislative framework. In some cases these have been premised on a traditional interpretation of rights that could apply to all; in other cases, the particular needs of the person with a disability or the special responsibility a State may have in relation to ensuring such a person's actual enjoyment of his or her rights was taken into account.³¹ In addition, there are many cases under the European Convention in which persons have succeeded in complaints that their claims to pensions or other benefits to which they are entitled as a result of a disability have not been adjudicated upon by an independent and impartial tribunal within a reasonable time.

Apart from these cases, which in essence involve the application of traditional interpretations of rights to cases brought by persons with disabilities, there are relatively few cases which have been brought under international instruments, and even fewer which challenge and lead to the transformation of existing interpretations to reflect the experiences and needs of persons with disabilities.

Perhaps the best-known case from the European Convention system is the case *X and Y v Netherlands*,³² in which the European Court held that the failure of the Netherlands to allow criminal prosecution of a person who had assaulted a young woman who was mentally disabled was a violation of article 8 of the Convention, since the State had an obligation to provide protection against serious invasions of a person's bodily integrity by other private individuals.

There have also been case in which efforts have been made to raise disability issues in relation to access to education, in which the European Convention organs have implicitly accepted that the right of access to education on a non-discriminatory involves an obligation to take positive steps to accommodate the needs of a person with a disability (though they have not found violations in the cases that have come before them).³³

²⁹ See, e.g., *X v United Kingdom*, European Court of Human Rights, Judgment of 24 October 1981 (holding that procedure for recall of patient to a psychiatric hospital did not satisfy requirement of review on the merits by an independent and impartial court); *Johnson v United Kingdom*, European Court of Human Rights, Judgment of 24 October 1997 (continued detention of an individual no longer suffering from mental illness pending his placement in a hostel a violation of right to liberty in view of inadequate safeguards).

³⁰ See, e.g., the important case of *Rosario Congo v Ecuador*, Inter-American Commission on Human Rights, Case 11.427, Report 63/99, 13 April 1999 (applying general human rights norms as well as those dealing specifically with the rights of persons with disability in case of detained person who had a mental disability)

³¹ See, e.g., *Herczegfalvy v Austria*, European Court of Human Rights, Judgment of 24 September 1994, para 82 ("The Court considers that the position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with...").

³² European Court of Human Rights, Judgment of 26 March 1985, Series A no. 91.

³³ See *McIntyre v United Kingdom*, European Commission of Human Rights, Application No. 29046/95, decision on admissibility, 21 October 1998 (rejecting claim that small primary school's refusal to install a lift costing £45,000 denied applicant right to education and to non-discrimination in the enjoyment of that right, in light of in view of other steps taken to accommodate the applicant).

Despite these successes, attempts to invoke the European Convention in other areas have not proved as successful. The limitations of the Convention's catalogue of rights³⁴ for protecting the human rights of persons with disabilities is vividly illustrated by the case of *Botta v Italy*. In this case, Botta, who was physically disabled, complained of a lack of access to the sea and lack of accessible toilets at a private beach in the resort town where he had gone on vacation. Contrary to the relevant national legislation the owner of the beach had not provided ramps or other access, and Botta was refused permission to drive onto the beach. He claimed that the State's failure to ensure that he and others in his position had access to the beach was a violation of his right to respect for private life guaranteed by article 8 of the Convention (among other provisions).³⁵

"The applicant asserted that he was unable to enjoy a normal social life which would enable him to participate in the life of the community and to exercise essential rights, such as his non-pecuniary personal rights, not because of interference by the State but on account of its failure to discharge its positive obligations to adopt measures and to monitor compliance with domestic provisions relating to private beaches."

The European Court rejected his claim on the ground that article 8 did not extend so far as to protect this sort of access. It concluded:³⁶

"the right asserted by Mr Botta, namely the right to gain access to the beach and the sea at a place distant from his normal place of residence during his holidays, concerns interpersonal relations of such broad and indeterminate scope that there can be no conceivable direct link between the measures the State was urged to take in order to make good the omissions of the private bathing establishments and the applicant's private life."

Yet even within this rebuff are the seeds of an approach that is more supportive of the equality of persons with disabilities emerges. The European Commission on Human Rights had rejected Botta's argument before it came to the Court. However, the Commission's decision was by a majority, and a number of Commission members elaborated an interpretation of the article in question that was much more responsive to the needs of the rights of a person in the situation of Botta.³⁷ They recognised that it was important to recognise the social dimensions of the right to develop one's personality and that therefore the State had a positive obligation to ensure access for all to public spaces and activities.

Thus, while there is some helpful jurisprudence internationally, these cases are largely confined to cases that can be dealt with fairly readily in terms of existing categories, and

³⁴ Until the recently adopted Protocol No 12 to the European Convention, there was no free-standing guarantee of equality under the Convention -- article 14 guaranteed only non-discrimination in the enjoyment of rights mentioned in the Convention and its protocols. However, even the Protocol will not mean much unless it is interpreted in a manner that is sensitive to the needs of persons with disabilities and the social context in which they live.

³⁵ *Botta*, at para 27

³⁶ *Botta*, at para 35

³⁷ See the concurring opinion of Mrs J Liddy and six other members of the Commission, the dissenting opinion of Mr B. Conforti (with whom four other members of the Commission agreed), and the separate dissenting opinion of Mr Loucaides).

do not extend the boundaries of existing concepts and categories. Overall, there has been little sustained examination of the extent to which the conceptual framework and practices of the human rights system are premised on ableist models or fail to address issues of concern to persons with different forms of disabilities. Representational issues appear barely to have made it to the agenda.

c. the potential of the international

The rights guaranteed by the international and regional human rights instruments are promised to all human beings, including all persons with a disability. The challenge is to ensure that those guarantees are interpreted and applied in a manner that advances the human rights of persons with disabilities, and that the disability rights advocates take advantage of the available international and national procedures to press these claims. The rights to equality and non-discrimination are central guarantees, but the potential uses of human rights norms are of course not limited to these -- all other substantive rights are relevant, and which one is most helpful will depend both on the factual situation involved and the range of norms that can be invoked under any available procedure.

There is a wide range of different procedures at international and regional level that may be available in any given case. But it is important to identify the purposes that may be served by resort to such procedures. International procedures and bodies are no panacea and their use has to form part of a broader strategy, whether at the international or national level.

