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**Human Rights Treaty Drafting through the Lens of Mental Disability:
the Proposed *International Convention on Protection and Promotion of the Rights and Dignity of
Persons with Disabilities***

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Draft Only

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These are the most devalued, disenfranchised people that you can imagine...[t]hey are so out of sight, so out of mind, so devoid of rights, really. Who cares about them anyway?¹

- Ron Honberg, Director of Legal Affairs for the National Alliance of the Mentally Ill

I. Introduction

In December 2001, the Mexican government put forward Resolution 56/168 in the United Nations (“UN”) General Assembly (“GA”).² The resolution called for consideration of a Convention on the human rights of persons with disabilities and further sought the immediate formation of an Ad-Hoc Committee (“Committee”). This Committee would “consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities”.³ Resolution 56/168 was passed without any vote. The Committee held its first session at UN Headquarters in New York from July 29 to August 9, 2002. In its initial report to the UN GA, the Committee recommended the adoption of a resolution that would, *inter alia*, invite “regional commissions and inter-governmental organisations, as well as nongovernmental organisations to make available to the Ad Hoc Committee suggestions and possible elements, to be considered in proposals for a Convention”.⁴ The GA subsequently passed Resolution 56/510, respecting the accreditation and participation of non-governmental organizations (“NGOs”) in the Committee,⁵ and Decision 56/474, which “requests the

¹ Eric M. Weiss, *A Nationwide Pattern of Death*, The Hartford Courant (Oct. 11, 1998), available at <http://www.copaa.com/newstand/day1.html> (last visited Sept. 27, 2003).

² Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, G.A. Res. 168, U.N. GAOR, 56th Sess., Agenda Item 119(b), U.N. Doc A/RES/56/168 (2001).

³ *Id.* Resolution 56/168 followed on the heels of the first world NGO Summit on Disability in March 2000. The resulting Beijing Declaration of Rights of People with Disability in the New Century strongly advocated for a disability-specific convention “to promote and protect the rights of people with disabilities, and enhance equal opportunities for participation in mainstream society”. See Article 6 of the BEIJING DECLARATION ON THE RIGHTS OF PEOPLE WITH DISABILITIES IN THE NEW CENTURY, adopted March 12, 2000 at the World NGO Summit on Disability, available at <http://www.unescap.org/decade/beijdeclarfin.htm> (last visited Oct. 22, 2003).

⁴ REPORT OF THE AD HOC COMMITTEE ON A COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES, at para. 16(7), U.N. Doc. A/57/357 (2002), available at <http://www.un.org/esa/socdev/enable/rights/adhoca57357e.htm> (last visited Oct. 21, 2003).

⁵ Accreditation and participation of non-governmental organizations in the Ad Hoc Committee established to consider proposals for a Comprehensive and Integral International Convention to Promote and Protect the Rights

Secretary-General to make, as needed and within existing resources, reasonable efforts to facilitate the participation by persons with disabilities in the meetings and deliberations of the Ad Hoc Committee...⁶

The second session of the Committee took place again in New York from June 16 to 27, 2003 and was marked by a significant increase in the participation of disability-related NGOs. Participating NGOs formed a caucus, called the International Disability Convention Caucus (“IDCC”). The IDCC elected a 15-member steering committee, consisting of seven members from International Disability Alliance (“IDA”) groups, five regional representatives, and one representative from each of the Center for International Rehabilitation, the Landmine Survivors Network, and other non-disability related NGOs. The session ended with a decision to form a 40 member Working Group, comprised of 27 representatives from Member States, 12 NGO representatives and one representative from a National Human Rights Institution.⁷ The Working Group met from January 5 to 16, 2004 for one session of ten working days to prepare a first draft of a Convention for consideration at the third session of the Committee in May 2004.⁸

The GA’s decision to pursue a Disability Rights Convention has been enthusiastically welcomed by the disability-related NGO community.⁹ Indeed, while the development of contemporary international human rights law since the 1948 Universal Declaration of Human Rights has advanced the interests of a number of marginalized, equality-seeking groups, it has simultaneously neglected the rights of persons

and Dignity of Persons with Disabilities, G.A. Res. 56/510, U.N. GAOR, 109th plenary meeting, 56th Sess., Agenda Items 8, 119(b), U.N. Doc A/RES/56/510 (2002).

⁶ Participation of persons with disabilities in the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, G.A. Decision 56/474, 56th session, Agenda items 8 and 119 (b), contained in A/56/49 Vol. III, (2002).

⁷ REPORT OF THE AD HOC COMMITTEE ON A COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES, at para. 15(1), (2), U.N. Doc. A/58/118 & Corr.1 (2003), available at http://www.un.org/esa/socdev/enable/rights/a_58_118_e.htm (last visited Oct. 18, 2003).

⁸ *Id.* at para. 15(4). The 12 NGO representatives on the Working Group include one representative from each of the seven IDA organizations, and one representative from each of the five distinct geographic regions identified by the IDCC members (Asia-Pacific, Africa, the Americas, West Africa and Europe).

⁹ While remaining mindful, of course, that the GA “has not yet endorsed the need for a human rights instrument...” See Eric Rosenthal & Clarence J. Sundram, *Recognizing Existing Rights and Crafting New Ones: Tools for Drafting Human Rights Instruments for People with Mental Disabilities*, in *THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES* 467, 468 (Stanley S. Herr, Lawrence O. Gostin and Harold Hongju Koh, eds., 2003).

with disabilities. In particular, it has neglected those who are arguably the most vulnerable to powerful, legalized coercion: persons diagnosed with mental disabilities.¹⁰

In this article, I explore whether, if established, such a Convention will in fact be an effective way to limit abuses of the rights of those diagnosed with mental disabilities. This analysis is informed by attempts to use international law to improve the rights of the mentally disabled. In Section II, I discuss the failure of international human rights law to effectively address these abuses to date. In Section III, I consider the debate surrounding the need for a disability-specific Convention. In Section IV, I argue that in order for the proposed Convention to be effective, and not simply a hollow mechanism, it must reject the traditional medical model of disability. Instead, the Convention should reflect a rights-based paradigm premised on a reformulation of "disability" as a social construct. To conclude, I discuss some of the principal issues facing the drafters relating to mental disability, including equality and non-discrimination, the right to physical and psychological integrity and monitoring. Drawing on my experience as a member of an NGO Delegation to the Working Group Meeting, I argue that NGO submissions pertaining to mental disability failed in helping to shape the normative content of broad statements of rights that are likely to be included in the final text of the proposed Convention. In an attempt to fill this gap, I make particular recommendations that I hope will assist the proposed Convention to realize its full potential.

II. The Shortcomings of International Human Rights Law with respect to Mental Disability

International law has made significant advances in protecting the rights of racial minorities,¹¹

¹⁰ As discussed by Rosenthal and Sundram, "many people are subject to discrimination based upon the improper perception that they have a current or past mental disorder". Thus, the term "mental disabilities" should be read liberally, to encompass those diagnosed with a mental disability and those "perceived as such by medical authorities or others." See Eric Rosenthal & Clarence J. Sundram, *International Human Rights In Mental Health Legislation*, 21 N.Y.L. SCH. J. INT'L & COMP. L. 469, footnote 2 (2002).

¹¹ International Convention on the Elimination of All Forms of Racial Discrimination, 660 U.N.T.S. 195, entered into force Jan. 4, 1969 [hereinafter CERD].

women,¹² children¹³ and migrant workers.¹⁴ In stark contrast, not only is there currently no international treaty that specifically guarantees the rights of those with disabilities (mental or otherwise), but the desire to codify such protections has been virtually non-existent. Attempts to address the issue of a Disability Rights Convention in a meaningful way by Italy at the forty-second session of the GA in 1987,¹⁵ and Sweden at the forty-fourth session in 1988,¹⁶ were both thwarted by the GA. This international ambivalence towards the plight of mentally disabled persons is not surprising given a shameful history of severe human rights abuses. Degrading living conditions, coerced “treatment”, scientific experimentation, seclusion, restraints - the list of violations to the dignity and autonomy of those diagnosed with mental disabilities is both long and egregious:

Human rights law and advocacy largely failed to offer any significant protection to the mentally ill in the decades following the Second World War. Thus, there occurred:

- (a) abusive medical experiments on mental patients in institutions;
- (b) gross overcrowding and abuse of physical constraints in US mental hospitals in the 1950s and early 1960s;
- (c) the abusive treatment of patients and denial of basic civil rights of patients in Japanese private mental hospitals in the 1970s and 1980s;
- (d) the long-term neglect and failure to provide adequate treatment in the colonies for mentally ill and retarded on the Greek island of Leros;
- (e) the widespread use of jails for the mentally ill in India...;
- (f) neglect on a massive scale in the psychiatric institutions of the former Soviet bloc (recent revelations about conditions in Hungary, Belarus, the Central Asian Republics as well as the Russian Federation itself);
- (g) the plight of the destitute and homeless mentally ill who have been ‘de-institutionalised’ in the United States and several western European countries.¹⁷

¹² Convention on the Elimination of Discrimination Against Women, G.A. Res. 34/180, 34 U.N. GAOR Supp. (No. 46) at 167, U.N. Doc. A/34/46, entered into force Sept. 3, 1981 [hereinafter CEDAW].

¹³ Convention on the Rights of the Child, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49, entered into force Sept. 2, 1990.

¹⁴ International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, G.A. res. 45/158, annex, 45 U.N. GAOR Supp. (No. 49A) at 262, U.N. Doc. A/45/49 (1990), entered into force 1 July 2003 [hereinafter Migrant Workers Convention].

¹⁵ U.N. document A/C.3/42/SR.16.

¹⁶ U.N. document A/C.3/44/SR.16.

