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International Disability Law—A New Legal Subject on the Rise: The Interregional Experts' Meeting in Hong Kong, December 13-17, 1999

by
Dr. Theresia Degener*

I. INTRODUCTION

Disability law has not been a field of legal research and teaching at many universities in the United States nor has it been widely acknowledged in other countries around the world. In North America and most European countries, the issue of disability as a subject of law has commonly been included in social security and welfare legislation, health law or guardianship law. Thus, disabled persons have been depicted not as subjects of legal rights but as objects of welfare, health and charity programs. The underlying policy has been to segregate and exclude people with disabilities from mainstream society, sometimes providing them with special schools, sheltered workshops, special housing and transportation. This policy has been deemed just because disabled persons were believed incapable of coping with both society at large and all or most major life activities.

Fortunately, when some countries made attempts to take a more integrative and inclusive approach to disability policy, major legal reforms resulted. Attempts to open up employment, education, housing, and goods and services for persons regardless of their disabilities have changed the understanding of disability from a medical to a social category. A key element of this new concept is the recognition that exclusion and segregation of people with disabilities do not logically follow from impairments, but rather from political choices based on false assumptions about disability. Inaccessibility problems do not so much re-

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sult from mobility, visual, or hearing impairments, but instead are a corollary of a political decision to build steps but not ramps, to provide information in printed letter version only or to exclude sign language or other forms of communication. Instead of viewing disability as the individual's problem, the focus has shifted to the environment and society as a whole and to the lack of consideration for human differences.

II.

DISABILITY AS A HUMAN RIGHTS ISSUE

With the paradigm shift from the medical to the social model of disability,¹ disability has been reclassified as a human rights issue. Law reforms in this area are intended to provide equal opportunities for disabled people and to combat their segregation, institutionalization and exclusion as typical forms of disability-based discrimination. With the evolution of civil rights legislation for disabled persons, such as the Americans with Disabilities Act (hereinafter ADA), the legal paradigm shifted from welfare law towards civil rights law. This new dimension of disability law has been welcomed as a major milestone on the path toward the eventual recognition of human rights of disabled people, an example more and more governments seem to be willing to follow.²

What remains unclear, however, is the scope of change. If the now undermined assumption that disability is a medical problem anchored much of the older welfare disability law, should government replace it with what we now call civil rights legislation? Do we still need benefits that were given as compensation for exclusion? What are the legal consequences of replacing the social model of disability with the medical model? Of course, this touches upon the delicate question of how to distribute resources in society.

Then, too, the issue is closely connected with another question that affects the outcome of law reforms in disability law, the principle of equality. The principle, one of the most fundamental human rights, is relational: equality for disabled people raises questions, such as compared to whom, to what extent, and under which circumstances? Is it enough to open the doors to education, employment, and political participation or do we need to help everyone get inside? Have we helped everyone get inside if schools, job premises, and public buildings are accessible but public transportation is not? Is it enough to prohibit invidious disability discrimination in employment or do we need to ensure that more subtle or even "good will" forms of discrimination are covered?³ Is it enough to allow some disabled people to live outside institutions or do we need to ensure that everyone gets out?⁴ Have we achieved equality if disabled work-

1. There is a large body of literature on this subject. See, e.g., VICTOR FINKELSTEIN, *ATTITUDES AND DISABLED PEOPLE: ISSUES FOR DISCUSSION* (1980); MICHAEL OLIVER, *THE POLITICS OF DISABLEMENT* (1990); MICHAEL OLIVER, *UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE* (1996); JENNY MORRIS, *PRIDE AGAINST PREJUDICE* (1991).

2. See *Implementation of the World Programme of Action Concerning Disabled Persons: Report by the Secretary General*, U.N. GAOR, U.N. Doc. A/54/388 (1999).

3. For example, should we include sheltered employment?

4. See, e.g., *Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581 (1999).

ers receive the same salary as non-disabled co-workers, but have to spend sixty percent of their salary on personal assistance services that the non-disabled employees do not need?

III. EQUALITY CONCEPTS

While there is consensus about the fundamental nature of the equality principle in domestic as well as in international law, the interpretation of this principle varies. The three main ways of understanding equality are as (1) formal or juridical equality, (2) equality of results, and (3) equal opportunity or structural equality.⁵

Juridical equality prohibits direct discrimination and aims at shifting the focus of a potential discriminator away from a characteristic such as race, gender, disability, or sexual orientation. Since it is deemed arbitrary to legitimize unequal treatment of such a characteristic, juridical equality requires ignoring the differences. This concept meets the demands of disability rights activists who try to overcome the medical model of disability, and it underlines the notion that disability is not the problem. To achieve equality, however, disability does have to be taken into account when it comes to providing access to accommodations such as architectural changes or program adjustments. Granting equal access to all members of various societies requires taking a look at the differences that exist among these members. Martha Minow has pointed to the moral policy dilemma of dealing with human differences such as disabilities.⁶ To ignore differences helps to prevent stereotypes and stigmatization but at the price of failing to do justice to the reality of difference. Taking difference into account does justice to the reality of difference but at the potential price of perpetuating false assumptions about the nature of difference.

Second, equality of results essentially examines disability with an outcome-analysis. Thus, according to equality of results, disabled workers who receive equal pay but have an unequal burden regarding their personal needs are discriminated against. At the core of this way of understanding equality stands the human rights theory that all human beings are of equal value and of equal human dignity. As there can be no justification for inherently equal beings to own common resources unequally, this theory legitimizes the demand for equal allocation of resources.