Using the different international procedures can serve a number of purposes: increasing public awareness of a particular case or issue, the development of jurisprudence that may be used by international and national advocates, bringing about law and policy change, and providing redress in individual cases. Ultimately, international procedures provide opportunities to exert pressure on government and others to bring about the changes which disability advocates seek to achieve.

d. the procedures and their possibilities

The major types of procedures available at the international level³⁸ -- in particular in the United Nations system -- are:

- (a) Reporting procedures under human rights treaties
- (b) Complaints procedures under human rights treaties
- (c) Special "thematic" and country procedures established within the framework of the United Nations Commission on Human Rights

In addition, opportunities exist within the three regional systems for the protection of human rights which presently exist: the Council of Europe system, the Inter-American system, and the system established under the African Charter on Human and People's

³⁸ This section does not deal with the political processes of the Commission on Human Rights, which provide opportunities for publicity and political pressure. Nor have I referred to the importance of studies prepared by the Sub-Commission on Protection and Promotion of Human Rights, or of the working groups established by the Sub-commission which have provided an important public forum for raising patterns of violations.

Rights. Space does not permit a full review of the procedures in each of the systems, but some or all of the different types of procedures mentioned above are to be found in the regional systems, and regional systems will often provide a more effective route for redressing violations.

The following gives a very brief sketch of the above procedure. In addition, I mention some of the initiatives that have been adopted to bring gender issues more into the work of those bodies and procedures -- since these may provide

1. TREATY-BASED PROCEDURES

a. *Reporting procedures*

Under each of the six principal United Nations human rights treaties,³⁹ States parties undertake to submit regular periodic reports on the measures they have taken to implement their obligations under the treaty in question. While many State do not submit their reports or submit them late, these procedures can nevertheless provide an occasion to raise the profile of disability issues and to put pressure on governments to take steps that they might otherwise have been unwilling to take.⁴⁰

The procedure involves the submission of the report by the government,⁴¹ followed by a review of the report at a public meeting at which government representatives are normally questioned by members of the supervisory committee, followed by the adoption by the committee of concluding observations on the situation in the country concerned. These concluding observations will normally identify those areas where the committee considers that the State is not complying with the treaty and will contain specific recommendations for action by the government.

Non-governmental organisations have come to play an important role in reporting procedures, both at the national level and the international level. Critical to the effectiveness of the procedure is the submission to the committees by NGOs of independent information to supplement or contradict the version given by governments. Committees are generally very receptive to NGO information and there are many opportunities to inform and influence the issues which a committee raises with governments and which it then includes in its recommendations to the government concerned. While some NGOs have raised disability issues before a number of the committees, there is considerable scope for the use of this forum to raise issues when a particular country is reporting and the issues fall within the scope of the treaty. All six treaties provide opportunities to raise disability issues.

b. *Individual complaint procedures*

Four of the six UN treaties have complaint procedures which permit individuals to lodge complaints with the supervisory committee alleging that their rights guaranteed under the treaty have been violated by a State, provided that the State concerned has accepted the procedure.⁴² A case can generally only be lodged by a victim of an alleged violation, and

³⁹ These are the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Forms of Cruel, Inhuman or Degrading Treatment or Punishment, and the Convention on the Rights of the Child.

⁴⁰ See generally Philip Alston and James Crawford (eds), *The Future of the UN Human Rights Treaty System* (Cambridge: Cambridge University Press, 2000).

⁴¹ A number of the committees have adopted reporting guidelines which require specific reference to disability issues by governments in their reports.

⁴² Under the First Optional Protocol to the International Covenant on Civil and Political Rights, article 22 of the Convention against Torture, article 14 of the International Convention on the Elimination of All Forms of Racial Discrimination and, from December 2000, the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women.

the victim must first exhaust any remedies that are available at the national level before the international committee can consider the complaint.

The proceedings are conducted on paper and follow an adversarial procedure. The outcome is a decision by the committee which has the format of a judicial decision. Although as a matter of international law these decisions are not legally binding on the State concerned, they are persuasive and are frequently implemented by governments, though not always immediately.

c. Inquiry procedures

Under the Convention against Torture and the Optional Protocol to the CEDAW Convention the respective committees have the power to institute an inquiry on their own initiative into the situation in a country, when the committee receives reliable evidence that torture is being systematically practised in a country, or if there are grave or systematic violations of the CEDAW Convention. The procedure has been initiated under the Torture Convention on only a few occasions, and the CEDAW procedure has yet to enter into force. But in an egregious case where there is systematic policy of using practices such as electroconvulsive shock therapy, it may be arguable that the procedure under the Torture Convention could be initiated, or, that under the CEDAW Optional Protocol if there was a pattern of gender discrimination in the treatment of women with disabilities.

2. CHARTER-BASED PROCEDURES

The UN Commission on Human Rights has established a variety of procedures that permit individual cases or patterns of rights violations to be brought to the attention of the Commission or one of the bodies it has established. Most of these fall into the category of what has been called *petition-information procedures* rather than *petition-recourse* procedures, that is they are not intended to provide individual redress, but to inform the body concerned of particular situations or the existence of particular types of violations that may need to be addressed.

a. Communication procedures

The oldest communication procedure that exists under the Commission on Human Rights is the procedure established by ECOSOC Resolution 1503. Under this procedure the Commission has power to examine situations in which there is evidence of a consistent pattern of gross violations. It is not intended to provide individual redress directly (though it may have that effect), and a person who submits a complaint which is processed under the procedure plays no part in the procedure after (s)he has submitted the complaint.

The procedure involves a preliminary examination of communications by the Sub-Commission on Promotion and Protection of Human Rights, which forwards cases in which it considers there is such a pattern to the Working Group on Situations of the Commission, which may in turn forward cases to the Commission. The details of the examination are confidential until the Commission decides to release details.

Assessments of this procedure vary, but on the whole the newer procedures adopted by the Commission appear to afford more useful opportunities to bring pressure to bear on governments than the 1503 procedure. Nevertheless, it may be an option that is worth considering as a supplement to other procedures.

