

HUMAN RIGHTS AND DISABLED PERSONS

ESSAYS AND RELEVANT
HUMAN RIGHTS INSTRUMENTS

edited by

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DISABLED PERSONS AND HUMAN RIGHTS: THE LEGAL FRAMEWORK

Theresia Degener

INTRODUCTION

Disabled people are the largest minority in the world encompassing more than 500 million persons, of which 2/3 live in developing countries. For a very long time disabled persons have been confronted with different kinds of disregard and mistreatment. Together with women and children, legal systems have excluded disabled persons as non-persons. Eugenic population policies were carried out with the aim of eliminating those deemed disabled through sterilization and killing programmes. What occurred during German National-Socialism was the most cruel and far reaching policy of this kind, but its ideology and goal were neither new nor exceptional. Modern disability policies were much more benign but were also based on the assumption of disabled people not being real citizens. Labelled non-productive members of society, disabled persons were – and often still are – excluded from the mainstream of society, often locked in large institutions called nursing homes, deprived of all that non-disabled people take for granted: liberty, social and political life, work, education, privacy, to name but a few areas. Disability policy has been based on welfare and charity concepts and has not allowed disabled persons to escape the object status and become self-determined subjects.

At the end of the United Nations Decade of Disabled Persons in 1992 a major change could be perceived at the international disability conference at Vancouver, Canada, which marked the end of the Decade.¹ More than 2000 disabled activists from all over the world – the majority coming from developing countries – convened to discuss and de-

¹ Major contributions are documented in: *Equalization of Opportunities, Proceedings of the 3rd World Congress of Disabled Peoples' International held at Vancouver, British Columbia, Canada, April 21-26, 1992.*

scribe on future international disability policies. Projects and papers were presented by disabled speakers, the cultural programme was dominated by disabled artists, and literature and other products sold by disabled persons. Even though these days in Vancouver were very exceptional, and in reality disability policy is designed and controlled by non-disabled functionaries at international and national level, these days reflected major achievements of the UN decade. Most importantly the paradigm of disability policy has shifted from the medical welfare model towards the concept of independent living. According to this philosophy disabled persons are the best experts about their own concerns and are citizens with rights and responsibilities. In particular the disability movement in the U.S.A., which already in the 1960s regarded itself as a civil rights movement, inspired disability groups all over the world to demand civil rights rather than goodwill. An increased pace of change during the decade was initiated by establishing organizations of disabled persons as an alternative to organizations for the disabled, thus, enabling disabled people to have significant impact on modern policies and standard setting. The fact that the UN Decade was accompanied by a tangible action plan supported this development.² The World Programme of Action concerning Disabled Persons, adopted by the General Assembly at its 37th session³ – which builds on the experiences gained during the predecessor of the decade the International Year for Disabled Persons in 1981⁴ – energetically demands for participation of disabled persons in all decision-making. Member States were asked to "actively seek out and encourage in every possible way the development of organizations composed of or representing disabled persons [...], establish direct contacts with such organizations and provide channels for them to influence government policies and decisions in all areas that concern them." The United Nations committed itself to close cooperation with disability organizations and advised other international organizations to do the same.⁵

² The UN has also produced "Guidelines for the Establishment and Development of National Coordinating Committees on Disability" which promote the principle of participation of organizations of disabled persons in national disability policy. ("Beijing Principles"), 1990 UN doc. A/C.3/46/4.

³ UN doc. A/37/52 (3 December 1982).

⁴ UN doc. A/31/23 (16 December 1976).

⁵ World Programme of Action (WPA), para. 91-94 and para.161.

The growing impact of the disability movement can be seen on two other important outcomes of the decade. A major event was the appointment of a Special Rapporteur on Human Rights and Disability by the Sub-Commission on Prevention of Discrimination and Protection of Disabilities in 1984. The final report of Leandro Despouy, which was presented in August 1991 and endorsed by the Commission on Human Rights and the General Assembly at their subsequent sessions, clearly reflects the input of the disability community, notably Disabled Peoples' International and other disability related non-governmental organizations (NGOs.) The report shows that the human rights of disabled persons are seriously violated all over the world in both of the classic fields of human rights, the civil and political sphere as well as in the area of economic, social and cultural rights. While the report has been perceived as a major milestone for the eventual recognition of disabled persons as subjects of human rights, the practical consequences have been very few. Apart from being published in the United Nations study series on human rights⁶ there have been no follow-up activities within the United Nations. Regrettably one of its most promising recommendations, the appointment of an ombudsperson for monitoring of human rights implementation for disabled persons, has not been implemented so far. At the Vancouver conference much hope was placed in the creation of an ombudsperson's position. In addition a petition for taking action on individual or collective human rights violations within the organization of Disabled Peoples' International was set up. While the United Nations could not come to a decision to establish a human rights bureau for disabled persons⁷, disability organizations have taken steps in this direction.

THE UNITED NATIONS HUMAN RIGHTS DIVISION

Despite the fact that disabled persons constitute the largest minority affected with serious human rights violations, disabled persons are not

6 Centre for Human Rights, *Human Rights and Disabled Persons*, by Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Human Rights Study Series 6*, United Nations, New York, 1993.

7 Cf. delegates' calls to other UN bodies, such as the Committee on Economic, Social and Cultural Rights and the Disabled Persons Unit, see UN Doc. A/48/95, (20 December 1992).

covered by the United Nations concept of minority. A recent study of the Sub-Commission on Prevention of Discrimination and Protection of Minorities states that only ethnic, linguistic or religious groups constitute a minority.⁸ Notwithstanding the fact that at least hearing impaired persons who use sign language could qualify as a linguistic minority, disabled persons have always been excluded from the United Nations concept of minorities.⁹

Disabled persons also find themselves at a disadvantage with other vulnerable groups in that there is, up to the present, no binding human rights instrument explicitly protecting their human rights. While the proposed adoption of a draft Convention on the Elimination of all forms of Discrimination against disabled persons was rejected by the General Assembly¹⁰, the Decade resulted in a new instrument of a different kind which is supposed to be the basic international legal standard for programmes, laws and policies on disability in future years. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (SIRE) were adopted by the General Assembly on December 20, 1993¹¹ with the purpose of achieving "positive and full inclusion of persons with disabilities in all aspects of society" under the "leadership role of the United Nations therein".¹²

The SIRE are firmly build on the principles and concepts enshrined in the World Programme of Action concerning Disabled Persons (WPA) which was the guideline for the UN Decade of Disabled Persons but has been readopted as the guideline for the future.¹³

The difference between the SIRE and the proposed Convention lies in the legal character of the instruments. Unlike a Convention the SIRE are legally non-binding because they cannot be signed and ratified by Member States. While the weak legal character of the Rules is regrettable, the advantage lies in the fact that they came into force at once with adoption by the General Assembly. Furthermore, as stated in the Introduction of the Rules, they can attain binding character as "Inter-

8 Eide, A., *Protection of Minorities*, UCN.4/Sub.2/1993/34 of 10 August 1993.

9 Lerner, A., *Group rights and discrimination in international law*, Kluwer: Dordrecht, 1991, at pp. 8-19.

10 UN Doc. A/C.3/42/SR.13 (1987).

11 UN Doc. A/48/96 (20 December 1992).

12 UN Doc. A/48/95 (20 December 1992).

13 UN General Assembly Resolution 48/99 of 20 December 1993.