Equality of results poses some thorny problems, however. The principle must first tackle the question of responsibility. Who is responsible for meeting

5. See Gerard Quinn, *The Human Rights of People with Disabilities Under EU Law*, in *THE EU AND HUMAN RIGHTS* 281, 290 (Philip Alston ed., 1999). Other equality concepts with respect to disability law have been described by Aart Hendriks, *The Significance of Equality and Non-Discrimination for the Protection of the Rights and Dignity of Disabled Persons*, in *HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS* 40-62 (Theresia Degener & Yolán Koster-Dreese, eds., 1995); and LISA WADDINGTON, *DISABILITY, EMPLOYMENT AND THE EUROPEAN COMMUNITY* 53-66 (1995).

6. See MARTHA MINOW, *MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW* 19-79 (1990).

these needs? Is it the State or the private sector? Second, equality of results might require a strong welfare state, which may interfere with the ideology of a free market system. At the same time equality of results may perpetuate injustice because its focus is on results more than on treatment. Segregated education for disabled students, for example, might be deemed legitimate if special schools for disabled students would provide the same educational opportunities and degrees as regular schools. To put it bluntly, if we accept equality of results as the sole way of understanding equality, mainstreaming disabled students into regular schools might be an illegitimate goal.

The third way in which to view equality, equal opportunity, is less rigid than the other two concepts in that it provides equal chances but not results. In this way, equal opportunity is more compatible with the market economy. It looks at the history of group discrimination and identifies traditional or classic forms of discrimination. The equal opportunity paradigm sees both stereotypes and structural barriers as obstacles to inclusion; one must ignore disability if stereotypes are the basis for action, but must consider it if changing the environment or social life in order to grant genuine access and inclusion. The key term for the latter is providing "reasonable accommodation," which was developed in the United States in the 1970s.⁷ Since then it has been adopted around the world, though rephrased in some countries.⁸

The concept of equal opportunity is currently the most frequently applied equality concept in modern disability legislation. One reason behind this might be that this equality concept is the most compatible with the free market economy, which is now the global economic model. Since civil rights legislation provides equal opportunities for underrepresented groups or minorities, it opens the gates for those who have not been able to participate in the market. In the absence of non-discrimination legislation there will always be instances in which the operation of the free market will produce unsatisfactory results for persons with disabilities, either individually or as a group. Thus, the concept of equal opportunity for all also aims to change the notion of the capitalist market. This latter goal might explain why those who have not been the beneficiaries of the market economy in the past support this intermediate model of equality.

IV. NATIONAL AND INTERNATIONAL DEVELOPMENTS

The reform process in disability law has been going on in all parts of the world. The United States and Canada were the first countries to adopt anti-discrimination laws and other human rights legislation for persons with disabilities, starting with scattered equality provisions in various areas of the law in the

7. See U.S. COMMISSION ON CIVIL RIGHTS, *ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES* (1983); GERARD QUINN ET AL., *DISABILITY DISCRIMINATION LAW IN THE UNITED STATES, AUSTRALIA AND CANADA* (1993).

8. For instance, the term "adjustments" instead of "accommodations" is used in U.K. law. See BRIAN J. DOYLE, *DISABILITY DISCRIMINATION: THE NEW LAW* (1996).

1970s and following with more comprehensive laws in the 1990s.⁹ The 1990s in particular was a banner decade for disability law; more than twenty nations enacted disability discrimination laws during this period.¹⁰ New equality laws for disabled persons have emerged at the national as well as at the supranational and international level. Today we have binding and non-binding declarations of international human rights explicitly for disabled persons that have been adopted by the General Assembly of the United Nations.¹¹ At the regional level, the Organization of American States and the European Union have passed strong equality legislation on disability.¹²

Major driving forces behind these legal changes have been national disability rights movements, which seemed to have been able to learn quickly from each other as well as cooperate among themselves at the international level. Due to the scarcity of comparative law and international disability law publications, legal research has accompanied the reform process predominantly with respect to national laws.¹³

V.

INTERREGIONAL EXPERTS' MEETING IN HONG KONG AS A FOLLOW UP TO THE BERKELEY MEETING

The Interregional Seminar and Symposium on International Norms and Standards Relating to Disability, which took place December 13-17, 1999 in Hong Kong (Special Administrative Region), People's Republic of China, was

9. The landmark law being the ADA of the United States. *See* Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 (1999). In Canada the 1982 Canadian Charter of Rights and Freedoms and the 1985 Human Rights Act contain anti-discrimination provisions for disabled persons. *See* CAN. CONST. (Constitution Act, 1982) pt. I (Canadian Charter of Rights and Freedoms); The Canadian Human Rights Act, R.S.C., ch. H-6, § 1 (1998) (Can.).