¹⁷ T.W. Harding, *Human Rights Law in the Field of Mental Health: A Critical Review*, 2000:101 ACTA PSYCHIATR SCAND 24, 25 (2000). For discussions on the Soviet government’s manipulation of psychiatry to serve state interests, see A. Young-Anawaty, *International Human Rights Norms and Soviet Abuse of Psychiatry*, 10:3 CASE W. RES. J. INT’L. 785 (1978) and V. Rood, *Soviet Abuse of Psychiatric Commitment: An International Human Rights Issue*, 9:3 CAL. W. INT’L. L. J. 629 (1979). For an examination of the historical and contemporary role and purposes of forensic psychiatry in China, see Robin Munro, *Judicial Psychiatry in China and its Political Abuses*, 14 COLUM. J. ASIAN L. 1 (2000). For NGO discussions of rights violations in the mental health context, see the various reports of Mental Disability Rights International, *available at*

This in no way suggests that international human rights instruments developed in the 20th century have no bearing on the rights of those diagnosed with mental disabilities. On the contrary, existing Convention-based rights, most notably under the International Covenant on Civil and Political Rights (“ICCPR”)¹⁸ and the International Covenant on Economic, Social, and Cultural Rights (“ICESCR”)¹⁹ have the potential to become important tools in disability rights advocacy, particularly with respect to drafting and interpreting domestic mental health legislation.²⁰ These obligations are especially important given that there is no guarantee that the UN will actually adopt an effective Disability Rights Convention, or any Convention at all. Further, there is no guarantee that governments would ratify such a Convention.²¹ However, in practice, these instruments have few provisions that relate directly to mental

<http://www.mdri.org/publications/index.htm> (last visited Oct. 21, 2003), including: NOT ON THE AGENDA: HUMAN RIGHTS OF PEOPLE WITH MENTAL DISABILITIES IN KOSOVO (2002); HUMAN RIGHTS & MENTAL HEALTH: MEXICO (2000); CHILDREN IN RUSSIA'S INSTITUTIONS: HUMAN RIGHTS AND OPPORTUNITIES FOR REFORM (1999); HUMAN RIGHTS & MENTAL HEALTH: HUNGARY (1997); and HUMAN RIGHTS & MENTAL HEALTH: URUGUAY (1995). See also the reports of the Mental Disability Advocacy Center, available at <http://www.mdac.info/> (last visited Oct. 22, 2003), including CAGE BEDS: INHUMAN AND DEGRADING TREATMENT IN FOUR EU ACCESSION COUNTRIES (2003) (a report on the use of cage beds in psychiatric facilities in the Czech Republic, Hungary, Slovakia and Slovenia); WRITTEN COMMENTS OF THE MENTAL DISABILITY ADVOCACY CENTER CONCERNING ESTONIA FOR CONSIDERATION BY THE UNITED NATIONS HUMAN RIGHTS COMMITTEE AT ITS 77TH SESSION (2003); and WRITTEN COMMENTS OF THE MENTAL DISABILITY ADVOCACY CENTER CONCERNING THE SLOVAK REPUBLIC FOR CONSIDERATION BY THE UNITED NATIONS HUMAN RIGHTS COMMITTEE AT ITS 78TH SESSION (2003). Last, see Rosenthal and Sundram, *supra* note 10, at 472 – 473:

People with mental disabilities are often deprived of liberty for prolonged periods of time without legal process; subjected to peonage and forced labor in institutions; subjected to neglect in harsh institutional environments and deprived of basic health care; victimized by physical abuse and sexual exploitation; and exposed to cruel, inhuman or degrading treatment.

¹⁸ International Covenant on Civil and Political Rights, G.A. Res. 2200A(XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), entered into force Mar. 23, 1976.

¹⁹ International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 49, U.N. Doc. A/6316 (1966) entered into force Jan. 3, 1976.

²⁰ The most relevant of these Convention-based rights include: the right to the highest attainable standard of physical and mental health; protections against discrimination; protections against torture, inhuman or degrading treatment; and protections against arbitrary detention.

²¹ Rosenthal and Sundram, *supra* note 10, at 470–471. While the issue of the application of existing international human rights instruments to those diagnosed with mental disabilities is beyond the scope of this article, see Rosenthal and Sundram, *supra* note 10 for the most comprehensive discussion available. For specific discussion on the applicability of the European Convention on Human Rights to mental health law, see Lawrence O. Gostin, *Human Rights of Persons with Mental Disabilities: The European Convention of Human Rights*, 23 INT’L J. L. & PSYCHIATRY 125 (2000); Gerard Quinn, *Civil Commitment and the Right to Treatment under the European Convention on Human Rights*, 5 HARV. HUM. RTS. J. 1 (1992); and T.W. Harding, *The Application of the European Convention of Human Rights to the Field of Psychiatry*, 9(4) MED. LAW. 1078 (1990).

disability and “[h]uman rights oversight bodies that monitor the mainstream conventions and establish reporting guidelines have dedicated little attention to the rights of people with mental disabilities.”²²

In the 1970s, the UN put forth its first instruments specifically addressing the rights of people with disabilities. However, both the Declaration on the Rights of Mentally Retarded Persons²³ and the Declaration on the Rights of Disabled Persons²⁴ reflected a “notion of disability that falls within the medical model, according to which disabled persons are primarily seen as individuals with medical problems, dependent on social security and welfare, and in need of segregated services and institutions.”²⁵ The late 1980s and early 1990s were characterized by further movement in the field of mental disability rights. In 1986, the Special Rapporteur appointed by the Sub-Commission on Prevention of Discrimination and Protection of Minorities authored a report titled “Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder.” Soon after, the Vienna 1993 World Conference on Human Rights “reemphasized the fact that people with mental and physical disabilities are protected by international human rights law”.²⁶ As a result of the recommendations of the Vienna Conference, the GA adopted a historic resolution in the 1993 “Standard Rules on Equalization of Opportunities for Persons with Disabilities” (“Standard Rules”). Though the Standard Rules are not part of a Convention, and thus lack “hard law” status, they were “a revolutionary new international instrument because they establish[ed] citizen participation by people with disabilities as an internationally recognized human right.”²⁷ Indeed, under the Standard Rules,

²² Rosenthal and Sundram, *id.*, at 474. It can also be argued that traditionally disability rights groups have not exhausted the existing routes: “[t]hese groups have filed few complaints with UN oversight bodies and have rarely submitted ‘shadow reports’ that can provide the UN bodies the facts needed to find governments in violation of international human rights law.” See Rosenthal and Sundram, *supra* note 9, at 477. This certainly raises the question of how much of the responsibility should be assigned to advocates and how much should be laid on the treaty system and oversight mechanisms themselves.

²³ G.A. Res. 2856 (XXVI), 26 U.N. GAOR Supp., at 93, U.N. Doc A/8429 (1971).

²⁴ G.A. Res. 3447 (XXX), para.4, 30 U.N. GAOR Supp. No. 34 at 88, U.N. Doc. A/10034 (1975).

²⁵ Theresia Degener & Gerard Quinn, *A Survey Of International, Comparative And Regional Disability Law Reform*, (paper presented at “From Principle to Practice: An International Disability Law and Policy Symposium”), available at <http://www.dredf.org/symposium/degener1.html> (last visited Oct. 22, 2003). A detailed discussion of the medical model, contrasted with the social model, is contained in part IV of this article.

²⁶ Rosenthal and Sundram, *supra* note 10, at 475.

²⁷ *Id.* at 476.

governments were “required to remove obstacles to equal participation and actively to involve disability NGOs as partners in this process.”²⁸

Most directly pertaining to the issue of mental disability, in 1991 the GA adopted the "Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care" ("MI Principles").²⁹ While the MI Principles are often referred to as the ““centrepiece”” of international human rights law in the field of mental health”,³⁰ they have been severely criticized for promoting a paternalistic medical-model perspective rather than a rights-based perspective, and for being weak on the right to refuse harmful neuroleptic antipsychotic treatment. For example, Gendreau, of the Universite de Montreal, has argued that Principle 11 “...gives an eloquent illustration of the medical orientation now formally recognized by the General Assembly of the United Nations.”³¹ While Principle 11(4) grants patients the right, subject to certain limitations, “to refuse or stop treatment”, it also requires that “[th]e consequences of refusing or stopping treatment must be explained to the patient.” While upon initial glance this provision may appear benign, Gendreau’s more nuanced reading reveals the subtle influence of the medical model perspective:

Why is this kind of information only required when a person refuses or wants to stop a treatment? On the contrary, it should be part of the right to information included in the definition of informed consent. This provision shows an obvious tendency to presume that the refusal of treatment always and exclusively has negative effects and that the acceptance of treatment always and exclusively has positive effects. It implies that everything must be done to make those who refuse treatment change their mind, whether or not they are competent, by stressing the consequences of the *negative choice* being made. In such circumstances, one may well doubt that a free decision was made by the patient and that an informed consent was validly obtained.³²

²⁸ Gerard Quinn and Theresia Degener, HUMAN RIGHTS AND DISABILITY: THE CURRENT USE AND FUTURE POTENTIAL OF UNITED NATIONS HUMAN RIGHTS INSTRUMENTS IN THE CONTEXT OF DISABILITY 35 (February 2002).

²⁹ Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, G.A. Res. 46/119, 46 U.N. GAOR, Supp. No. 49, Annex at 188-192, U.N. Doc. A/46/49 (1991). For a discussion of using MI Principles as a tool in interpreting relevant sections in human rights conventions, see Eric Rosenthal & 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).

³⁰ Harding, *supra* note 17, at 24.

³¹ Caroline Gendreau, *The Rights of Psychiatric Patients in the Light of the Principles Announced by the United Nations: A Recognition of the Right to Consent to Treatment?*, 20:2 INT'L J. L. & PSYCHIATRY 259, 270 (1997).