The Commission on the Status of Women also has a communications procedure, under which a working group of the Commission examines communications on the status of women and reports to the Commission. To date that procedure has produced relatively little in terms of individual redress or policy developments, but there is no reason why it could not be used to raise violations of the human rights of women with disabilities.

b. Thematic procedures

Of potentially greater utility for disability rights advocates are the *thematic* mechanisms of the Commission on Human Rights. Since the early 1980s the Commission has established a number of procedures which focus on specific types of violations. There are now over [20] such procedures, which include a number of working groups (such as the Working Group on Disappearances) and special rapporteurs (such as the Special Rapporteur on Extrajudicial, Summary and Arbitrary Executions).⁴³

The mandates of the different mechanisms vary slightly, but they engage in some or all of the following activities:

- receipt of allegations of specific violations of rights covered by the procedure and the raising of those alleged violations with the government concerned (sometimes as an *urgent* matter) in order to clarify a case
- the preparation of analytical studies on specific types of violations, including the circumstances which lead to the occurrence of those violations and recommendations of the steps that need to be taken to avoid such violations
- visits to countries (at the invitation of those countries) in order to examine the observance of certain rights in those countries.

Each year the special rapporteurs and working groups prepare reports to the Commission -- these are publicly circulated documents and they are considered at the Commission (though generally superficially). The reports generally contain details of the cases which have been sent to governments for comment/action, and the response by governments.

Although these procedures are not formally set up to provide an individual remedy via a quasi-judicial procedure,⁴⁴ in some cases they can in fact provide a remedy in an individual case, as a result of a matter being raised directly with a government. In addition, they may provide a forum in which policy initiatives can be developed.

Of particular interest to disability rights activists would be the Special Rapporteur on torture, the Special Rapporteur on violence against women, the Special Rapporteur on education, and the Special Rapporteur on adequate housing among others.

c. Country procedures

The Commission has also established a number of country-specific mechanisms, which are mandated to examine and report on the observance of human rights in the country subject to the procedure. There are relatively few of these but, depending on the particular mandate,⁴⁵ they may also provide a forum in which violations of the human rights of persons with a disability could be raised.

⁴³ See the list at www.unhcr.ch/html/menu2/7/b/tm.htm (visited 17 October 2000)

⁴⁴ Although the Working Group on Arbitrary Detention conducts itself in this manner and adopts "opinions" in individual cases.

⁴⁵ See the list at www.unhcr.ch/html/menu2/7/a/cm.htm (visited 17 October 2000)

3. *other procedures*

Procedures in other fora may also offer opportunities to obtain redress in an individual case or to give an issue or a case prominence. These include:

- the individual communications procedure of UNESCO, under which the UNESCO Executive Board considers individual communications of alleged violations of rights within its fields of activities
- the complaint procedures of the ILO which allow trade unions and others to bring complaints of violations of ILO conventions to the ILO for examination
- under the Council of Europe: individual complaints under the European Convention on Human Rights, and collective complaints under the European Social Charter (as well as reporting procedure under the latter)
- within the Inter-American system: individual complaints may be brought before the Inter-American Commission on Human Rights and the Court under the American Convention and Declaration, as well as specialised conventions on torture, violence against women and the recent convention on the human rights of persons with disability
- under the African Charter there are both reporting and complaints mechanisms, the latter beginning to process an increasing number of complaints.

e. **what needs to be done at the international level**

There are a number of initiatives that could be taken to give disability rights issues and activists a more prominent place on the international human rights agenda

Training in the use of reporting and other procedures

A critical aspect of any strategy is to enhance the knowledge of disability rights advocates so that they can access the available procedures to raise the issues of concern to them. Thus it is important to organise training for disability advocates in this field, as well as for human rights advocates on disability issue and disability standards. There are many models for this type of course and many bodies that have experience in the use of international procedures -- working together with disability advocates appropriately targeted courses could be developed.

Preparation of a manual on using human rights procedures

There are a number of manuals that have been published which give practical guidance to advocates in the use of one or more international human rights procedures. Some of these focus on a specific procedure, while some focus on ways of raising specific violations (such as violence against women or violations of the right to housing) under a number of procedures.

It would be useful to prepare a manual which would assist advocates in using international procedures to address violations of rights, as well as to invoke international standards at the domestic level.⁴⁶

⁴⁶ One manual that might serve as a model is Women, Law and Development International and Human Rights Watch Women's Rights Project, *Women's Human Rights Step by Step: A Practical Guide to Using*

Creation of a network and focal points for the collection of source material

Knowledge of case law and other legal developments in other countries can be of great value to advocates in their own countries. Similarly, having a network to seek advice and resources from litigation or other problems can be an extremely effective way of sharing knowledge. A great deal of relevant material has already been collected by organisations such as Interights, and any efforts to build new collections of resources should take these into account -- it may be better to explore collaborations with such organisations rather than seeking to reinvent the wheel.

Encouraging the human rights bodies to give disability a more prominent place in their work

The human rights bodies have been encouraged to adopt a range of initiatives in response to the attention that their records of dealing with gender issues have received. There are similar initiatives that could be proposed in relation to disability.

For example, the Committee against Torture has appointed one of its members to act as a rapporteur on gender issues -- the same could be done in respect of disability issues, and the member concerned could focus on issues relating to the detention of persons with a disability.

The Human Rights Committee recently adopted a general comment in which it examined all articles of the ICCPR from a gender perspective. While articles 2 and 3 of the ICCPR specifically refer to discrimination on the ground of sex, the Covenant also covers discrimination on the ground of disability, and there would be no reason why the Committee should not undertake a similar exercise in relation to discrimination on the ground of disability in the enjoyment of ICCPR rights. A similar request could also be made to the CEDAW Committee (to expand its rather brief references to disability issues in its general recommendations). The Committee against Torture could make an important contribution by adopting a general comment on issues relating to the arbitrary detention of persons with a disability. The CERD Committee could also be asked to explore the interaction of race and disability, especially in light of its recent general recommendation on the interaction of gender and racial discrimination. All the Committee could be asked to review their guidelines to ensure that they are asking States to report on disability issues that fall within the scope of the treaty in question.

However, such changes are often initiated and supported from outside committees, and then taken up by an interested member of a committee. It is important therefore to stimulate committees to take up these issues and, if necessary, put pressure on them until they do address the issues.

This can be done by preparing analyses of the record of the committee in examining disability issues and suggesting ways in which that record could be improved (for example, the Division for the Advancement of Women recently undertook an analysis of gender in the work of the treaty bodies, that provide a useful basis for evaluating the

International Human Rights Law and Mechanisms to Defend Women's Human Rights (Washington, DC, 1997), though there are others that would also serve as useful models.

work of those committees.). Bringing committee members together with disability activists also needs to be done in a structured manner -- either a meeting with individual committees or a meeting at which members from a number of committees discuss the issues with disability activists. An NGO-sponsored conference could focus on these issues and bring members of the committees to discuss them with activists. The Special Rapporteur may also wish to explore opportunities for briefing the committees on issues of particular concern to them in the field of disability, in particular by appearing before them while they are in session.