10. *See, e.g.*, Disability Discrimination Act (1992) (Austl.); AUS. CONST. art. 7 (1997); Law of the People's Republic of China on the Protection of Disabled Persons (1990); Law on Equal Opportunities for Persons with Disabilities (1996) (Costa Rica); FIN. CONST. § 5 (1995) (now FIN. CONST. § 6 (2000)); CODE PÉNAL arts. 225, 416-14 (Fr.); GRUNDGESETZ [constitution] art. 3(3) (F.R.G.); Disability Discrimination Ordinance, Cap. 487 (1995) (H.K.); Act XXVI on Provision of the Rights of Persons Living with Disability and their Equality of Opportunity (1998) (Hung.); The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (1995 (No. 1 of 1996)) (India); Employment Equality Act of 1998, Equal Status Bill of 1999 (Ir.); Equal Rights for People with Disabilities Law, 5758 -1998 (Isr.); Act Relating to Employment Promotion, etc. of the Handicapped, Law No. 4219 (1990) (S. Korea); Human Rights Act of 1993 (N.Z.); Republic of Malawi (Constitution) Act of 1994, chap. III, sec. 13 (g); Magna Carta for Disabled Persons (Republic Act No. 7277) (1991) (Phil.); Disability Discrimination Act (1995) (U.K.); S. AFR. CONST. § 9 (1996); Protection of the Rights of Persons with Disabilities Act, No. 28 of 1996 (Sri Lanka); Law on the Prohibition of Discrimination Against Persons With Disabilities in Employment, SFS No. 1999-132, (1999) (Swed.); UGANDA CONST. chap. IV, sec. 21(2) (1995); Disabled Persons Act of 1992 (Zimb.).

11. *See infra* Part VI.

12. *See infra* Part VIII.

13. *See, e.g.*, QUINN, *supra* note 7; DISABILITY, DIVERS-ABILITY AND LEGAL CHANGE (Melinda Jones & Lee Ann Bassar Marks eds., 1999); WADDINGTON, *supra* note 5; HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS, *supra* note 5; MARGE HAURITZ ET AL. JUSTICE FOR PEOPLE WITH DISABILITIES: LEGAL AND INSTITUTIONAL ISSUES (1998); Quinn, *supra* note 5; Marcia Rioux, *The Place of Judgement in a World of Facts*, J. INTEL. DISABILITY RES., Apr. 1997, at 102-11.

one of the first attempts to create a forum for international disability law. The Equal Opportunities Commission of Hong Kong organized the Hong Kong Seminar in cooperation with the Centre for Comparative and Public Law, Faculty of Law, University of Hong Kong; the United Nations' Division for Social Policy and Development was a sponsor.

Hong Kong was an appropriate location for the meeting for two reasons. Much like the United Nations Decade on Persons with Disability (1983–92),¹⁴ the years 1993 until 2002 were declared the Asian and Pacific Decade of Disabled Persons.¹⁵ In addition, Hong Kong has one of the most far-reaching anti-discrimination laws for disabled persons in this region. The Disability Discrimination Ordinance (hereinafter DDO) of 1995 prohibits disability-based discrimination in the private and public sphere and covers such significant areas as education, employment, housing, sports, access to premises and the provision of goods and services.¹⁶ The DDO is one of only three pieces of anti-discrimination legislation in Hong Kong¹⁷ and has a strong monitoring body, the Hong Kong Equal Opportunities Commission (hereinafter EOC), which is eager to break new ground in the elimination of discrimination.¹⁸

Nearly fifty experts in law and disability policy from all regions of the world participated in the Hong Kong meeting, which was intended to promote awareness and understanding of the existing human rights framework for persons with disabilities. Another goal was to provide a forum to examine critically the current international legal and policy initiatives relating to persons with disabilities.

The Hong Kong meeting was a follow up to a smaller meeting that convened a year earlier at Boalt Hall Law School, University of California at Berkeley (hereinafter Boalt Hall). In December 1998, fifteen international experts in law and policy analysis participated in an Expert Group Meeting on International Norms and Standards Relating to Disability convened by the United Nations, in cooperation with Boalt Hall and the World Institute on Disability.¹⁹ The Berkeley expert meeting identified priority areas for further research and action in international disability law and policy.²⁰ Specifically, the priority areas

14. See *Implementation of the World Programme of Action Concerning Disabled Persons and the United Nations Decade of Disabled Person*, G.A. Res. 44/70, U.N. GAOR, 44th Sess., Supp. No. 49, at 191, U.N. Doc. A/44/49 (1990).

15. E.S.C.A.P. Res. 48/3, U.N. ESCOR, Supp. No. 11, at 113, U.N. Doc. E/1992/31-E/ESCAP/889 (1992).

16. Disability Discrimination Ordinance, Cap. 487 (1995) (H.K.).

17. The others are the Sex Discrimination Ordinance, Cap. 480 (1995) (H.K.) and the Family Status Discrimination Ordinance, Cap. 527 (1997) (H.K.).

18. It handled more than 1,200 complaints within the first three years and had a success rate of 66% for cases that proceeded to conciliation. See Equal Opportunities Commission, *Statistics* (visited Apr. 4, 2000) <<http://www.eoc.org.hk/enquiries/enquiries.htm>>.

19. The World Institute on Disability is a nonprofit public policy center of and for people with disabilities based in Oakland, CA.

20. The report can be viewed at United Nations, *Report of the United Nations Consultative Expert Group Meeting on International Norms and Standards to Disability* (visited Apr. 3, 2000) <<http://www.un.org/esa/socdev/enable/disberk0.htm>>.

included comparative legal research, research on implementation of domestic and international laws, and research on the role of the judiciary.