³² *Id.* at 272. Gendreau concludes her analysis with the following condemnation of the MI Principles:
 ...far from recognizing the lay character of the decision to accept or to refuse a treatment, these Principles consecrate a particular medical approach to human rights. In fact, the right to treatment

Further, the World Network of Users and Survivors of Psychiatry (“WNUSP”) has questioned the credibility of the MI Principles, given that they “...were developed without significant involvement by psychiatric users and survivors.”³³

III. The Debate regarding a Disability-Specific Convention

The present lack of a Disability Rights Convention can arguably be attributed more to disinterest than concrete objections.³⁴ Other than the potential counter-productive repetition of existing mechanisms,

predominates with health as a strong symbolic underlying value. This health value, I must underline, is exclusively reduced to a medical perspective and it implies, for the psychiatric patient, the obligation to be treated without due consideration of his or her capacity to consent to treatment. This means that the U.N. Principles effectively confer a supreme right of intervention upon medical authorities pursuing "the improvement of mental health care." They impose a dichotomous conception of the protection of the person's rights and freedoms in which the right to treatment is set in opposition to the other human rights, without sufficient regard to a patient's own representation of health. Such a perspective is obviously in concordance with the discourse founded on health held by well-represented participants to the drafting process of the U.N. Principles. This is also in clear opposition with the other discourse founded on autonomy and equality held by a minority of participants.

Id. at 276.

³³ WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY PRELIMINARY STATEMENT ON THE UNITED NATIONS PRINCIPLES FOR THE PROTECTION OF PERSONS WITH MENTAL ILLNESS TO THE UN COMMISSION ON HUMAN RIGHTS (2000), available at <http://www.wnusp.org/docs/nyreport.html> (last visited Oct. 21, 2003).

³⁴ The U.S. has expressed support for a Disability Rights Convention, but has stated that it will not become a party given its “comprehensive domestic laws protecting those with disabilities”. See STATEMENT BY RALPH F. BOYD, UNITED STATES ASSISTANT ATTORNEY GENERAL FOR CIVIL RIGHTS, TO THE UN GENERAL ASSEMBLY AD HOC COMMITTEE (June 18, 2003), available at <http://www.aapd.com/docs/missionun.html> (last visited Oct. 18, 2003). In response, the U.S. International Council on Disabilities issued the following indictment of the U.S. government’s position:

...we nonetheless believe the official U.S. Government position ignores the fundamental need for a United Nations Convention. Essentially, the U.S. has taken the position that a Convention is not necessary for the United States because we have excellent disability law, and that it is the responsibility of each country to develop its own laws also. Therefore, it will neither support nor oppose a Convention, but will offer "technical assistance" to the Ad Hoc Committee as requested.

While we certainly appreciate the sovereign right and necessity of each country to develop their own laws, the U.S. position misses the point on several levels:

The role of [an] international Convention is never intended to supercede superior domestic laws, nor is it to replace the need for development of domestic law. Rather, a Convention provides a statement of universal human rights principles that underpin and reinforce domestic law where it exists, and provide minimum standards for what any domestic law - existing or new - should contain.

The notion that Americans with disabilities - and, indeed, US disability law - would not be served by such a Convention, implies that the international human rights framework is not relevant to the United States and furthermore undermines the global importance of international human rights

which will be discussed below with respect to the issue of treaty monitoring, perhaps the most credible objection to the proposed Convention is that it will have the effect of further dramatizing differences between individuals with disabilities, and thus will be stigmatizing in and of itself. This “dilemma of difference”³⁵ reflects the concern that by addressing difference in an individual instrument, policy-makers may reinforce and perpetuate marginalization. On the other hand, if difference is not addressed in an individual instrument, marginalization/stereotypes may be avoided, though the risk is that difference is ignored.

This argument, however, is insufficient to thwart a potential Convention. Rather than perpetuating marginalization, a disability-specific Convention affords the international community the opportunity to acknowledge difference and bring it into the mainstream. This is especially important vis a vis mental disability, which carries with it a stigma that is arguably more entrenched than other forms of disability-related stigma. Further, this fear did not prevent the adoption of other thematic conventions. In other words, there is no reason to think that this marginalization would occur with respect to those with mental disabilities when no evidence can be found of its existence with respect to racial minorities, children and women.³⁶

Instead, the reasons supporting a disability-specific Convention are many. As previously discussed, international human rights instruments and treaty monitoring bodies have all but ignored the

law. It is arrogant and disingenuous of the US (1) to declare that it has experience and expertise in such laws and (2) to offer technical assistance for a Convention that it has already declared as unnecessary.

The U.S. disability community believes that the government is missing the opportunity to draw upon its national experience and contribute in a meaningful way to a critical international policy process to which the disability community - both in the US and abroad - has attached great importance.

RESPONSE OF THE UNITED STATES INTERNATIONAL COUNCIL ON DISABILITIES (USICD) TO THE STATEMENT OF THE U.S. GOVERNMENT POSITION AS DELIVERED BY THE ASSISTANT ATTORNEY GENERAL FOR CIVIL RIGHTS (June 18, 2003), available at <http://www.aapd.com/docs/generalcivilrights.html> (last visited Oct. 18, 2003).

³⁵ As described by scholar Martha Minow. See MARTHA MINOW, MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION AND AMERICAN LAW (1990).

³⁶ Quinn and Degener, *supra* note 28 at 297.

issues confronting those with disabilities.³⁷ A thematic Convention is the strongest way to ensure that those with disabilities remain “visible”.³⁸ With this visibility comes the articulation of specified rights and the mechanisms necessary for ensuring compliance (in other words, a primary, centralized body to monitor compliance, coupled with a detailed reporting mechanism). Further, it has been argued that the very process of treaty-making can result in key benefits, such as heightening public awareness of rights, bringing to the surface ignored rights violations, developing NGO and government knowledge-bases (which can evolve into law and policy reform and public-education initiatives), coalition building between disability organizations (and between these organizations and non disability-related civil society actors), catalyzing programmatic developments and facilitating the cost-effective collection of data.³⁹ Last, the absence of a binding disability-specific Convention means that there will continue to be minimal consideration given to the correlation between disability and poverty. As stated by World Bank President James D. Wolfensohn, “[f]our hundred million disabled people live in the world's developing countries. All too often their lives go hand in hand with poverty, isolation and despair.”⁴⁰ Wolfensohn goes on to note that “[m]ore than 1.3 billion people worldwide struggle to exist on less than \$1 a day, and the disabled in their countries live at the bottom of the pile.”⁴¹

IV. The Social Model of Disability vs. The Medical Model: The Move to a Rights-Based Paradigm

The draft and eventual final text of the proposed Convention will be the end result of negotiating the tensions between two opposed theoretical models. Disability has traditionally been defined according to the “medical model” which continues to be the dominant model of healthcare in countries such as the

³⁷ “[I]nternational human rights forums have been generally unresponsive to the situation and specific needs of persons with disabilities.” See Philip Alston, *Disability and the International Covenant on Economic, Social and Cultural Rights: The Legal Framework*, in HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS 94 (Theresia Degener and Yolán Koster-Dreese, eds., 1995).

³⁸ Quinn and Degener, *supra* note 28 at 297.

³⁹ NATIONAL COUNCIL ON DISABILITY, UNDERSTANDING THE ROLE OF AN INTERNATIONAL CONVENTION ON THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES (June 12, 2002), available at http://www.ncd.gov/newsroom/publications/unwhitepaper_05-23-02.html (last visited Oct. 20, 2003).

⁴⁰ James D. Wolfensohn, *Poor Disabled and Shut Out*, WASHINGTON POST, Dec. 3, 2002, A25, available at http://www.worldbank.org/wbi/B-SPAN/docs/wolfensohn_op_ed_120302.pdf (last visited Oct. 22, 2003).

⁴¹ *Id.*

U.S. This model construes disability as “...an observable, mental, sensory or psychological deviation from normality caused by disease, trauma or another health condition.”⁴² Under the medical model, the functional limitations arising from these conditions can sometimes be prevented or managed by medical treatment.⁴³ In that regard, the individual is considered problematized and thus is “an object for clinical intervention.”⁴⁴ This model can be contrasted with the social model, which advocates for an understanding of disability as a social construct:

Perceiving disability as a condition similar to illness and exclusively as a functional limitation means that disability is considered as an individual rather than a societal problem, and that solutions are searched in the individual sphere...Thus, neither the society nor the environment have to be changed...The disability movement rejects this medical approach because of the subjectivity of the defining process and the power relations in which it takes place. What is regarded as a disability depends to a great extent on individual, societal, cultural and medical perceptions of what is “normal” and this in turn depends very much on the point of comparison.⁴⁵

Applying this paradigm to mental health specifically, clinical psychologist A. Galves has argued as follows:

The conception of human beings that is reflected by mainstream psychiatry is overly narrow and reductionistic. It portrays human beings as a mass of random chemical and physical dynamics at worst and weak, dependent, irrational victims at best. Psychiatry has lost track of the most important and valuable parts of human beings: their drives, instincts, emotions and wills. Without an accurate conception of the organism they are treating, it is impossible for psychiatrists to provide effective treatment.⁴⁶

⁴² Aart C. Hendricks, *Different Definition – Same Problem – One Way Out?*, in *DIABILITY RIGHTS LAW AND POLICY: INTERNATIONAL AND NATIONAL PERSPECTIVES* 195, 199 (Mary Lou Breslin and Silvia Yee, eds., 2002).

⁴³ *Id.*

⁴⁴ Quinn and Degener, *supra* note 28, at 14. For further elaboration on traditional disability models, see Gareth Williams, *Theorizing Disability*, in *HANDBOOK OF DISABILITY STUDIES* 123 (Gary L. Albrecht, Katherine D. Seelman & Michael Bury eds., 2001).

⁴⁵ Theresia Degener, *Disabled Persons and Human Rights: The Legal Framework*, in Degener and Koster-Dreese, *supra* note 36, at 13. See also H. Hahn, *Towards a Politics of Disability: Definitions, Disciples, and Policies*, 22:4 *SOC. SCI. J.* 87 (1985); and P. Abberly, *The Concept of Oppression and the Development of a Social Theory of Disability*, 2:1 *DISABILITY, HANDICAP & SOC'Y* 5 (1987).