In relation to the thematic mechanisms, the women's human rights lobby shows how one might proceed. In 1996 the Commission on Human Rights requested all of its thematic mechanisms to ensure that they integrated gender perspectives in their work.⁴⁷ While in some cases this had led to little more than a formal incantation of the requirement and perhaps some sex-disaggregated statistics, it is an important first step and a similar requirement in relation to disability might usefully be considered.

f. using the international standards in domestic litigation

In addition to developing law and policy and seeking redress at the international level, it is frequently more important to pursue these goals through domestic mechanisms. One important dimension of this work is encouraging courts and tribunals and other bodies such as human rights commissions or ombuds institutions to draw on international standards in the process of interpreting and applying national constitutions and laws. There has been a great deal of interest and activity in this field over the past decade, and some of the initiatives already taken in order to encourage the use of general human rights norms and human rights norms relating specifically to women and children by domestic courts could be built on and emulated.

These initiatives have included the organisation of judicial colloquia at which judges, academics, NGOs and others have examined the possibilities for the greater use of international standards in domestic litigation. The Commonwealth Secretariat has been particularly active in this regard, having organised a series of judicial colloquia on the use of international human rights norms in domestic litigation,⁴⁸ as well as three colloquia focusing specifically on the use of international norms to advance women's human rights.⁴⁹ (The Gender and Youth Affairs Division of the Secretariat has also commissioned the preparation of a compilation of international and national case law which use international standards to advance women's human rights). The United Nations has also organised a number of similar colloquia, focusing in particular on the domestic use of the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women.

⁴⁷ CHR Resolution 1996/48

⁴⁸ See generally *Commonwealth Secretariat and Interights, Developing Human Rights jurisprudence: Conclusions of Judicial Colloquia and other meetings on the Domestic Application of International Human Rights Norms and on Government under the Law 1988-92* (London, Commonwealth Secretariat, 1992).

⁴⁹ See, e.g., Andrew Byrnes, Jane Connors and Lum Bik (eds), *Advancing the Human Rights of Women: Using International Instruments in Domestic Litigation: Papers and statements from the Asia/South Pacific Regional Judicial Colloquium, Hong Kong 20-22 May 1996* (London: Commonwealth Secretariat, 1997), and Kirstine Adams and Andrew Byrnes (eds), *Gender and the Judiciary: Using International Human Rights Standards to Promote the Human Rights of Women and the Girl-Child at the National Level* (London: Commonwealth Secretariat, December 1999).

These seminars have provided considerable impetus to the greater use of international norms at the domestic level, in particular by bringing together comparative material and establishing networks that can be drawn on when issues arise litigation in different countries. It would be useful to consider organising similar colloquia for judges and others to encourage the expanded use of international standards in cases involving disability rights.

In many countries considerable use has already been made of international standards in domestic litigation, a process assisted and in some cases stimulated by the efforts mentioned above. Not only has this happened in the field of general human rights norms and women's human rights,⁵⁰ but there have also been cases in the field of disability rights where courts have drawn on international standards. In order to promote these developments, it is critical both to educate disability activists in the international standards, but also human rights and other advocates in relation to disability-specific international standards.

G. Conclusion

In many ways disability rights issues and advocates are in a position similar to that faced by women's human rights 15 years ago. The human rights system offers some prospects but also many challenges that will need to be overcome by conceptual analysis, legal and political strategising, and energetic lobbying. But the opportunities are there, if we are but prepared to take hold of them.

⁵⁰ See the proceedings of the judicial colloquia referred to above for the use of general international norms, and in relation to use of the CEDAW Convention specifically, see Andrew Byrnes, "Using International Human Rights Norms in Constitutional Interpretation to Advance the Human Rights of Women", paper presented at the 50th Anniversary Conference, Faculty of Law, University of Colombo, Sri Lanka, 23-26 July 1998.

**Let the world know - International seminar on human rights and disability
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Pre-paper 6

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**PROMOTION AND ENFORCEMENT OF THE RIGHTS OF DISABLED
PERSONS A SOUTH AFRICAN PERSPECTIVE - SOME IDEAS ON THE
PROCESS GETTING THE VIOLATIONS**

1. Introduction

*"No one gives us rights. We win them in struggle. They exist in our hearts before they exist on paper. Yet intellectual struggle is one of the most important areas of the battle of rights. It is through concepts that we link our dreams to the acts of daily life."*⁵¹

I have been asked to provide some ideas and procedures for getting NGO's and governments involved and engaged in the process of collecting and providing information on infringements of human rights. I will attempt to do this within the context of the South African perspective and hope that this will enrich the discussions. I do not profess that the South African system is the best, but it should be seen in the context of a new democracy that is able to experiment with new paradigms especially in the human rights arena.

2. Monitoring Bodies under the UN System

The role of the UN as far as the promotion, protection and enforcement of Human Rights is concerned is set out in Art. 1(3) of the Charter, which states that,

“ The purposes of the United Nations are:

⁵¹ Albie Sachs, *Protecting Human Rights in a New South Africa* vii (1990).

To achieve international co-operation in solving international problems of an economic, social, cultural or humanitarian character and in promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion...”

To this end two organs of the United Nations are particularly involved in the promotion and enforcement of Human Rights norms.

2.1 The General Assembly (GA) of the United Nations is required to initiate studies and make recommendations for the purpose of promoting international co-operation in the economic, social, cultural, educational and health fields and assisting in the realisation of human rights and fundamental freedoms for all without distinction as to race, sex, language or religion. To assist in achieving this and in line with its mandate, the GA has passed declarations and treaties that set out the Human Rights norms and through these treaties, the organs that are empowered to monitor and ensure compliance with these treaties. Several of these treaty-bodies have devised monitoring mechanisms that operate to ensure the observance of human rights.

There are no human rights treaties that specifically protect the rights of disabled persons. The treaties will be applicable through the anti-discrimination clauses that are in each treaty. The two important treaties are the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. These treaties do not contain provisions specifically related to disability. Nevertheless the general human rights guarantees apply to all persons, including disabled persons. Therefore the provisions of the both Conventions may be invoked for the protection on disabled persons.

With reference to the rights of disabled persons, the following bodies operate as follows: -

2.2 The Committee on Economic, Social and Cultural Rights (ICESCR committee).

Article 2 of the International Covenant on Economic, Social and Cultural Rights sets out the principle of non-discrimination, and requires that the rights set out in the covenant be enforced without discrimination on any of the listed grounds.