The Hong Kong meeting set out to build upon the Berkeley findings and to work on three main subjects, organized into the following clusters: Cluster One, international norms and standards relating to disability; Cluster Two, capacity building to promote and monitor the implementation of norms and standards for persons with disabilities; Cluster Three, approaches to definitions of disability. While Cluster One was the most interesting with respect to the development of international disability law, Clusters Two and Three addressed significant aspects of this evolving area of law. I shall mention their contents briefly here.

Cluster Two focused on the role of disability rights organizations in the implementation of international and regional human rights instruments. Just as in most areas of human rights law, the role of non-governmental organizations (hereinafter NGOs) is immensely important. While national governments theoretically bear the legal duty to implement international human rights law, in reality, they rarely accomplish human rights promotion and protection. Without the work of international and national human rights NGOs, the status of human rights law today would be far from where it is now.²¹ Disability rights organizations only recently entered the international human rights movement and, while impressive actions have been taken,²² a need for training in human rights advocacy among disability rights NGOs remains. Cluster Two thus focused on pilot training in this area, which was facilitated by a special purpose Internet site.²³

Cluster Three concentrated on the long standing issue of defining disability, which has been the quest for different disciplines such as medicine, biology, sociology and law for centuries. The legal definition of disability determines whether a medical or a socio-political model of disability is fostered. Participants reviewed a number of definitions of disability found in national and international laws, which generally fell into two categories. The first emphasized individual deficits of disabled persons, thus evoking the medical model of disability. The second category focused on the social, economic, political and legal barriers that result in disability, similar to the social model of disability. Participants also reviewed the current revision process of the International Classification of Impairments, Disabilities and Handicaps (hereinafter ICDH), which the World Health Organization (hereinafter WHO) first adopted in 1980.²⁴ Disability rights experts have criticized this definition as being too medical-centered

21. See Irwin Cotler, *Human Rights as the Modern Tool of Revolution*, in *HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE* 7-20 (Kathleen E. Mahoney & Paul Mahoney eds., 1993); HENRY J. STEINER & PHILIP ALSTON, *INTERNATIONAL HUMAN RIGHTS IN CONTEXT: LAW, POLITICS, MORALS* 456 (1996).

22. For a recent impressive investigation into the situation of incarcerated mentally ill persons, see Michael Winerip, *The Global Willowbrook*, N.Y. TIMES MAG., Jan. 16, 2000, at 58-67.

23. See WorldEnable, *An Internet Accessibility Initiative* (visited Apr. 3, 2000) <<http://www.worldenable.net>>.

24. See WORLD HEALTH ORGANIZATION, *INTERNATIONAL CLASSIFICATION OF IMPAIRMENT, DISABILITIES AND HANDICAPS* (1980).

and too focused on the individual. In July 1999, the WHO published ICIDH-2,²⁵ which is currently being tested in the field.

Participants concluded that legal definitions of disability serve different purposes and that there thus cannot be one overall definition of disability. For example, a medical definition may be appropriate if one's purpose is clinical care or personal care benefits. However, if the goal is to ensure human rights, the medical model would not be adequate because it most likely results in limiting the rights of disabled persons. In any event, participants recommended that persons with disabilities and their organizations play a central role in any decision-making process about definitions. Having briefly summarized the work of Cluster Two and Cluster Three at the Hong Kong meeting, I shall now return to Cluster One, international norms and standards relating to disability, as the focal point for the rest of this article.

VI.

OVERVIEW OF INTERNATIONAL LAWS RELATING TO DISABLED PERSONS

Despite being one of the largest minority groups in the world, encompassing 600 million persons (of which two out of three live in developing countries), disabled people have been rather ignored during the first three decades of the United Nations' existence. The drafters of the International Bill of Human Rights did not include disabled persons as a distinct group vulnerable to human rights violations. None of the equality clauses of any of the three instruments of this Bill, the Universal Declaration of Human Rights (1948) (hereinafter UDHR), the International Covenant on Civil and Political Rights (1966) (hereinafter ICCPR), and the International Covenant on Economic, Social and Cultural Rights (1966) (hereinafter ICESCR), mention disability as a protected category.²⁶ If disability is addressed as a human rights issue in these documents, it is only in connection with social security and preventive health policy.²⁷

Only in the 1970s, with the promulgation of the Declaration on the Rights of the Mentally Retarded Persons (1971)²⁸ and the Declaration on the Rights of Disabled Persons (1975),²⁹ did persons with disabilities become subjects of human rights declarations. Even these early instruments reflect a notion of disability within the medical model, according to which disabled persons are primarily seen as persons with medical problems, dependent on social security and

25. See WORLD HEALTH ORGANIZATION, ICIDH-2: INTERNATIONAL CLASSIFICATION OF FUNCTIONING AND DISABILITY (1999).

26. See Universal Declaration of Human Rights, G.A. Res. 217, U.N. Doc. A/810, at 71 (1948); International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A, U.N. GAOR, 21st Sess., Supp. No. 16, at 49, U.N. Doc. A/6316 (1967); International Covenant on Civil and Political Rights, G.A. Res. 2200A, U.N. GAOR, 21st Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1967).

27. See Universal Declaration of Human Rights, art. 25, G.A. Res. 217, U.N. Doc. A/810, at 71 (1948); International Covenant on Economic, Social and Cultural Rights, art. 12, G.A. Res. 2200A, U.N. GAOR, 21st Sess., Supp. No. 16, at 49, U.N. Doc. A/6316 (1967).