⁴⁶ DAVID OAKS, HOW TO HAVE MAD PRIDE WHILE YOU'RE PROTESTING IN FRONT OF THOUSANDS OF PSYCHIATRISTS, available at: http://www.mindfreedom.org/mindfreedom/m18_main.shtml (last visited Oct. 21, 2003). In his resignation letter from the American Psychiatric Association, Dr. Loren Mosher (former head of the Center for Studies of Schizophrenia at the National Institute of Mental Health in Washington, D.C.) states: “No longer do we seek to understand whole persons in their social contexts -- rather we are there to realign our patients' neurotransmitters. The problem is that it is very difficult to have a relationship with a neurotransmitter -- whatever its configuration. So, our guild organization provides a rationale, by its neurobiological tunnel vision, for keeping our distance from the molecule conglomerates we have come to define as patients.” See Letter from Dr. Loren Mosher to Dr. Rodrigo Munoz, then President of the American Psychiatric Association (Dec. 4, 1998), available at <http://hem.fyrlistorg.com/mosher/resig.pdf> (last visited Oct. 22, 2003).

Though some commentators have suggested that “[o]ver time, this medical model of disability is being replaced”,⁴⁷ it is abundantly clear that with respect to mental disability, the prevailing model is still the medical-model. Indeed, it is not only the medical community that has resisted understanding mental illness as a social construct: “[t]he disability movement has also, at times, been reluctant to include people with mental health problems. The fear of mental illness which stalks society at large is shared by many who otherwise are active in challenging social exclusion and who argue, in other contexts, that disability resides in the attitudes of society rather than in physical or mental variations from the norm.”⁴⁸ I would caution that we must remain vigilant of the medical-model’s intrusion into the Convention drafting process. If past international human rights instruments, such as the MI Principles, are any indicator, there is certainly reason for concern.⁴⁹ The strongest assertion of this model thus far in the drafting process has come from the Pan American Health Organization (“PAHO”), which serves as the World Health Organization’s (“WHO”) Regional Office for the Americas and as the health organization of the Inter-American System. PAHO’s submission to the Committee is retrogressive and unhelpful to the development of a strong Convention calling as it does for the incorporation of the MI Principles, “*especially with regard to consent to treatment...*”⁵⁰

⁴⁷ Arlene S. Kanter, *The Globalization of Disability Rights Law*, 30 SYRACUSE J. INT’L L. & COM. 241, 247 (2003).

⁴⁸ Kate Harrison, *Disability and Mental Health Law*, in LAW, RIGHTS AND DISABILITY 193 (Jeremy Cooper, ed., 2000). Indeed, in reviewing materials on the “social model of disability”, I was struck by the lack of any meaningful discussion regarding mental disability.

⁴⁹ See footnotes 31 – 33 above.

⁵⁰ PAN AMERICAN HEALTH ORGANIZATION (MENTAL HEALTH AND SPECIALIZED PROGRAMS UNIT), CONTRIBUTIONS AND PROPOSAL FOR A CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES, *available at* <http://www.un.org/esa/socdev/enable/rights/uncontrib-paho.htm> (last visited Oct. 21, 2003) [emphasis added]. In general there has been a strong medical-model voice in international bodies’ attempts to address mental health issues. For example, the WHO is presently developing a “Manual on Mental Health Legislation” (“Manual”). The purpose of the Manual is to bring “...together information on international norms and standards in the area of mental health and human rights, as well as best practice information on mental health law in countries, in order to inform and assist countries wishing to formulate and implement legislation.” See WHO MENTAL HEALTH AND HUMAN RIGHTS PROJECT, *available at* http://www.who.int/mental_health/media/en/606.pdf (last visited Oct. 19, 2003). The draft Manual, which is arguably at least somewhat reflective of a rights-based perspective, was circulated for discussion amongst stakeholders and received the following comments from a noted Professor of Law and Psychiatry at Harvard University:

The argument in favour of a rights-based approach focusing on individual dignity, rather than a medical-based approach focusing on treatment, is not simply related to concerns about the efficacy and repercussions of the actual treatment. It also relates to the methodology that results in the prescription of treatment. As discussed above, the social construct theory holds that despite the assertions of those supporting the medical-model paradigm, what is labeled as disability “is not generally selected through a neutral or disinterested process” but rather “through an apparatus of power”.⁵¹ The connection between the biases of mental health practitioners and psychiatric diagnoses is quite illustrative of this concern:

The fact that physicians consider treatment and cure to be their first priority should, however, be recognized as a powerful value system that will inevitably skew professional judgment. For example, a physician's doubts about a patient's competence to accept or refuse treatment are typically resolved in the patient's favor if the patient wishes to accept treatment; the patient's competence is challenged only if she refuses treatment. In addition, medical professionals readily sacrifice patient autonomy to protect patients from harm or to reduce risks to their health.

...

Members of a given profession also tend to share a professional consensus on many issues -- particularly regarding diagnoses and treatments -- for which there is actually little or conflicting empirical support. For example, mental health professionals rely heavily on interviews for diagnosis even though studies show that interviews are not

...it seems rather to be the work of lawyers who have been trapped in a time warp since the 1970s. This draft of the manual would impose on the rest of the world the complex array of legal restrictions and red tape that antipsychiatry ideologues imposed on American psychiatry back in that era.

...

...the draft's experts have the same basic goal as the antipsychiatry legal advocates of the 1970s. Every psychiatric intervention is to be contested on legal grounds. One can find lots of verbiage in the draft about the importance of families, about the plague of mental illness and about the need for treatment. But the actual provisions come straight from the most radical rights-driven models of the 1970s. The underlying rationale in the 1970s was skepticism about the reality of mental disorders and the efficacy and risks of psychotropic drugs. Thirty years later, this skepticism, often based on ignorance and bias, cannot be justified.

Alan A. Stone, M.D, *Commentary: On Formulating Mental Health Codes for the World*, (July 2002), available at <http://www.psychiatrytimes.com/p020701c.html> (last visited Oct. 19, 2003). The premise that the Manual is reflective of a rights-based paradigm is hotly contested. Mental disability rights NGOs have issued equally scathing critiques of the draft Manual, but for the opposite reason, arguing that it “obscures and justifies human rights violations such as forced interventions and incarceration by labelling them as treatment.” See COMMENTS ON THE DRAFT WHO MANUAL ON MENTAL HEALTH LEGISLATION (July 12, 2001), available at http://www.wnusp.org/docs/dr_m_funk.html (last visited Oct. 19, 2003).

⁵¹ Quinn and Degener, *supra* note 28, at 15. Reliance on allegedly “objective” medical research and assessments is key to the medical-model paradigm and vigorously defended by its supporters. As stated by Dr. Alan A. Stone, Touroff-Glueck Professor of Law and Psychiatry in the faculties of law and medicine at Harvard University, “Lawyers may have a different perspective, but physicians usually look to the available empirical evidence and insist on proof that a method works.” See Stone, *id.*

particularly likely to yield valid results; many standard tests relied upon by mental health professionals are similarly deficient. Worse, studies show that professionals have great confidence in their own judgments and are highly resistant to changing them, even when these judgments are based on invalid tools of diagnosis. Evidence suggests that some professional judgments in the mental health field are made within minutes of meeting the client.

...

Treatment for health problems, especially mental health problems, requires an understanding of the patient's culture and personal history. Researchers have observed that "as the sociocultural distance between the clinician and his patient increases, diagnoses become less accurate." This problem is particularly intense in the public sector where the involuntary "clients," unlike their caretakers, are disproportionately members of racial minorities and are indigent. In state and county hospitals, black men are hospitalized at a rate 2.8 times greater than white men, and black women at a rate 2.5 times greater than white women. By contrast, only about 2% of psychiatrists are black. Out of 273,600 licensed psychologists in this country in 1986, only 10,000 were black. Ninety percent of the 3,209 doctorates in psychology in 1989 were awarded to whites.

Studies on diagnosis and treatment confirm what these statistics suggest: members of minorities are misdiagnosed far more often than white patients. The misdiagnosis usually takes the form of overdiagnosing schizophrenia in black patients; blacks are diagnosed with schizophrenia at almost twice the rate of white inpatients. Because schizophrenia is generally considered one of the most serious mental disorders, misdiagnosis may be one explanation for the fact that minorities are involuntarily committed to state institutions at a statistically disproportionate rate. Once there, black men are far more likely to be subject to seclusion than white men.⁵²

If we accept a social construct theory of disability, the logical progression is a move to a rights-based paradigm that focuses on the dignity of the individual and the responsibility of the State "...to

⁵² Susan Stefan, *Leaving Civil Rights to the "Experts": From Deference to Abdication Under the Professional Judgment Standard*, 102 YALE L.J. 639, 657 - 660 (1992) (footnotes omitted). T.W. Harding, of the Institute of Forensic Medicine, University of Geneva, has attributed failings in psychiatry partially to the context in which it originated:

It is important to recall several facts about the origins of psychiatry:

- (a) it was closely linked with legal and forensic medicine, and therefore associated with the judicial system and social control;
- (b) it developed largely outside academic centers of medicine; indeed, when the first chairs of psychological medicine were established in Berlin (Prof. Griesinger) and Edinburgh (Prof. Robertson), the basis of institutional psychiatry began to be questioned;
- (c) it adopted enthusiastically theories of criminal anthropology, in particular the concepts of degeneration and atavism, which underpin the concepts of innate dangerousness and untreatability.

Even modern, 'scientific' psychiatry has problems of ridding itself of the consequence of these dubious origins, which are still reflected in existing legal provisions.