In enforcing the rights under the covenant, Article 26 requires States Parties to submit reports to the Economic and Social Council (ECOSOC) of the UN on measures that have been taken and progress made in achieving the rights. Through the ECOSOC, the reports of the States Parties may be transmitted to the Commission on Human Rights for study and general recommendations⁵². The ECOSOC may also co-operate with the specialised agencies of the UN to ensure observance of these rights⁵³. Under Article 20 of the Covenant, the ECOSOC is empowered to receive comments from both the States parties

⁵² Article 19

⁵³ Article 26

and the specialised agencies on the general comments made by the Commission on Human Rights under article 19.

The Committee assumed the responsibility of a supervisory task in the disability field in 1994 through a General Comment No. 5. Therefore there is a need for NGO's to be aware of these developments in order to be able to use the system for reporting of violations.

South Africa has not as yet ratified this Covenant and it is therefore not in force as far as South Africa is concerned. Reference is however made to it in line with sec. 39 (1) (b) of the Constitution, which requires that International Law be considered when interpreting the provisions of the Bill of Rights.

It is important that a move be made towards that ratification of the Covenant so as to guarantee commitment to the provisions therein and furthermore to open up new monitoring mechanisms to ensure their implementation. Ratification provides an important tool of collections of violations.

2.3 Human Rights Committee. (ICCPR Committee).

Article 26 of the Covenant guarantees equal protection for all without discrimination. The ICCPR Committee is established under article 28 of the International Covenant on Civil and Political Rights.

As with the ECOSOC, it is empowered to receive Country Reports by the States Parties on measures taken to enforce the rights under the Covenant⁵⁴. Article 41 also permits States Parties to make inter-state complaints. However to make use of this process, a State Party must have made a declaration recognising the competence of the Committee to receive and consider such complaints.

Complaints by individuals are provided for under article 1 of the first optional protocol of the ICCPR. The State Party against which the complaint is made must be party to this optional protocol that recognises the competence of the Committee to receive and consider such complaints.

The ICCPR has been ratified by South Africa and therefore the provisions and the monitoring mechanisms are in force.

2.4 Committee on the Rights of the Child (CRC)

The Convention on the Rights of the Child provides that States parties shall ensure that children are protected from discrimination on among others, the ground of disability. Article 23 of the Convention deals specifically with the rights of the disabled. Under this section, States Parties are required to ensure the dignity of the child and to promote self-

⁵⁴ Art.40

reliance and facilitate the child's active participation in the community. In recognition of the special care that disabled children and their car-givers require, the convention requires that assistance be rendered free of charge⁵⁵.

Article 43 of the Convention, establishes the Committee on the Rights of the Child. The States Parties are required to submit reports to the Committee on the measures that they have taken to realise the rights of the child under the convention. To provide the Committee with a comprehensive understanding of the implementation of the convention in the State Party.

Following its signature and ratification of the Convention in 1995, South Africa submitted its Initial Country Report to the CRC⁵⁶. The report stated that under the Curriculum 2005 additional initiatives were envisaged within the school environment, including programmes to encourage non-discrimination and facilitate inclusion, especially of children with disabilities. The report stressed the challenge of addressing the economic and social disparities that continue to exist. The Committee in its concluding observations recommended that legislation be developed to ensure conformity between the convention and domestic legislation. The Committee was also of the view that the ratification of other international human rights instruments would strengthen the efforts of the State party in meeting obligations under this convention. The NGO's are allowed to submit a supplementary report.⁵⁷

The Committee specifically welcomed the establishment of the Human Rights Commission as an independent monitoring mechanism. It further recommended the establishment of clear child-friendly procedures to register and address complaints from children and that an awareness campaign be carried out to ensure effective use of these procedures by children. The Committee itself does not have an internal mechanism for dealing with complaints by children. The Special Rapporteur in line with the Recommendation 35 of the Commission hopefully will undertake this issue for Social Development.

2.4 Special Rapporteur

As a Charter-based organ of the UN, the **Economic and Social Council (ECOSOC)**, to make recommendations for the purpose of promoting respect for, and observance of, human rights and fundamental freedoms for all. To fulfil this mandate and in line with Art.68 of the Charter, ECOSOC has set up commissions for the promotion of human rights. These functional commissions include the Committee on NGO's, the Commission on the status of women and the Commission on Human Rights and most importantly the Commission for Social Development under which the Special Rapporteur is located and other various working groups. The ECOSOC has also appointed special rapporteurs to deliberate and report on specific issues.

⁵⁵ Articles 22.

⁵⁶ CRC/C/51/Add.2) Submitted 4 December, 1997.

⁵⁷ Article 45 of the Convention on the Rights of the Child.

The appointment of the Special Rapporteur of the commission for social Developments on Disability is an important step in recognizing the rights of disabled persons. The recommendation of the 35th session of the UN Commission for Social Development for the renewal of the mandate of the Special Rapporteur is most welcome especially in view of the acceptance by UN agencies that disability has to include in human rights sphere.

3. Some Ideas to Ensure Collections of Violations

3.1 Civil Society

The existence of a strong NGO sector ensures compliance with human rights standards and norms. The strengthening of robust vigilant civil society as represented by NGO's is a prerequisite for bringing violations to the fore. Such a sector has a role to even abrogate for itself the role of "watching the watchdogs" thereby ensuring that State funded Independent Institutions task with the promotion and protection of human rights violations are meeting their obligations. The effect of this role is that, National Institutions are not only subject to scrutiny from their principals i.e. (Parliament) but also civil society. The likely benefit in this process is that complaints or violations are fed through to National Institutions by this sector and are kept on the spotlight till successful conclusion.

3.2 Collaboration between Government and NGO's

Collaborative strategies between Governments and NGO's are a creative way of achieving processes of collection of violations. National Action Plans for the promotion and protection of Human Rights as an example, may serve as a tool for facilitating a monitoring strategy. This NAP need not be the prerogative of Governments only, but has to be inclusive and thereby ensuring thorough consultation with the NGO's. This may guarantee legitimacy, but over and above, will engender a sense of ownership that reflects strong civil society sentiments and perspectives. Strong and uncompromising monitoring mechanisms are likely to be included thereby ensuring a clear and firm commitment for monitoring. Government can be held accountable on its undertakings and commitments as provided in the NAP. This relationship may ensure a systematic reporting of violations.