28. G.A. Res. 2856, U.N. GAOR, 26th Sess., Supp. No. 29, at 93, U.N. Doc. A/8429 (1972).

29. G.A. Res. 3447, U.N. GAOR, 30th Sess., Supp. No. 34, at 88, U.N. Doc. A/10034 (1976).

welfare and in need of segregated services and institutions. It was also during this time that the General Assembly affirmed that the "other status" phrase of the equality provisions of the International Bill of Human Rights covered disabled persons.³⁰

Throughout the 1970s and the 1980s, the General Assembly of the United Nations passed a number of resolutions that led to the 1982 World Programme of Action Concerning Disabled Persons (hereinafter WPA), the guiding instrument for the United Nations Decade of Disabled Persons 1982–1993.³¹ The first two goals of the WPA, prevention and rehabilitation, reflected a more traditional approach to disability law and policy; the third goal, equalization of opportunities, set the path for change at the international level. Equalization of opportunities is defined as:

the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities are made accessible to all.³²

Throughout the decade, the equal rights component of disability policy and law became the main target of the emerging international disability rights movement.

Other major events that helped to shift the paradigm from the medical to the human rights model of disability were two thematic reports, one on human rights in the field of mental health and one on human rights violations with regard to disabled persons; the United Nations Commission on Human Rights prepared both.³³ These reports were the first to recognize disability as a thematic subject within the human rights division of the United Nations, which in turn helped in regarding disabled persons not only as recipients of charity measures but as subjects of human rights (violations). While one report resulted in a non-binding international human rights instrument protecting disabled persons in institutions,³⁴ the outcome of the other has been rather poor. No significant follow-up activities were taken under the auspices of the U.N. Commission of Human Rights. While other significant guidelines and standards were adopted during the decade,³⁵ the proposal for a binding treaty on the human rights pro-

30. For a more comprehensive analysis see Hendriks, *supra* note 5.

31. G.A. Res. 37/52, U.N. GAOR, 37th Sess., Supp. No. 51, at 185, U.N. Doc. A/37/51 (1983).

32. *World Programme of Action Concerning Disabled Persons: Report of the Secretary-General*, Addendum at 21, U.N. GAOR, U.N. Doc. A/37/351/Add.1 (1982).

33. See *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder: Report by the Special Rapporteur, Mrs. Erica-Irene Daes*, U.N. Sub-Commission on Prevention of Discrimination and Protection of Minorities, U.N. Doc. E/CN.4/Sub.2/1983/17; *Human Rights and Disabled Persons*, U.N. Centre for Human Rights, U.N. Sales No. E.92.XIV.4 (1993).

34. See *The Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 46/199, U.N. GAOR, 46th Sess., Supp. No. 49, at 188, U.N. Doc. A/46/49 (1992).

35. See, e.g., *The Talline Guidelines for Action on Human Resources Development in the Field of Disability*, G.A. Res. 44/70, U.N. GAOR, 44th Sess., Supp. No. 49, Annex, at 196, U.N. Doc. A/44/49 (1990).

tection of disabled persons did not find majority support within the General Assembly in 1987.

As a compensatory alternative, the General Assembly adopted the non-binding U.N. Standard Rules on the Equalization of Opportunities for Persons with Disabilities (hereinafter StRE) in 1993.³⁶ The StRE firmly build on the WPA and clearly accentuates equality, now defined as follows:

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.³⁷

In contrast with other non-binding international disability instruments, the StRE have a Special Rapporteur and a panel of experts who have the mandate to promote and monitor the implementation of the rules. The panel of experts consists of ten representatives of the six major international non-governmental organizations in the disability field.³⁸ The reports reflect a clear human rights approach in monitoring performance, although the monitoring body is placed under the auspices of the United Nations Commission for Social Development instead of the Commission on Human Rights.³⁹

VII.

PROTECTION UNDER GENERAL HUMAN RIGHTS INSTRUMENTS

Increasingly, NGOs that focus on disability have an impact on how traditional human rights norms are interpreted and implemented as well as on how modern human rights instruments are designed.⁴⁰ While disability was a forgot-

36. See *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, G.A. Res. 48/96, U.N. GAOR, 48th Sess., Supp. No. 49, at 202, U.N. Doc. A/48/49 (1994) [hereinafter *Standard Rules*]. For comment, see Theresia Degener, *Disabled Persons and Human Rights: The Legal Framework*, in HUMAN RIGHTS AND DISABLED PERSONS, *supra* note 5, at 9-39, and Bengt Lindqvist, *Standard Rules in the Disability Field—A New United Nations Instrument*, in HUMAN RIGHTS AND DISABLED PERSONS, *supra* note 5, at 63-68.

37. *Standard Rules*, *supra* note 36, ¶¶ 24-27, at 204.

38. The organizations were as follows: Disabled Peoples' International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf and World Federation of Psychiatric Survivors and Users.

39. See *Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Report of the Special Rapporteur of the Commission for Social Development*, U.N. GAOR, U.N. Doc. A / 50 / 374, Annex (1995) (first report); *The Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Final Report of the Special Rapporteur of the Commission for Social Development*, U.N. GAOR, U.N. Doc. A/52/56, Annex (1996) (second report); *Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Final Report of the Special Rapporteur of the Commission for Social Development on Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on His Second Mission, 1997-2000*, U.N. Economic and Social Council, U.N. Doc. E/CN.5/2000/3 (1999) (third report); see also Dimitris Michailakis, *The Standard Rules: A Weak Instrument and a Strong Commitment*, in DISABILITY, DIVERS-ABILITY AND LEGAL CHANGE, *supra* note 13, at 117, 119, and 130.

