International Seminar on the Measurement of Disability

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Report of a Seminar on Human Rights and Disability
(Almåsa Conference Centre, Stockholm, Nov 5-9, 2000)

(Office of the Special Rapporteur on Disability of the United Nations Commission for Social Development 2001)
Measuring Progress From Rights on Paper to Rights in Reality

In the last two decades, there has been a growing awareness that persons with disabilities are entitled to the same human rights as everyone else. Through much effort, the protection of these rights is now recognized as the responsibility of human rights monitoring bodies.

The next challenge is to turn that legal recognition into real change for persons with disabilities. That was the purpose of a seminar held in Stockholm, Sweden late last year. The Seminar was held by Dr. Bengt Lindqvist who is the United Nations Special Rapporteur on Disability. Attending were twenty seven experts on disability issues and human rights, representing 16 countries, as well as observers, guests and support staff.

The goal was to create a set of practical guidelines to help disability rights groups in their task of identifying and reporting human rights abuses.

The United Nations has taken responsibility to address disability issues as part of its main human rights activities. In 1993, the UN created an instrument called the Standard Rules on the Equalization of Opportunities for Persons with Disabilities outlining basic standards that should be followed by governments when designing their laws, policies and programs on disability.

In 1998, the UN adopted a landmark resolution stating clearly that any discrimination or unfair differential treatment of persons with disabilities not in line with the Standard Rules is a violation of human rights. The UN adopted a second resolution in 2000 which gave the High Commissioner for Human Rights, with the help of the Special Rapporteur on Disability, the responsibility to find new, stronger measures to monitor and protect the human rights of persons with disabilities.

As Dr. Lindqvist told the Seminar, the doors of the human rights system are now 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.
This call to action brought the participants of the Seminar together with a specific goal: to create guidelines that could be used by Disabled Persons Organizations and International Non-government Organizations in their work to identify and report violations of the human rights of persons with disabilities.

The guidelines are practical advice on how to collect and report information. Suggestions included sample forms setting out particular questions to ask, manuals with clear explanations of human rights standards and examples of rights violations. In addition, suggestions were made about how to best get this information out to the UN, the international community and national governments.

A guiding consideration was that all reporting documents and practices be usable. The work of collecting information and reporting abuses should be done primarily by persons with disabilities themselves - people that come from different cultural backgrounds and have different levels of understanding, reading and skills.

It is essential that persons with disabilities be involved in the design of the documents and practices that will be used. Documents should be clear and concrete with many examples and explanations. They should be user friendly and available in alternative formats so that all persons with disabilities can participate. In addition, special training and support should be given to make sure all systems of collecting and reporting information can be properly used.

The Seminar identified five separate areas that must be monitored for human rights abuses - individual cases of abuse, the laws of a particular country, legal cases, government programmes, services and practices, and finally, media representations of persons with disabilities. As each of these areas poses unique challenges for information gathering, the Seminar made suggestions and offered ideas that were specific to each area.

Individual cases of abuse occur frequently among persons with disabilities. Quite often victims do not see the point in reporting abuses or fear further abuse as a result of reporting. The reality is that documenting and reporting individual cases of abuse is crucial in raising awareness and support and makes it difficult for governments to falsely claim that their citizen's rights are respected. To be effective, reports of individual abuse must be accurate, quickly reported and be made with sensitivity to the safety of the victim.

The Seminar suggested that each organization have one person who is responsible for investigating and reporting incidents of human rights abuse. This specialist would receive training in how to carefully investigate reports to get accurate information and protect the victim.
Reporting forms should be clear and easy to use with examples of what kind of information is necessary. Manuals can also be made available that explain specific human rights and give examples of what sorts of actions are violations of those rights.

Finally, the specialist would be responsible for passing completed reports on to national and international organizations that deal with abuses of human rights, including the UN Commission on Human Rights.

The laws and policies of a country can appear to protect human rights but be used in a way that create inequality and actually violate the human rights of persons with disabilities. This means that the laws of a country must be reviewed and compared to international standards to make clear what impact the laws are having on the rights of their citizens.

Seminar participants recognized that there are already many groups that are involved in this sort of review (for example, university departments, social policy agencies and human rights organizations). It was suggested that the expertise and resources of these groups be more focused on disability issues. Information collected relating to disability issues could be separately documented and made available in a form that others can understand and share.

Legal cases and decisions are just as important as the written laws of a country - regardless of what a law says, what matters is how it is interpreted. The Seminar proposed that an international web site be created that would contain important legal cases from international courts and the courts of individual countries.

All cases would be compared to international human rights standards and norms. The web site would also have a user friendly guide to international human rights laws and standards.

Individual countries would be responsible for their own web sites which would report cases from their country. This would likely be done by each country's ministry of justice or by other organizations like law schools or human rights bodies. The international web site, which would be a collection of all national sites, would be run by the UN's Office of the High Commissioner for Human Rights.

Government programmes, services and practices usually have the greatest impact on the daily lives of persons with disabilities.
Yet, it is often very difficult to do a thorough review of the actual effect of these programmes.

To overcome this, the Seminar proposed that special reporting manuals be made available to disability rights groups. Each manual would deal with a specific issue - for instance, one manual would address access to education, another would deal with voting. Each manual would cover all programmes, services and practices that affected the specific issue.

The manuals would contain detailed lists of questions and examples of how to properly fill them out. Completed manuals could be sent to the UN and be used to measure how well specific governments are complying with international standards and human rights guarantees.

The media may be the most significant influence in forming public opinion. It has a tremendous impact on how people around the world think about persons with disabilities and disability issues in general. Media events must be monitored to make sure that they do not promote ideas and images that infringe the human rights of persons with disability.

The Seminar recommended that a new body be created called the Disability Rights Media Watch that would be responsible for monitoring media across the world for human rights abuses.

This body would gather accurate information about media abuses and create reports. Reports would then be made available internationally to all disability rights groups, the UN and government agencies. The Disability Media Watch would work closely with other media watch groups and give advice to disability rights groups on media issues.

The ideas that have come out of the Stockholm Seminar will provide valuable direction to all disability rights groups and allow them to more effectively let the world know about the abuses persons with disabilities face every day.

These ideas must now be put into action and refined. This will lead to strong and effective ways of measuring our progress and promoting respect for the human rights of persons with disabilities. It is the next obvious step in moving from rights on paper to rights in reality.

The full report of the Stockholm Seminar, as well as some additional documents in connection with the seminar, are available from the office of the UN Special Rapporteur on Disability, Spektern, S-103 33 Stockholm, Sweden, fax: +46-8 611 8003, e-mail: un-spec.rapp@telia.com.