See Harding, *supra* note 17, at 25.

tackle socially created obstacles in order to ensure full respect for the dignity and equal rights of all persons.”⁵³ Such a rights-based approach is an essential step forward in disability advocacy and must inform the drafting of the proposed Convention for it to be effective. This approach empowers persons with disabilities to transform what have traditionally been viewed as needs into claimable rights: “[i]n reorienting the focus from needs to rights, people with disabilities may be recognized as active rights-bearing individuals who are participants in their own development and who should be consulted accordingly in development decision-making.”⁵⁴

V. Recommendations in Drafting the Proposed Disability Rights Convention

While a Disability Rights Convention is needed and would be a move towards recognizing and protecting the rights of those with disabilities, “there is also a need for the drafters of any new disability rights instruments to proceed with caution.”⁵⁵ In particular, Rosenthal and Sundram have cautioned that in formulating a new instrument, regard must be had to existing instruments in order to avoid mistakes that have thwarted past attempts at codifying disability rights.⁵⁶ Indeed, while it might appear self-evident upon initial consideration, there is great peril in drafting a new instrument that provides *fewer* protections than existing instruments.⁵⁷

It is also necessary to remain mindful of the relationship between the ideal and the real. States and stakeholders advocating for the inclusion of particular protections and principles must consider how far ahead a human rights treaty can progress beyond what the international community is prepared to

⁵³ Quinn and Degener, *supra* note 28, at 14. Indeed, the disability rights movement has been referred to as the “next generation” civil rights movement. *Id.* at 15.

⁵⁴ NATIONAL COUNCIL ON DISABILITY, *supra* note 38. As stated by Quinn and Degener, *id.* at 296:

The need for a holistic approach to disability is consonant with the postulate that civil and political rights, on the one hand, and economic, social and cultural rights, on the other, are interdependent and interrelated... This is not the freedom of welfare, which places people with disabilities in gilded cages and locks them into cycles of dependency and despondency. It is economic, social and cultural justice, which liberates people with disabilities so that they can play their part in – and contribute their share to – inclusive societies.

⁵⁵ Rosenthal and Sundram, *supra* note 9, at 470.

⁵⁶ *Id.*

⁵⁷ *Id.*

accept. For example, the Migrant Workers Convention was essentially the result of states that regularly receive migrant workers capitulating to the demands of states from where migrant workers often originate (e.g. Mexico, the Philippines). It was, in fact, in the interests of the “receiving countries” to be non-responsive. Thus, though it came into force on July 1, 2003, no receiving countries have ratified it. At worst, the Convention can be seen as a sort of “ghost treaty” that will never have any real meaning. With this principle in mind, while disability-related NGOs admirably represented the perspectives of persons with disabilities at the Working Group Meeting, in general they did not come prepared to engage with states on legal issues. Rather, particular submissions (e.g. that the proposed Convention should have direct application to private parties and should create rights not previously recognized in international human rights law, rather than acknowledging that existing rights are applicable to persons with disabilities and focusing on how to implement them) served only to undermine NGO credibility and to unnecessarily raise the backs of states.⁵⁸

Progressive Realization

The issue of whether governments would be obligated to take immediate action to effect the provisions of the proposed Convention relating to economic and social rights is fundamental. The ICESCR provides that governments “undertake to take steps...with a view to achieving progressively the full realization of the rights recognized in the present Covenant”.⁵⁹ While Rosenthal and Sundram point to the “extensive body of jurisprudence and comment” interpreting the progressive realization requirement as involving some level of immediate obligation, it should be noted that such commentary

⁵⁸ See also WNUSP’s suggestion that the Convention should include a sort of paramountcy clause, where other international instruments that are “in contravention with or derogation of the provisions of this convention [are] deemed void ab initio.” SUBMISSION TO THE UNITED NATIONS AD HOC COMMITTEE ON A COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION TO PROMOTE AND PROTECT THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES (2003), available at <http://www.un.org/esa/socdev/enable/rights/contrib-wnusp.htm> (last visited Oct. 22, 2003) [hereinafter WNUSP SUBMISSION].

⁵⁹ ICESCR, *supra* note 19, Art. 2(1).

essentially stems from the Committee on Economic, Social and Cultural Rights' General Comment No. 3, which represents the Committee's interpretation of the ICESCR.⁶⁰ However authoritative, General Comments are not binding in law.⁶¹ I suggest that a more favorable approach would be to include a provision imposing immediate obligations where those obligations are within the state party's means:

In relation to the economic, social and cultural rights set forth in [Part III of] this Convention, States Parties undertake to give immediate effect to those aspects of those rights which are capable of immediate implementation (including, but not limited to obligations of non-discrimination in the enjoyment of those rights) and in relation to other aspects of those rights, to take steps to the maximum of their available resources with a view to achieving progressively the full realization of those rights by all appropriate means, including particularly the adoption of legislative measures.⁶²

Definition of Disability

As recognized by participants in the June 2003 Asian and Pacific regional expert group meeting held in Bangkok, there is a range of potential definitions of "disability" should the Committee elect to include a definition. Thus, in keeping with the social model of disability advocated by this article, it is essential that any "definition of disability should not be restrictive. For example it should cover physical, sensory, intellectual, psychiatric and multiple disabilities. It should acknowledge that disability can be permanent, temporary, episodic and perceived...[i]t has a range of implications for social identity and

⁶⁰ Committee on Economic, Social and Cultural Rights, General Comment No. 3, 5th Sess., U.N. Doc.E/1991/23 (1991).

⁶¹ Though it can be argued that states' acquiescence to General Comments over time allow them to form part of customary international law, this is far from satisfying: "Alston and Quinn... believe international jurisprudence effectively imposes immediate obligations on states to adopt strategies that will lead to the full realization of economic, social and cultural rights, as set out in this Covenant. Whilst this may be true as an abstract statement of international law, the reality is more pedestrian." Jeremy Cooper, *Improving the Civil Rights of People with Disabilities Through International Law*, in LAW, RIGHTS AND DISABILITY 193 (Jeremy Cooper, ed., 2000).

⁶² CHAIR'S DRAFT ELEMENTS OF A COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION ON PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES, Art. 2(1), available at <http://www.un.org/esa/socdev/enable/rights/wgcontrib-chair1.htm> (last visited Jan. 31, 2004) [hereinafter Chair's Draft]. Unfortunately, this provision in the Chair's Draft was not included in the Working Group Draft submitted to the Committee. See DRAFT COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION ON THE PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES, CRP.4, plus CRP.4/Add.1, Add.2, Add.4 and Add.5, available at <http://www.un.org/esa/socdev/enable/rights/ahcwgreportax1.htm> (last visited Jan. 31, 2004) [hereinafter Working Group Draft].

behaviour, and largely depends upon context.”⁶³ National Human Rights Institutions (“NHRIs”) from across Africa (including those from Kenya, Niger, Malawi, Mauritius, Rwanda, South Africa, Tanzania, Uganda and Zambia) met in Munyonyo-Kampala, Uganda in June 2003 to discuss the proposed Convention. The NHRIs have appropriately recommended that any definition of discrimination must “recognise the impact of dual or multiple discrimination faced by individuals such as women, children, refugees, minorities or persons with multiple disabilities or other status.”⁶⁴ With respect to those suffering from mental disability, perhaps the most important consideration besides inclusiveness is that any definition “...is comfortable both for people with disabilities who identify with medical terminology and diagnosis, and for those who reject medical terminology and identify with disability as a social and political category only.”⁶⁵

Equality and non-discrimination

Certain delegations to the Working Group preferred a treaty based on non-discrimination rather than one that adopts a comprehensive approach. For example, the European Union’s (EU) draft submission to the Working Group emphasizes issues of discrimination and equality of opportunity.⁶⁶ This was not, however, the preference of the majority of participants. Whichever way the Committee decides, undoubtedly the issue of discrimination is pertinent for those with any sort of disability and is particularly resonant for persons diagnosed with mental disabilities.⁶⁷

⁶³ BANGKOK RECOMMENDATIONS ON THE ELABORATION OF A COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION TO PROMOTE AND PROTECT THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES (2003), *available at* <http://www.worldenable.net/bangkok2003/recommendations.htm> (last visited Oct. 22, 2003) [hereinafter BANGKOK RECOMMENDATIONS].

⁶⁴ FINAL DECLARATION OF THE REGIONAL WORKSHOP ON PROMOTING THE RIGHTS OF PERSONS WITH DISABILITIES: TOWARDS A NEW UN CONVENTION (June 6, 2003), *available at* http://www.dpi.org/en/resources/topics/convention/documents/conv_FINAL-Declaration-Kampala-disability.pdf (last visited Oct. 18, 2003).

⁶⁵ WNUSP SUBMISSION, *supra* note 58.

⁶⁶ INTERNATIONAL CONVENTION ON THE FULL ENJOYMENT OF ALL HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS BY PERSONS WITH DISABILITIES, *available at* http://www.un.org/esa/socdev/enable/rights/a_ac265_2003_crp13_add2.htm (last visited Jan. 31, 2004).

⁶⁷ See Rosenthal and Sundram, *supra* note 10, at 472 – 473:

At the Working Group meeting, WNUSP (the sole accredited NGO representing the mental health consumer/survivor perspective) questioned the necessity of distinguishing between direct and indirect discrimination as advocated by the EU. It argued that such a distinction creates a sort of “loophole” for discrimination to exist and pointed out that CEDAW and CERD are silent on this issue. In other words, while a provision or policy that directly targets a historically disadvantaged group is not justifiable, specifying indirect discrimination necessarily leaves open the possibility that employers, service providers etc. will be able to establish a defense or justification for the discrimination.⁶⁸ As per WNUSP, this could pose a real danger for mental health consumer/survivors. Though not explicitly stated at the Working Group, the idea is that this “loophole” could be used, for example, to justify forced psychiatric hospitalization.