40. While the focus is here on the human rights division of the U.N., it should be mentioned that the Special Agencies such as WHO, ILO or UNESCO have also taken an equal opportunity

ten category when the ICCPR and the ICESCR were drafted, these treaties are currently interpreted in a way that supports the human rights approach to disability. General Comment No. 18 to the ICCPR, which deals with the right to equality (ICCPR art. 25), is a clear statement that the concept of formal equality does not apply. It affirms that equal treatment does not always mean identical treatment and that States have a duty to take steps to eliminate conditions that perpetuate discrimination.⁴¹

The Committee on Economic, Social and Cultural Rights went even further and adopted a General Comment on how to interpret and implement the ICESCR with respect to persons with disabilities.⁴² General Comment No. 5, which the committee adopted in 1994, is the only legal U.N. document to date that broadly defines disability-based discrimination:

Both de jure and de facto discrimination against persons with disabilities have a long history and take various forms. They range from invidious discrimination, such as the denial of educational opportunities, to more "subtle" forms of discrimination such as segregation and isolation achieved through the imposition of physical and social barriers. For the purpose of the Covenant, "disability-based discrimination" may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodations based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.⁴³

The Comment also emphasizes the human rights approach to disability by including a clear demand for anti-discrimination legislation: "In order to remedy past and present discrimination, and to deter future discrimination, comprehensive anti-discrimination legislation in relation to disability would seem to be indispensable in virtually all States parties."⁴⁴

In a similar vein, the Committee on the Elimination of Discrimination Against Women has adopted General Recommendations that ask State parties to include specific information on the status of disabled women,⁴⁵ and has addressed the issue of disability in other thematic recommendations.⁴⁶

approach to disability in recent years. As a strong binding instrument, ILO Convention No. 159, Convention Concerning Vocational Rehabilitation and Employment (Disabled Persons), 1983, is worth mentioning. See *Convention No. 159: Convention Concerning Vocational Rehabilitation and Employment (Disabled Persons)*, in INTERNATIONAL LABOR ORGANIZATION, 2 INTERNATIONAL LABOR CONVENTIONS AND RECOMMENDATIONS 1919-91 (1992). For an overview of the specialized agencies see Theresia Degener, *Disabled Persons and Human Rights: The Legal Framework*, *supra* note 36, at 20-33.

41. See *General Comment No. 18, Report of the Human Rights Committee*, U.N. GAOR, 45th Sess., Supp. No. 40, at 175, U.N. Doc. A/45/40 (1990).

42. See Philip Alston, *Disability and the International Covenant on Economic, Social and Cultural Rights*, in HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS, *supra* note 5, at 94-105.

43. *General Comment No. 5 (1994): Persons with Disabilities*, U.N. ESCOR, Supp. No. 2, at 102, ¶ 15, U.N. Doc. E/1995/22 (1995).

44. *Id.* ¶ 16.

45. See *General Recommendation No. 18, Report of the Committee on the Elimination of Discrimination Against Women*, U.N. GAOR, 46th Sess., Supp. No. 38, at 3, U.N. Doc. A/46/38 (1992).

46. See, e.g., *General Recommendation No. 24, Report of the Committee on the Elimination of Discrimination Against Women*, U.N. GAOR, 54th Sess., Supp. No. 38, at 6, ¶ 25, U.N. Doc. A/54/38/Rev.1 (1999).

More recent human rights treaties, such as the International Convention on the Rights of the Child, include specific provisions concerning persons with disabilities that reflect a strong human rights approach.⁴⁷

VIII.

REGIONAL DEVELOPMENTS

At the regional level, three laws are worth mentioning in the context of promotion of human rights of persons with disability.

In Europe, both the Council of Europe as well as the European Community have taken steps to ameliorate the fact that disabled persons long had the status of invisible citizens.⁴⁸ The 1996 revision of the European Social Charter (hereinafter ESC) displays a departure from the one-dimensional welfare approach taken in 1961 when the ESC was adopted. Article 15 of the revised ESC contains a clear commitment to equal opportunities for disabled persons: "The right of persons with disabilities to independence, social integration and participation."⁴⁹

The European disability movement within the legal framework of the European Community has moved further and more firmly towards anti-discrimination. At the 1996 inter-governmental conference held to revise the European Treaties, a new article (art.13) was included in the Treaty Establishing the European Community.⁵⁰ This article gives the Community the ability to take action to combat discrimination on a number of grounds, including disability. The new provision is significant in that it embraces the human rights or social model of disability and that it recognizes that disability discrimination exists.⁵¹

Within the Inter-American system, a very recent development has been the adoption of the 1999 Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (hereinafter IACPWD). While it does not contain individual rights, it is the first regional treaty to define disability-based discrimination. Article 1 (2) states:

- (a) The term "discrimination against persons with disabilities" means any distinction, exclusion, or restriction based on disability, record of disability, condition resulting from a previous disability, or perception of a disability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise by a person with a disability of his or her human rights and fundamental freedoms.
- (b) A distinction or preference adopted by a state party to promote the social integration or personal development of persons with disabilities does not con-

47. For a discussion of art. 23 of the United Nations Convention on the Rights of the Child, see Thomas Hammerberg, *The Rights of Disabled Children—The UN Convention on the Rights of the Child*, in *HUMAN RIGHTS AND DISABLED PERSONS*, *supra* note 5, at 147-58.