3.3 International Obligations

International obligations provide a rallying point on which NGO's and Government intersect on violations gathering processes. Although there are tensions as the former are bound to report violations without any compromise whereas the latter tends to report with circumspections ensuring minimum public damage and negative image.

The ability of NGO's to provide a supplementary country report is a useful tool of ensuring a balance and objective assessment of International obligations.eg Convention on the Rights of the Child⁵⁸.

⁵⁸ Convention on the Rights of the Child.

3.4 Legal Framework

Constitutional legal framework generally inculcates a human rights culture to the extent of fostering intolerance to violations as societal norms. It's the underlying power of solid legal standards that promote awareness and ensures that there is a concomitant increase in reporting of violations.

The South African context provides a healthy legal framework that promotes and protects human rights. Such a legal framework is underpinned by the Constitution⁵⁹, which has entrenched a Bill of Rights that is binding to the all organs of the State, to both natural and juristic persons and goes to an extent of including the Socio-economic rights as well. At the employment level, equity legislation⁶⁰ has been passed together with legislation that outlaws discrimination.

3.5 Policy Framework

The South African government in collaboration with the DPO's developed an Integrated National Disability Strategy which is underpinned by social model of disability and the principles of equalizations of opportunities of disabled persons.

An office that specifically manages co-ordination within government on policy issues on disability has been set up in the President's office. Offices on status of disabled persons have been set up at Premier's Offices at provincial level. These offices are meant to ensure uniform monitoring on all disability issues including violations and compliance or non-compliance with disability standards. A presence of an institution of disabled person placed at the top level of the executive arm of government, promotes awareness and ensures compliance with disability standards and norms.

To consolidate democracy and to achieve equality a law called Promotion of Equality and Prevention of Unfair Discrimination Act was passed. This law is meant to prevent and prohibit unfair discrimination and harassment: to promote equality and eliminate unfair discrimination; to prevent and prohibit hate speech.⁶¹ Interconnectivity between all equity and human rights law engenders a sense of violations intolerances thereby facilitating reporting.

3.6 Parliamentary Legislation Processes.

The South African experience has made the legislation development more transparent than before. They have process which engages and solicit comments, views and positions from the public before they becomes Acts of Parliament has offered an opportunity of shaping laws for NGO's plus civil society at large. Consequently the NGO sector has developed expertise of legislation monitoring and advocacy skills. This process has enriched the gathering of violations. DPO's are lagging behind in this field of legislation monitoring and advocacy. I suspect that it has to do with focus on resources mobilization and development.

⁵⁹ Constitution of the Republic of South Africa, Act 108 of 1996

⁶⁰ Employment Equity Act 55 of 1998.

⁶¹ Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000.

3.7 Independent National Institutions.

There are several of these bodies set up in terms of the Constitution. The SAHRC is the one task with the promotion, protection and monitoring of human rights. In line with the Paris Principles on National Institutions the SAHRC is governed by the following principles:

- "It is independent, and subject only to the Constitution and the law, and must be impartial and must exercise its powers and perform its functions without fear, favour or prejudice.
- Other organs of the state must assist such institution to ensure its independence, impartiality, dignity, and effectiveness.
- No person or organ of state may interfere with its function.
- Its accountable to the National Assembly⁶²."
- Because the Commission has the complaint driven component, as its enabling legislation obliges it to respond to any complaint received. The promotional work inevitably brings about complaints of violations.

Unfortunately complaints are received mainly the more affluent members of our society.

4. Regional Systems

Under the African Charter of Human and Peoples' Rights, individuals are protected from discrimination⁶³ and are guaranteed equality before the law and equal protection of the law⁶⁴. The Charter further guarantees the rights of the aged and the disabled to special measures of protection in keeping with their physical or moral needs⁶⁵.

The African Commission is authorised⁶⁶ to receive communications on Human Rights violations from States and from individuals including Non-Governmental Organisations (NGO's). Article 62 of the Charter requires that States make reports to the Commission on the measures they have taken in the observance of Human Rights.

In examining the complaints, the Commission should be guided by the Charter and international human rights principles⁶⁷. The decisions of the Commission are however not binding on the States parties and are subject to the approval of the Assembly of Heads of State and Government of the OAU (AHSO). As a result they are liable to influence from the political nature of the AHSO.

⁶² Section 181 of the South African Constitution.

⁶³ Article 2

⁶⁴ Article 3

⁶⁵ Article 18 (4)

⁶⁶ Under articles 47-59

⁶⁷ Ankumah, Evelyn.A. – The African Commission on Human and Peoples' Rights – Practice and Procedures" Martinus Nijhoff Publishers p. 24.

5. Monitoring Systems in South Africa.

The Constitution of the Republic of South Africa in sec. 9(3) prohibits discrimination on the grounds of disability. Sec. 27 (1) (c) further require that measures be taken to assist those who are unable to assist themselves. To this end, the Government provides a Disability Grant to assist those who are unable to assist themselves owing to disability.

Under the Constitution various independent bodies are established to monitor the observance and enforcement of Human Rights. The Human Rights Commission is empowered to investigate and report on the observance of Human Rights. It has performed this function through the preparation and publication of an annual report of Socio-economic rights.

The Commission also handles complaints from individuals and the public in general in line with its constitutional mandate under s.184. The Commission is also authorised to carry out research on human rights issues.

The Human Rights Commission has received recognition for its work from among others, the Committee on the Rights of the Child (CRC), which noted that there is a need for adequate funding to ensure its effective functioning⁶⁸.

It is important also that the recommendations of the Commission be given full consideration when brought to the bodies responsible for the implementation of human rights.

5.1 The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000, prohibits discrimination on the grounds of disability⁶⁹ The State further has an obligation to promote equality⁷⁰.

The Act, in Chapter 4 constitutes the Magistrates' and High Courts as Equality Courts within their jurisdictions. There is however a need for rules and regulations to guide their operation. Sec. 32 establishes the Equality Review Committees, which are empowered to advise on the operation of the Act and the impact of other legislation on the right to equality.

It is clear therefore that the mechanisms for the monitoring and enforcement of Human Rights are in existence, however several are not applicable to South Africa or are not yet operational. It is imperative that the system be enforced so as to establish a strong system and to strengthen the existing structures that guarantee the rights of the disabled in society.

⁶⁸ Concluding Observations of the CRC on the Initial Country Report of South Africa – CRC/C/15/Add.122

⁶⁹ S.9

⁷⁰ S.24 and S.25.