This position was echoed by Canada, though for reasons unrelated to mental disability. In the 1999 case of *British Columbia (Public Service Employee Relations Comm.) v. B.C.G.S.E.U.* (“*Meiorin*”),⁶⁹ the Supreme Court of Canada restructured the analytical approach to be applied in all discrimination cases. The Court noted that the distinction between direct and indirect, or “adverse effects,” discrimination was artificial, as most discrimination does not fit into such neat and well-defined categories. Given that the threshold distinction was difficult to establish, it was seen as problematic that divergent results flowed from the way the discrimination was characterized. The Court also pointed out that judges might purposely classify a rule as direct discrimination or adverse effect discrimination

[They] are often denied opportunities to receive an education, to work, or to enjoy the benefits of public services or other accommodations... In some countries, people with mental disabilities are subject to de jure discrimination - the arbitrary denial of rights that are afforded to all other citizens. Improper discrimination may also take place against people with no disability at all - if they are improperly viewed as having a mental disorder, or if they once experienced a mental disorder earlier in life.

⁶⁸ The EU presented this simple, but instructive, example: if a state agency were to mandate that individuals pass a sight test before obtaining a driver’s license, this might be neutral on its face (in other words, not direct discrimination), but have the indirect effect of discriminating against those who are visually impaired. However, the state should have the ability to argue that this restriction is necessary. The resulting text in the Working Group Draft reads as follows: “Discrimination does not include a provision, criterion or practice that is objectively and demonstrably justified by the State Party by a legitimate aim and the means of achieving that aim are reasonable and necessary.” See Working Group Draft, *supra* note 62 (Art. 7(3)).

⁶⁹ *British Columbia (Public Service Employee Relations Comm.) v. B.C.G.S.E.U.* [1999] 3 S.C.R. 3 (Can.).

depending on whether they preferred to see the rule preserved or struck down. In recognition of these issues, the Court decided to bring the two analytical approaches together such that the distinction between direct discrimination and adverse effects was irrelevant.⁷⁰

The problem with this approach is two-fold. First, whereas a defense to discrimination was previously only available with respect to indirect discrimination, with this reformulation, the duty to accommodate to the point of undue hardship is made a key element of any defense to a claim of discrimination (in other words, even in situations respecting direct discrimination). More importantly, *Meiorin* was situated within the context of discrimination based on sex. It is arguable that unlike other forms of discrimination, discrimination in the context of disability is rarely overt, but rather is embedded in cultures that do not accommodate disability.⁷¹ Thus, the utility of indirect discrimination is that it permits challenges to more covert forms of discrimination. While it is true that this leaves open the ability for a defense to indirect discrimination, this defense should be tightly circumscribed and should only become “live” after all efforts have been made to reasonably accommodate the difference of disability.

Perhaps the more interesting question, however, is the link between reasonable accommodation and disability. The duty of state parties to reasonably accommodate those with disabilities became one of the most debated and important aspects of the Working Group session. Without doubt, key ground was made. In the sub-group established by New Zealand Ambassador Don McKay (who acted as Coordinator of the Working Group) there was agreement among delegations on the need for a concept such as reasonable accommodation in the proposed Convention in order to secure compliance with the principle of non-discrimination. There was also widespread agreement on the need to keep the notion both general and flexible in order to ensure that it could be readily adapted to different sectors (e.g., employment,

⁷⁰ For support of this unified approach, see David M. Lepofsky, *The Duty to Accommodate: A Purposive Approach*, 1 CAN. LAB. L.J. 1 (1993).

⁷¹ See Rosenthal and Sundram, *supra* note 10, at 472 – 473: “In many cases, the laws do not actively discriminate against people with mental disabilities, but they may place improper or unnecessary barriers or burdens on individuals with mental disabilities.”

education, etc.) and in order to respect the diversity of legal traditions. Further, there was general agreement that the process of determining what amounts to a reasonable accommodation should be both individualized (in the sense that it should consciously address the individual's specific need for accommodation) and interactive as between the individual and the relevant entity concerned. It was also understood that the availability of state funding should limit the use of 'disproportionate burden' as a reason by employers and service providers not to provide reasonable accommodation.

However, there was strong disagreement over whether a failure to reasonably accommodate should itself constitute discrimination. Most notably, Ireland (which has presidency of, and thus represented, the EU), contrary to the Bangkok Recommendations and the Chair's Draft, was of the view that it would be out of place in a Convention such as the one proposed to dictate the manner by which the concept of reasonable accommodation should be achieved or framed under relevant domestic legislation. Contrary to this position, the link between a failure to reasonably accommodate and discrimination is what gives efficacy to the principle of non-discrimination and should not be left to the imagination.⁷² In that regard, General Comment No. 5 of the Committee on Economic, Social and Cultural Rights interprets reasonable accommodation as a corollary to non-discrimination by specifically containing a definition of disability that includes a "denial of reasonable accommodation based on disability..."⁷³

*States' Obligations*⁷⁴

In the context of states' obligations, the Mexico Draft is particularly useful with respect to mental disabilities. *Inter alia*, it includes provisions that would "prevent persons with disabilities from being

⁷² This argument was supported at the Working Group, *inter alia*, by delegations from Germany and the European Disability Forum.

⁷³ Committee on Economic, Social and Cultural Rights, General Comment No. 5, 11th Sess., U.N. Doc. E/C.12/1994/13 (1994).

⁷⁴ With respect to states' obligations in general Rehabilitation International argued at the Working Group that six overarching principles must be remembered: (1) states should take effective measures in both the legal and administrative spheres; (2) states should act to expunge laws that are not in harmony with the spirit of the proposed Convention; (3) states should ensure that failure to reasonably accommodate persons with disabilities constitutes discrimination; (4) states should take steps with a view towards mainstreaming disability; (5) states should include persons with disabilities and their representative organizations as partners in the design and review of all policies that relate to them; and (6) states should take steps to eliminate stereotypes regarding persons with disabilities.

subjected to any form of exploitation, abusive, or degrading treatment in hospitals and psychiatric institutions”⁷⁵ and would have both private and public psychiatric facilities “painstakingly monitored by the health authorities in order to ensure that the living conditions of and treatment administered to said institutions' patients are in keeping with respect for their dignity and human rights.”⁷⁶ The Mexico Draft also impressively provides unfettered access for psychiatric patients to their medical records,⁷⁷ but should be reworded so that this access is only provided to patients, not family members, unless patient approval is first obtained.

(i) The Right To Physical And Psychological Integrity

Perhaps the most pressing issue facing those diagnosed with a mental disability is the right to physical and psychological integrity. The two most salient aspects of this right involve forced psychiatric hospitalization and forced treatment. WNUSP has made its position on these issues very clear: “[t]he right to autonomy of mind and body, to reject unwanted treatments, is...crucial. The right to say "No" is central to the preservation of mental and bodily integrity.”⁷⁸ The implication of this position is that the Convention “should prohibit unwanted medical and related interventions as a form of torture or cruel, inhuman or degrading treatment or punishment...[and] prohibit any kind of confinement or internment based in whole or in part on disability.”⁷⁹

(ii) Forced Psychiatric Treatment

Certainly WNUSP’s position has traditionally been seen as being on the fringes, and

⁷⁵ TEXT OF ELEMENTS FOR A UNITED NATIONS COMPREHENSIVE AND INTEGRAL INTERNATIONAL CONVENTION TO PROMOTE AND PROTECT THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES, Art. 11, available at <http://www.sre.gob.mx/discapacidad/elements.htm> (last visited Oct. 22, 2003).

⁷⁶ *Id.* (Art. 12(c)).

⁷⁷ *Id.* (Art. 12(e)). The importance of this provision cannot be overstated. In countries such as Canada, physicians in particular provinces (for example, Ontario) are able to prevent patients from viewing their own records if disclosure of the clinical record is likely to result in “serious harm to the treatment or recovery of the patient while in treatment at the psychiatric facility”. This is an unacceptably ambiguous test that deprives patients of a most basic and essential right. See Mental Health Act, R.S.O. c. M.7 (1990).

⁷⁸ WNUSP SUBMISSION, *supra* note 58.

⁷⁹ *Id.* This position was supported at the Working Group by the delegations representing Inclusion International (an NGO that focuses on advocacy for the human rights of people with intellectual disabilities), the World Federation for the Deaf and Disabled Peoples’ International.

undoubtedly, it is the antithesis of the medical model.⁸⁰ Rosenthal and Sundram have observed that “[a]ctivists who are fighting for a ban on coercive treatment...may find it impossible to gain political support of language of this kind”,⁸¹ and further point to the need to “make practical compromises” in order to secure widespread ratification.⁸² The reality of this observation became apparent at the Working Group meeting, as the EU and states such as Canada, Japan, India and Sierra Leone expressed trepidation at a blanket prohibition on forced institutionalization and treatment.

In adopting an inflexible bargaining stance at the Working Group meeting, WNUSP missed a key opportunity to help shape the normative content of broad statements of rights that are more likely to be accepted by states. This opportunity was invaluable when considering that while the EU and the above-mentioned states supported the principle that such deprivations of liberty should not take place without appropriate legal safeguards, no delegation came to the Working Group with suggestions on what those safeguards, or the principles underlying them, should be. In an attempt to fill this gap as the Committee goes deeper into the drafting process, certain recommendations can be made. First, the only acceptable “practical compromises” would involve a governing principle that limits forced treatment to the rarest of occasions. The WHO’s “Principles” respecting mental health allude to this by stating that findings of

⁸⁰ At least with respect to forced treatment, however, the supplement proposed to the Standard Rules by former Special Rapporteur on Disability Bengt Lindqvist (which will come before the Commission on Social Development in February 2004), appears to lend support to this position:

States should recognize that persons with disabilities have the same right to self-determination as other citizens, including the right to accept or refuse treatment.

...

States should ensure that medical facilities and personnel inform people with disabilities of their right to self-determination, including the requirement of informed consent, the right to refuse treatment and the right not to comply with forced admission to institutional facilities. States should also prevent unwanted medical and related interventions and/or corrective surgeries from being imposed on persons with disabilities.

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 THIRD MANDATE, 2000-2002, 25, U.N. Document E/CN.5/2002/4.

⁸¹ Rosenthal and Sundram, *supra* note 9, at 492.