48. See Lisa Waddington, *The European Community's Response to Disability*, in *DISABILITY, DIVERS-ABILITY AND LEGAL CHANGE*, *supra* note 13, 139-53; Quinn, *supra* note 5.

49. European Social Charter, Europ. T.S. No. 163. However, the medical model has not been clearly abandoned when it states that sheltered employment should be provided if mainstream employment "is not possible by reason of the disability" (emphasis added). *Id.* art. 15(2).

50. See Treaty Establishing the European Community, Nov. 10, 1997, O.J. (C 340) 1 (1997).

51. For details see Waddington, *supra* note 48, at 148; Quinn, *supra* note 5, at 312.

stitute discrimination provided that the distinction or preference does not in itself limit the rights of persons with disabilities to equality and that individuals with disabilities are not forced to accept such distinction or preference. If, under a state's internal law, a person can be declared legally incompetent, when necessary and appropriate for his or her well being, such declaration does not constitute discrimination.⁵²

IX.

CRITICAL REVIEW OF INTERNATIONAL DISABILITY NORMS AT THE HONG KONG MEETING

Participants of Cluster One of the Hong Kong meeting noticed that disability rights NGOs had successfully countered the myths so long associated with the welfare model of disability, prompting a pragmatic shift away both from the view that disability is a condition that requires a cure and from the resulting policies of institutionalization and exclusion. The current international legal framework encompasses a new understanding whereby living with a disability is something for society to accept and accommodate.

While the Cluster One members recognized the critical fact that the major part of international disability rights law is "soft law" with no binding obligations for States parties to the United Nations, they deemed these numerous instruments significant for at least two reasons. First, these instruments should be viewed as vital tools in crafting strategies to advance the disability agenda locally, nationally and internationally. Second, these soft instruments are valuable interpretations of broad treaty obligations of relevance to disabled people and have the potential to contribute to the corpus of customary international law in the field of disability rights.

In this regard, the participants welcomed treaties that address disability, such as General Comment No. 5 to ICESCR. It was recommended that other treaty bodies consider the adoption of similar comments on the application of their respective treatment, taking into account the existing jurisprudence of other treaty and charter-based bodies. Participants agreed that placing international disability rights within the human rights division rather than in the social development division of the United Nations is important, and they recommended that the Commission on Human Rights reinforce the importance of the disability issue through various actions. While participants acknowledged that the first human rights reports on mental health and on disability were appropriate first steps, they deemed more in-depth investigations of systematic and individual violations of the human rights of persons with disabilities necessary. Considering the scarce resources allocated to the investigation of human rights violations against disabled women, Cluster One participants recommended that the Special Rapporteur on Violence Against Women of the Commission on Human Rights

52. Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities, A.G. Res. 1608, 29th Sess., O.E.A. Doc. OEA/Ser. P AG/doc.3826/99 (1999). For the period prior to the new treaty see INSTITUTO INTERAMERICANO DE DERECHOS HUMANOS, *LOS DERECHOS HUMANOS DE LA PERSONAS CON DISCAPACIDAD* (Rodrigo Jiménez ed., 1996).

consider taking up the issue of violence against disabled women as a theme for a detailed study in one of her future annual reports.

Furthermore, participants considered the adoption of the first regional anti-discrimination convention on disability rights and expressed their agreement that this represented a success for the disability movement in the Inter-American region. Concerns were nonetheless expressed that the definition of discrimination in this treaty excluded declarations of incompetence. Advocates emphasized that in many cases, persons with mental disabilities are declared incompetent without the due process protections guaranteed under international human rights law. Participants reached consensus on supporting the treaty with the proviso that ratifying States enter a reservation with respect to these declarations of incompetence.

Participants of Cluster One, however, did more than recognize progress in the development of international human rights norms. The experts also paid attention to certain legal developments in the field of bioethics, because of their potentially adverse effects on disability rights. In particular, Cluster One reviewed the new European Convention on Human Rights and Biomedicine, adopted by the Council of Europe in 1997,⁵³ from a disability rights perspective. Article 17(2) of this treaty allows non-therapeutic medical experiments to be performed on persons unable to give their informed consent.⁵⁴ This result was seen as incompatible with article 7 of the ICCPR⁵⁵ and the Nuremberg Code of 1947.⁵⁶

Another drawback was seen in the fact that the Statute for the International Criminal Court (hereinafter ICC) fails to address the rights and concerns of disabled victims, whereas it protects other groups such as children and women. In response, the participants suggested that an additional protocol on disability supplement the statute of the ICC.

X.

A NEW INTERNATIONAL TREATY ON DISABILITY?

A major portion of the debate focused on the desirability of a new international treaty on the rights of persons with disability. Participants recognized that States are reluctant to adopt yet another special human rights treaty. The concern is that the abundance of existing human rights treaty obligations has created a "treaty fatigue" because Member States are already burdened by and unable to fulfill their existing reporting obligations.⁵⁷

53. See European Convention on Human Rights and Biomedicine, Europ. T.S. No. 164.

54. See *id.* art. 17(2).

55. See International Covenant on Civil and Political Rights, G.A. Res. 2200A, U.N. GAOR, 21st Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1967).