6. Conclusion

The DPO's have to make a paradigm shift by including human rights monitoring and violations collections as part of their development work. This is not made easier by the poverty and inequality existing in the country that of necessity determines the agenda for the work of the DPO's. Human rights systems especially the enforcements mechanism involves complex legal issues, which are by their nature only accessible to the more affluent members of the community. Clearly the collaboration between Governments and NGO's must be based on clear legal framework over and above goodwill.

**Let the world know - International seminar on human rights and disability
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Pre-paper 7.

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Introduction

Modern society is founded on the following two basic principles: -

1. Every individual has a right to equality, and
2. All those civil, political, economic and social as well as cultural rights would be available to all individuals without discrimination of any kind.

These principles are reflected not only in the constitutions of all the states but, also in the Charter of the United

Nations. Ever since the inception of the United Nations, international community has attached a greater importance to the attainment of ultimate goal of real equality for all individuals without discrimination of any kind. Towards this end, United Nations has not only adopted Universal Declaration Of Human Rights but also adopted the following two important Covenants: -

1. International Covenant On Economic, Social, and Cultural Rights and
2. The international Covenant on civil and political rights.

We are here concerned with the issue of the strategies to be employed for ensuring that violations of the rights of PWD are perceived and dealt with as 'violation of human rights' in accordance with the relevant international instruments as well as relevant legal frame works. Before endeavoring to conceptualize a workable strategy, it is important to

critically examine the forms of violation of rights of PWD and their linkages with the concept of human rights as understood by human rights activists.

Different forms of violation of rights of PWDs :

Historically, PWDs have been victimized of attitudinal barriers, which are responsible not only for their exclusion from the mainstream society but also for deprivation and discrimination on the grounds of disability. All international instruments are based on the recognition of right to equality. No doubt, in theory, one may say that this right to equality embodied in these instruments also applies to PWDs but, in practice, more than often, Persons with disabilities are denied their rights. It is quite evident from the fact that many policies and laws of member States either do not provide for protection to the rights of the disabled viz positive discrimination in their favour or in certain cases there are policies and such laws which impede the participation of PWDs on equal footing.

Infact, the discrimination as well as violations of rights of persons with disability are largely related to their economic and social rights.

A very cursory analysis of the case law available and reports of certain studies indicate the following common forms of violations of their rights: -

- (a) Denial of equality of opportunities in earning their livelihood
- (b) Absence of conducive environment & required facilities at the work place.
- (c) Denial of/ removal from employment under the guise of set medical fitness standards.
- (d) Denial of career enhancement opportunities to persons with Disabilities.
- (e) Denial of equal access to educational programmes due to non-availability of required facilities and specially trained manpower for the purpose.
- (f) Denial of accessible transport services and barrier free built environment as well as public facilities.
- (g) Denial of freedom of decision making due to cultural bias and prejudices in matters of family, political and cultural life.
- (h) Emotional, sexual and physical harassment.
- (i) Discrimination against a disabled member of the family in the matter of distribution of family property.
- (j) Denial of necessary measures to ensure exercise of franchise by Person with Disabilities.

Besides these forms of discrimination, there are some other forms of violations of rights of Person with Disabilities, which either arise out of an existing legal provision, or absence of special legislative provision to meet the special needs of a particular disability group. E.g. Many contract laws do not recognise persons with mental illness as a competent party to the contract. This results into violation of their valuable economic rights. Similarly, in many procedural laws, both civil and criminal, there are no provisions to provide for special needs of a particular disability group such as persons

with speech and hearing impairment. This violates their right to equal treatment and equal protection of law.

After having identified some more prevalent forms of violations of rights of persons with Disabilities, it is important to analyse how the violations could be remedied by taking recourse to the remedies available through various international declarations and conventions related to human rights. To begin with, a perusal of universal declaration of human rights reveal that international community has unequivocally and unambiguously recognised liberty, equality and dignity of all individuals to be the prime consideration in the governance of the member states. Article 1 of this declaration lays down that “All human beings are born free and equal in dignity and rights.”

In order to bring these common forms of violations of rights of Person with Disabilities within the ambit of this declaration and other international covenants which supplement this human rights declaration, it should be clearly understood that “equality as envisaged by this declaration and other related conventions is the “equality among the equals”. Hence, it is of critical important that member states provide for special measures necessary to compensate for the limitations imposed due to disability to bring persons with Disabilities on equal footing with non disabled counterparts enabling them to enjoy the right of equality assured by the said declaration.

The above stated forms of violation can be identified as violation of either the international covenant on economic, social and cultural rights or of civil and political rights or convention on the rights of the child, e.g. all forms of violation related to employment or earning livelihood violate following provisions of individual covenant on economic, social and cultural rights:

- (a) Article 6 recognizes “the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses and accepts.” Thus, when there’s a denial of job opportunity on the ground of disability, the aforesaid article is clearly infringed.
- (b) Article 7 refers to the “right of everyone to the enjoyment of just and favourable conditions of work which ensure adequate remuneration”. Thus, when the workplace is not suitably modified or adopted to ensure equality of opportunity to persons with disability in the matter of employment, the same would be qualified to be treated as violation of article 7.
- (c) Article 11 recognizes that everyone has the “right to an adequate standard of living for himself and his family, including adequate food, clothing and housing”. Available statistics show that world over this article is violated grossly in the case of persons with disabilities as they have been marginalised both by administrative

actions and absence of suitable legislative and policy measures to enable persons with disabilities to enjoy this right.

- (d) Article 15 recognizes the “right of everyone to take part in cultural life”. In action on the part of member states to make places connected with cultural activities accessible is a grotesque violation of the aforesaid right.

Another important international instrument viz. 'Covenant on civil and political rights' is also violated by most of the states. Article 25 of the aforesaid covenant “establishes the right of everyone to take part in the conduct of public affairs, directly or through freely chosen representatives; to vote and be elected at periodic elections by universal suffrage; and to have access, on general terms of equality, to public service in his country”. But, member states have not cared to provide for special measures to make polling booths accessible to enable person with disabilities to exercise their franchise freely and secretly.

There's yet another important international instrument viz. 'Convention on the rights of the child' which establishes "the rights of a disabled child to effective access to and reception of education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development". This obligation of the state is often violated than implemented, since majority of children with disability are excluded from any form of education, work, training, social, sports and cultural and recreational activities as well as preparation for their ultimate economic rehabilitation.