⁸² *Id.* at 493.

incapacity to make treatment decisions “will typically be the case *occasionally but not systematically*”.⁸³ Regard should also be had for the Council of Europe’s concept of “proportionality”, where any protective measures are required to be proportional to the needs of the individual concerned. In other words, there should be recognition of varying degrees of capacity. Such protective measures should also alter the “...rights and freedoms of the person concerned to the minimum extent which is consistent with achieving the purpose of the intervention.”⁸⁴ In these rarest of occasions where an individual is found to lack capacity to consent to treatment, treatment should only be administered with the consent of his/her legally authorized representative or substitute decision-maker. Further, if the individual expressed any prior instructions with respect to psychiatric treatment, at a time when he/she was capable, these previously expressed wishes must be respected.⁸⁵

Individuals who are to be the subject of forced treatment should be provided with alternatives to antipsychotic medications. It should not be presumed that chemical treatment modalities represent the only viable path. Rather, psychological science studies have further “...established conclusively that an intensive interpersonal intervention...within a “therapeutic community” context – and staffed by nonmedical, nonprofessional personnel – could substantially reduce the use of [neuroleptic medications].”⁸⁶

⁸³ Principle 4, MENTAL HEALTH CARE LAW: TEN BASIC PRINCIPLES (1996), *available at* http://www.who.int/mental_health/media/en/75.pdf (last visited Oct. 18, 2003) [emphasis added]. In reality, this is often far from the case. Ontario, Canada is often praised for having progressive mental health legislation. However, as co-counsel for the interveners Mental Health Legal Committee and Mental Health Legal Advocacy Coalition in *Starson v. Swayze*, the author submitted statistics to the Supreme Court of Canada demonstrating that the Ontario Consent and Capacity Board overwhelmingly rejects patients’ applications challenging psychiatrist’s findings of incapacity respecting treatment. In 2001, for example, there was a staggering 94 percent rejection rate. See Memorandum of Argument of the Proposed Intervenors, The Mental Health Legal Committee and The Mental Health Legal Advocacy Coalition (Motion For Leave To Intervene) at 11, *Starson v. Swayze* [2003] S.C.C. 32 (Can.) (No. 28799).

⁸⁴ COUNCIL OF EUROPE, PRINCIPLES CONCERNING THE LEGAL PROTECTION OF INCAPABLE ADULTS, RECOMMENDATION No. R (99) 4 Adopted by the Committee of Ministers on 23 February 1999 (Principle 6).

⁸⁵ These principle are reflected in Articles 6(3) and 9 of the Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, reprinted in 36 ILM 821 (1997).

⁸⁶ D. Cohen, *A Critique of the Use of Neuroleptic Drugs in Psychiatry*, in FROM PLACEBO TO PANACEA: PUTTING PSYCHIATRIC DRUGS TO THE TEST (S. Fisher & R. Greenburg, eds.) 173, 200 – 2001 (1997).

Since their introduction to psychiatry in 1952, neuroleptic or “antipsychotic” drugs such as haloperidol, chlorpromazine, olanzapine, risperidone and clozapine have been prescribed to millions of individuals diagnosed as suffering from various psychotic disorders. However, studies have concluded that these medications, described as “one of the most behaviorally toxic classes of psychotropic drugs”, enjoy no more than a 34% net effectiveness rate in terms of their ability to reduce relapse.⁸⁷ A remarkable WHO study shows a correlation between low reliance on antipsychotic medication and recovery. Beginning in 1969, this research identified patients diagnosed with schizophrenia in nine countries (China, Colombia, Czechoslovakia, Denmark, India, Nigeria, USSR, United Kingdom and the U.S.) and monitored their progress over the next eight years. The most striking result was that the patients from the three poorest countries (where doctors did not generally keep the patients on antipsychotics) did dramatically better than patients in the developed countries (where the majority of patients were kept on antipsychotics). At the five year mark, while more than 75 percent of patients in the three developing countries were either without symptoms or at least functioning fairly well, only 35 percent of the patients in the developed countries enjoyed a similar level of success.⁸⁸

The distressing side-effects of neuroleptic medications were discussed by the Honourable Mr. Justice Robins in the Canadian case of *Fleming v. Reid*:

[T]he efficacy of the drugs is complicated by a number of serious side effects which are associated with their use. These include a number of muscular side effects known as extra-pyramidal reactions: dystonia (muscle spasms, particularly in the face and arms, irregular flexing, writhing or grimacing and protrusion of the tongue); akathisia (internal restlessness or agitation, an inability to sit still); akinesia (physical immobility and lack of spontaneity); and Parkinsonisms (mask-like facial expression, drooling, muscle stiffness, tremors, shuffling gait). The drugs can also cause a number of non-muscular side effects, such as blurred vision, dry mouth and throat, weight gain, dizziness, fainting, depression, low blood pressure and, less frequently, cardiovascular changes and, on occasion, sudden death.

⁸⁷ *Id.* at 173 - 174, 192, 201-202.

⁸⁸ J. Leff, *The International Pilot Study of Schizophrenia: Five-Year Follow-Up Findings* 22 PSYCHOLOGICAL MED. 131 (1992); ROBERT WHITAKER, *MAD IN AMERICA: BAD SCIENCE, BAD MEDICINE, AND THE ENDURING MISTREATMENT OF THE MENTALLY ILL* 227-228 (2002). Whitaker, at 228-229, observes that this study was simply dismissed by Western psychiatrists and went unexplored given that it was “so threatening to Western medicine”.

The most potentially serious side effect of anti-psychotic drugs is a condition known as tardive dyskinesia. This is a generally irreversible neurological disorder characterized by involuntary, rhythmic and grotesque movement of the face, mouth, tongue, and jaw. The patient's extremities, neck, back and torso can also become involved. Tardive dyskinesia generally develops after prolonged use of the drugs, but it may appear after short term treatment and sometimes appears even after treatment has been discontinued.⁸⁹

After surveying the scientific literature, the United States Supreme Court in *Washington v. Harper* acknowledged that between 10 and 25 percent of all patients treated with antipsychotic medications display the symptoms of tardive dyskinesia.⁹⁰ Further, the notion that newer neuroleptic medications possess therapeutic advantages over older medications is by no means undisputed. Rather, it has been argued that there is no clear advantage to newer neuroleptic medications and that any perceived advantage is solely attributable to the fact that newer medications are less potent.⁹¹ Last, beyond the physiological repercussions, forced treatment with antipsychotic medications can have a more nuanced effect on the sense of self of persons diagnosed with mental disabilities:

A particular treatment decision may be contrary to deeply held social, medical, political or religious values of a person with a mental disability. Coerced treatment may violate an individual's sense of control over his or her life, health, and body. When professionals override a person's decisions about health care, treatment or services, this may strip a person of a sense that he or she is respected by medical or other public authorities. Once a person has been subjected to involuntary treatment in a mental health facility, he or she may never again feel safe or trusting of mental health or other government services. A person who is going through a period of great mental anguish and need may be particularly sensitive to feelings of this kind. While it may be hard to quantify the subjective feelings of humiliation and degradation caused by coercive treatment, there is no doubt that these feelings may be very intense.⁹²

⁸⁹ Fleming v. Reid (1991) 4 O.R. (3d) 74, 84 (Ont. C.A.). See also Cohen, *supra* note 86, at 204 – 207 and J. Ballesteros, A. González-Pinto & A. Bulbena, *Tardive Dyskinesia Associated with Higher Mortality in Psychiatric Patients: Results of a Meta-Analysis of Seven Independent Studies*, 20:2 J. OF CLINICAL PSYCHOPHARMACOLOGY 188, 193 (2000). For more on the harmful side-effects of antipsychotic neuroleptic medications see, generally, P. Breggin, *Brain Damage Dementia and Persistent Cognitive Dysfunction Associated with Neuroleptic Drugs: Evidence, Etiology, Implications* 11 J. MIND BEHAV. 425 (1990); PETER R. BREGGIN AND DAVID COHEN, YOUR DRUG MAY BE YOUR PROBLEM: HOW AND WHY TO STOP TAKING PSYCHIATRIC MEDICATIONS (1999); PETER R. BREGGIN, TOXIC PSYCHIATRY: WHY THERAPY, EMPATHY, AND LOVE MUST REPLACE THE DRUGS, ELECTROSHOCK, AND BIOCHEMICAL THEORIES OF THE “NEW PSYCHIATRY” (1994); Alexander Brooks, *The Right to Refuse Antipsychotic Medication: Law and Policy*, 39 RUTGERS L. REV. 339 (1987).

⁹⁰ *Washington v. Harper*, 494 U.S. 210, 230 (1990).

⁹¹ D.C. Smith, *Are Newer Antipsychotics Better?*, 3:1 ETHICAL HUM. SCI. SERVICES: INT’L J. CRITICAL INQUIRY 61 (2001).

⁹² Rosenthal and Sundram, *supra* note 10, at 524.

(iii) Forced Psychiatric Hospitalization

The proposed Convention should also limit forced psychiatric confinement to the rare situations where it can be clearly established that the individual, as a result of a mental disability, is either at risk of serious bodily harm to her/himself or others. However, given that these rationales for commitment are often inaccurately applied and not adhered to, I advocate language that is in harmony with Article 5(4) of the European Convention on Human Rights, which states that “Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.”⁹³ This sort of provision is particularly meaningful given that psychiatric review boards often deny those diagnosed with mental disabilities the benefit of procedural protections,⁹⁴ thus falling victim to the medical model assertion that these safeguards “...can work against the best interests of patients”⁹⁵ and that “...no benefit, to the patient, can be expected to result from challenging the validity of [an involuntary committal] certificate on a technicality.”⁹⁶ Further, it is essential that a physician’s determination of “dangerousness” leading to a forced psychiatric admission should not result in the automatic finding that an individual is also incapable of consenting to treatment or managing finances, and thus an accompanying loss of further rights.⁹⁷

⁹³ European Convention for the Protection of Human Rights and Fundamental Freedoms, November 4, 1950, 213 U.N.T.S. 221.