56. For the text of the Code, see *THE NAZI DOCTORS AND THE NUREMBERG CODE 2* (George J. Annas & Michael A. Grodin eds., 1992).

57. For more on this problem of human rights implementation see STEINER, *supra* note 21, at 559.

However, participants cited six principal arguments in favor of a new treaty on disability rights. First, a new treaty would be a significant advance in the creation of binding law. In contrast, the current international standards represent a regime that is little more than a “toothless tiger” when it comes to actual human rights advocacy. Second, a new treaty would result in claims for additional attention and resources within the human rights division of the United Nations, on governments and on other organizations. Third, a treaty on disability rights would provide an opportunity to add specific content to the human rights of persons with disabilities and address hitherto unexplored areas, such as the right to be different. In light of recent developments in the area of bioethics and biomedicine concerning the right to be different, participants felt that this right might be as fundamental as the right to equality for persons with disabilities.⁵⁸ Fourth, a new treaty would also provide disability rights organizations with the opportunity to promote human rights for persons with disabilities in domestic contexts. Fifth, a new treaty would be a catalyst for empowering and mobilizing the global disability rights movement. Finally, the adoption of a disability treaty would place the disability agenda squarely within the United Nations human rights program. Thus, this step would underscore the fact that disability was primarily a human rights rather than a social welfare issue.

The debate ended with a clear statement that the United Nations, member States and disability rights organizations should initiate the process for the adoption of an international treaty dealing specifically with the human rights of disabled persons. However, participants also felt a strong desire to formulate three guiding principles that should be observed. First, the process of drafting any new treaty should be open, inclusive and representative of the interests of all persons with disabilities. Second, disabled persons must be principal participants in the drafting of any new treaty at all stages of the drafting process. Finally, any new treaty must neither dilute any existing international provisions on disabled person’s rights nor undermine any national disability standards that provide a higher level of protection of rights.

XI.

CONCLUSIONS

The Interregional Seminar and Symposium on International Norms and Standards Relating to Disability in Hong Kong gave evidence that international disability rights is an emerging area of law. Experts from over fifty countries exchanged experiences about current law reforms in disability issues that all seem to follow a certain trend, namely moving from welfare law to civil rights for persons with disabilities. While important aspects such as comparative disability law and the role of the judiciary in implementing disability law reforms were not discussed in depth, participants presented some interesting examples of

58. For more on this issue see Degener, *supra* note 36, at 36; Katarina Tomasevski, *The Right to Health for People with Disabilities*, in *HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS*, *supra* note 5, at 131–46.

domestic disability law. A significant number of countries seem to have modeled their modern disability discrimination legislation on the American with Disabilities Act and its predecessors.⁵⁹

Then, there were countries like Uganda who chose different paths for participation and inclusion for disabled persons. The 1995 constitution of Uganda contains equal rights provision for disabled persons in section 21(2) and section 35.⁶⁰ Based on these provisions, the Uganda legislature adopted some impressive laws according to which a certain number of seats in elected political bodies at all levels are allocated for people with disabilities. More than 1800 disabled persons have been elected since then, including five persons with disabilities as members of the federal parliament.⁶¹

The Hong Kong meeting only briefly addressed the role of the judiciary. Experts seemed to be less enthusiastic with respect to the role of judges in disability law reforms. The shared experience was that judges tend to adhere to the medical model of disability and perpetuate prejudices about disabled persons. A rather eccentric example discussed was a 1993 decision of a German district court.⁶² The Flensburg Court decided that German travel agencies have to pay damages to non-disabled tourists who feel disturbed and disgusted by the presence of disabled tourists in their hotel.⁶³

The Hong Kong meeting provided a long needed forum for disability rights activists and international lawyers to discuss human rights of disabled persons. While it would have been laudable to have a higher representation of disabled experts at the meeting, international disability law gained momentum as a field of research and practice.

59. On the U.K. law see BRIAN J. DOYLE, *DISABILITY DISCRIMINATION: THE NEW LAW* (1996). Before the Irish disability discrimination laws were adopted, comparative legal research was undertaken. See QUINN, *supra* note 7. For Asia and the Pacific see UNITED NATIONS, ECONOMIC AND SOCIAL COMMISSION FOR ASIA AND THE PACIFIC, *LEGISLATION ON EQUAL OPPORTUNITIES AND FULL PARTICIPATION IN DEVELOPMENT FOR DISABLED PERSONS: EXAMPLES FOR THE ESCAP REGION* (1997).

60. See UGANDA CONST. §§ 21(2), 35, available at <<http://www.uganda.co.ug/chapt4.htm>> (visited Apr. 4, 2000).

61. This is according to an interview between the author and Jenny Kern, an attorney from Berkeley, CA, who interviewed Andrew Wonsolo, then the director of the National Union of Disabled People in Uganda, during an exploratory trip to Uganda in 1998. The National Union is the umbrella national policy making organization for disabled people in Uganda.

62. Amtsgericht Flensburg, Urteil vom 27.08.1992 – 63 C 265/92, 46 NEUE JURISTISCHE WOCHENSCHRIFT 272, (1993).

63. See *id.*