Probably, recognising the constant and common forms of violations and also treating these violations as human right issues, the UN in its General Assembly by resolution no. 2856 of disabled persons in rural areas, outline new criteria for creating jobs and, perhaps most importantly, point out the need to consult disabled persons themselves in planning and formulating policies and programmes that will affect their integration or re-integration into active working life.

In resolution 2856 (XXVI) of 20 December 1971, the General Assembly proclaimed the Declaration on the Rights of Mentally Retarded Persons. According to the declaration "the mentally retarded person should enjoy the same rights as other human beings, including the right to proper medical care, economic security, the right to training and rehabilitation, and the right to live with his own family or with foster parents. Furthermore, the Assembly declared that there should be proper legal safeguards to protect the mentally retarded person against every form of abuse if it should become necessary to restrict or deny his or her rights".

Thereafter, in 1975, the General Assembly of UN adopted the Declaration on the rights of disabled persons, which proclaimed that "disabled persons have the same civil and political rights as other human beings. The declaration states that disabled persons should receive equal treatment and services, which will enable them to develop their capabilities, skills to the maximum and will hasten the process of their social integration or

reintegration". This declaration may be regarded as the extension of the universal declaration of human rights having specific focus on the protection of rights of Persons with Disabilities on the same lines as the human rights of non disabled persons.

There are certain other international declarations/ covenants/ resolutions where there is either specific reference to the rights of person with disabilities or general provisions applicable to Person with Disabilities also e.g. ILO convention no. 159 concerning vocational rehabilitation of the disabled. This convention is aimed at obliging the member states to ensure equal access to training and employment.

Since the procedures laid down in various international covenants as well as Universal Declaration on human rights and not adequately cover the violations of rights of persons with disabilities, another international instrument of critical importance for persons with disabilities is the standard rules on the equalisation of opportunities for persons with disabilities. These rules can be used both as a tool for assessment of the progress made by member states towards ensuring equality of opportunity to persons with disabilities on one hand and also as a mechanism to collect information on discrimination and violation of various rights established by important international covenants listed here in above.

Strategies and recommendations for collection and documentation of information on human rights issues

The procedures established by international covenants on human rights are primarily based on the need for collecting and documenting information to ensure the implementation of these covenants. For enforcement of covenants related to human rights, the following three procedures at international level have been established.

- a) **Reporting Procedures:** This is the first step for addressing any violations of human rights as any individual violation or general violation of human rights may be reported either through individual petitions or general petitions, to the commissions of the human rights and other relevant committees.
- b) **Complaint Procedures:** This is adopted mostly in the case of individual violation of human rights in order to seek intervention by international bodies, the complaint has to be founded on very credible grounds.
- c) **Thematic and Country Procedures**

Despite these well established procedures, we have not been able to use them for mainstreaming human rights issues of Person with Disabilities. Whatever little use has been made by disability rights activists, has been in the area of civil liberties and in the matter of abuse or torture in institution care, particularly related to Persons with mental illness and severe disability.

Therefore, before developing a strategy for documentation of violation of human rights of Person with Disabilities, one has to explore the reasons for not having used available instruments, document, procedures and remedies. Probably, this is primarily because of lack of education and awareness about possibilities at the institutional level among disability organisations. Secondly, it can also be attributed to the general understanding of the meaning of human rights violations, which are often equated to arbitrary detentions, arrests and tortures in criminal investigating agencies.

Human rights activists also do not perceive isolation of social and economic rights of Person with disabilities as Human Rights issues concerned by the inclusion of persons with disabilities. In view of the poor reporting, the UN General Assembly in its 56th session adopted resolution no. 2000/51 and called upon the member states to cover fully the question of the human rights of persons with disabilities in complying with reporting obligations under the relevant United Nations human rights.

Generally all methods employed for the collection of information of the data may also be applied for collection and documentation of information on violation of human rights of persons with disabilities. These may include collection of information through questionnaires, research studies, reference and review of case law digests,

reports of human rights organisations and commissions at regional, national and international level, reports of various judicial or quasi-judicial law enforcing bodies envisaged under respective laws on protection of rights of disabled persons and by searching through media archives etc.

In order to use the above mentioned sources of information collection effectively, it would be imperative to involve:

- a) Disability Organisations
- b) Human Right activists
- c) Human Right advocates
- d) Regular and Open Universities
- e) Human Rights commissions and bodies at national and regional levels.
- f) Funding agencies such as European Union, World Bank, Asian Development Bank etc.

In addition, the following steps are to be taken urgently in this direction:

- a) Preparation of manuals – one targeted at education of disability rights activists and the other at the Human Rights activists advocates and those responsible for the reporting under the relevant conventions and treaties as well as institutions engaged in reviewing laws at national levels.
- b) Organisation of short term training programmes and seminars on the human right instruments and procedures for the above said target group.

- c) Preparation of a Questionnaire for collection of information through NGO's in the disability sector, Human Right Sector, and social development sector and bodies responsible respectively for reviewing laws at the National Level such as law commissions.

The crucial issue to be addressed in any such endeavour in the identification of a nodal agency for collection, analysis, processing and documentation of the information.

There is a need for involving all major international disability organisations such as WBU, World Federation of the Deaf, DPI, RI and Inclusion international in this process. It would be desirable and more effective if all the above mentioned major disability organisations form a joint group to undertake this important task with professional support. The nodal agency established for this purpose should initiate dialogue with Organisations like Secretariat of common wealth, European Union, SAARC, ESCAP and Chancellor of Open University to plan training programmes and seminars and to prepare manuals and to hold awareness colloquia with members of the judiciary and Human Right Commissions.

c) Conclusion

In conclusion, it is suggested that:

- a) a questionnaire to collect information be designed in a manner that information is elicited on the most common forms of human rights violation of persons with disabilities within the framework of human rights covenants and treaties.
- b) that the questionnaire be so designed that it systematically gives information for reporting the instances of violation
- c) the data collected in form of petitions and complaints through the questionnaire be systematically qualified, edited forwarding it to the appropriate commissions and committees at the international level.
- d) that open universities through the mode of distance education can play a vital role in spreading the education and awareness among the disability rights activists and human rights activists which is vital to collection of data and reporting of cases of violation to the international bodies.

Finally, the ombudsman and the other quasi-judicial institutions at the national level can work as meaningful partners in the endeavour of collection of data, e.g. the institution of Chief commissioner Disabilities in India can provide ready data on the violation of human rights of persons with disabilities.