⁹⁴ In general, mental health jurisprudence has not evolved in a manner that affords the same level of procedural protection to individuals in the criminal justice systems. As argued by one commentator in the Canadian context: “...courts have been overly reliant on a paternalistic model of mental health law and that such reliance has led to the under-development of procedural protections for individuals facing involuntary commitment.” See I. Grant, *Mental Health Law and the Courts*, 29 OSGOODE HALL L.J. 747, 749 (1991).

⁹⁵ J.E. Gray, R.L. O’Reilly & G.W. Clements, *Protecting the Rights of People with Mental Disabilities: Can we Achieve both Good Legal Process and Good Clinical Outcomes?*, 23:2 HEALTH L. IN CANADA 25, 26 (2002).

⁹⁶ *Id.* at 30. For a refutation of this position, see Aaron A. Dhir, *The Maelstrom of Civil Commitment in Ontario: Using Examinations Conducted During Periods of Unlawful Detention to Form the Basis of Subsequent Involuntary Detention under Ontario’s Mental Health Act*, 24:2 HEALTH L. IN CANADA (2003).

⁹⁷ For example, in the Canadian province of British Columbia, treatment is “deemed to be given with the consent of the patient” held involuntarily in a psychiatric facility. See Mental Health Act, R.S.B.C. c. 288, s. 31(1) (1996).

(iv) Justiciability and Monitoring

The liberty interests at stake under the right to bodily and psychological integrity underscore the need for clear provisions on justiciability⁹⁸ and a strong monitoring mechanism. With respect to the former, the strongest statement currently exists in the ICCPR, which requires states to “develop the possibilities of judicial remedy”.⁹⁹ With regard to the Disability Rights Convention, stronger wording is preferable: “[t]he rights guaranteed by the convention must give rise to enforceable remedies in national tribunals, and states must also accept an obligation to protect against violation of rights by non-governmental agents.”¹⁰⁰ This position was echoed by the Bangkok Recommendations, which state that “[t]here should be enforcement mechanisms, including provision of remedies, within institutional and/or judicial systems.”¹⁰¹

The Working Group did not have time to address the issue of an international monitoring mechanism for the potential Convention, which will thus be left for the Committee. The type of mechanism which might be established should not only satisfy the desire to have strong follow-up, but also meet the concern of avoiding the counter-productive repetition of existing mechanisms (given that states will undoubtedly argue that further treaty obligations will create an unfair and unmanageable burden and that a Convention that overlaps with existing instruments will create confusion for states with respect to their obligations).

The proposed Convention will be the first to be negotiated after the current UN reform initiatives respecting treaty monitoring began.¹⁰² These reforms will consider, *inter alia*, the concept of a “core

⁹⁸ “[W]hether the courts can...provide a remedy for aggrieved individuals claiming a violation of those rights”. Henry J. Steiner and Philip Alston, *INTERNATIONAL HUMAN RIGHTS IN CONTEXT: LAW, POLITICS, MORALS*, 275 (2nd ed. 2000).

⁹⁹ ICCPR, *supra* note 18 (Art. 2(3)(b)).

¹⁰⁰ WNUSP SUBMISSION, *supra* note 58. In British Columbia, instead of being afforded the right to challenge the “deemed consent” (referred to in footnote 97) before a court or tribunal, the patient is given only the opportunity to “request a second medical opinion on the appropriateness of the treatment authorized”. It is notable that the second opinion relates only to the appropriateness of the treatment, not the administration of treatment itself. See *Mental Health Act, R.S.O. c. M.7, s. 31(2)* (1990).

¹⁰¹ BANGKOK RECOMMENDATIONS, *supra* note 63.

¹⁰² Set against the backdrop of these reforms, it is possible that the eventual final text could be three to four years away.

expanded document”, whereby states would be required to submit one comprehensive report that speaks to the state’s core obligations under all relevant human rights treaties. Though the single-report suggestion will likely be resisted by most states (preferring instead a more fragmented approach) and Committee members themselves (who have a vested interest in maintaining the status quo), this initiative should be regarded as a positive step in human rights monitoring as it would result in the public placing a heightened level of importance on the report, forcing states to take such reports more seriously.

International instruments currently contain two primary mechanisms to monitor government compliance: state reporting and individual complaints. In the event that the idea of a “core expanded document” does not find favor, one alternative to the present treaty monitoring body system would be to set-up an Ombudsperson’s office to receive and investigate complaints arising from the Convention.¹⁰³ Indeed, if we view human rights monitoring broadly, to include “...observing events, visiting sites and holding discussions with government authorities to obtain information and to pursue remedies”,¹⁰⁴ arguably, an Ombudsperson is in a much better position to fulfill these tasks than a treaty-based committee. With respect to economic, social and cultural rights, an Ombudsperson’s office could also undertake budget analysis and track statistics in order to monitor state compliance.¹⁰⁵ However, even with an Ombudsperson, there would be reason to remain skeptical given that generally “their remedial powers are usually recommendatory rather than binding, and their ability to effect compliance rests

¹⁰³ “Several international organizations have successfully established ombudspersons. The EU, for example, has created an Ombudsman who has over the years established himself as an indispensable feature of EU governance.” See Florian Hoffmann & Frédéric Mégret, *Fostering Human Rights Accountability: An Ombudsperson for the United Nations?*, GLOBAL GOVERNANCE (forthcoming 2004).

¹⁰⁴ Disability Rights Promotion International, PHASE I REPORT: OPPORTUNITIES, METHODOLOGIES, AND TRAINING RESOURCES FOR DISABILITY RIGHTS MONITORING 27 (October 2003).

¹⁰⁵ Obviously, such an undertaking need not be limited to the work of an Ombudsperson. For a discussion on the use of budget analysis in general, see Jim Shultz, *Promises to Keep: Using Public Budgets as a Tool to Advance Economic, Social and Cultural Rights* (2002), available at <http://www.internationalbudget.org/themes/ESC/FullReport.pdf> (last visited Jan. 31, 2004). UNIFEM’s “Gender Responsive Budget Analysis” is illustrative of how budgets may be studied to focus on the rights of particular vulnerable groups. See *What is Gender Responsive Budget Analysis?*, available at http://www.unifem.org/index.php?f_page_pid=19 (last visited Jan. 31, 2003). In fact, at the Working Group Meeting, Lebanon argued that states should be obliged to prepare their national budgets with their Convention obligations in mind.

primarily on the publicity of their reports, rather than on formal prosecutorial competences.”¹⁰⁶ For example, while the “Swedish Disability Ombudsman” has the power to receive, examine and investigate reports from persons alleging that they have been excluded or discriminated against on the grounds of disability, with respect to ensuring compliance, he is particularly impotent: “[He] may contact other authorities, businesses or organisations in order to achieve an improvement for people with disability. If the matter involves inadequacies in current legislation...[he] can draw the attention of the Government to this.”¹⁰⁷ Thus, it is perhaps best to conceive of the Ombudsperson as working alongside the committee structure, rather than acting as a substitute.

Most radical, however, is the draft Convention produced by Professor Scheinin of Åbo Akademi University’s Institute for Human Rights (Finland). Scheinin’s draft omits any mention of a new committee for the proposed Convention. Instead, it proposes a disability Ombudsperson who would represent claimants in submitting communications under the existing treaties that allow for petitions (i.e. CERD, ICCPR and CEDAW).¹⁰⁸ This is a fascinating suggestion that is worthy of consideration during the Committee’s deliberations. Indeed, the position of this paper is that existing Convention-based rights have direct relevance to those diagnosed with disabilities, but that oversight bodies systemically ignore disability-related issues. The establishment of an Ombudsperson to represent claimants has the potential of remedying this problem, while at the same time helping to avoid the counter-productive repetition of existing mechanisms.

If a more traditional committee structure is established, it must be part of a strong monitoring framework “to gauge the levels of implementation and provide guidance on best practices. This monitoring mechanism should be empowered to engage all relevant levels, including states,

¹⁰⁶ Hoffmann & Mégret, *supra* note 103.

¹⁰⁷ See <http://www.ho.se/start.asp?lang=en&sida=996> (last visited Jan. 31, 2003).

¹⁰⁸ DRAFT INTERNATIONAL CONVENTION ON THE FULL ENJOYMENT OF ALL HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS BY PERSONS WITH DISABILITIES, Arts. 9 – 10, *available at* http://www.abo.fi/instut/imr/research/Scheinin_draft_convention.doc (last visited Jan. 31, 2003).

intergovernmental organizations, non-governmental organizations and individuals.”¹⁰⁹ The monitoring body should be empowered not only to accept and evaluate mandatory reports, but also to hear complaint petitions from individuals and NGOs and conduct its own investigations into alleged breaches of the Convention. Admittedly, and in harmony with my comments above respecting the need to remain mindful of the relationship between the ideal and the real, the establishment of a right to petition may have to come in the form of an Optional Protocol, especially given that the proposed Convention will include not only civil and political rights, but economic and social rights as well.¹¹⁰ Perhaps even more important than providing a sort of mechanism by which to seek a “remedy”, a complaint procedure would hopefully result in a line of jurisprudence from the oversight committee that would provide a coherent set of principles which would inform the interpretation of the proposed Convention. Last, it is essential that the committee assigned the monitoring role be composed of human rights experts,¹¹¹ and include those with disabilities. In this regard, article 7 of the Kallehaug Draft reads as follows:

...there shall be established a Committee on the Rights of Persons with Disabilities, which shall carry out the function hereinafter provided.

The Committee shall consist of 12 disability experts of high moral standing and recognised competence. The members of the committee shall be elected by the States Parties from among their most prominent national leaders of *organisations of disabled persons*, scholars and scientists and shall serve in their personal capacity, consideration being given to gender and equitable geographical distribution as well as to various kinds of impairment.¹¹²

¹⁰⁹ DISABLED PEOPLES' INTERNATIONAL, POSITION PAPER REGARDING A NEW INTERNATIONAL HUMAN RIGHTS CONVENTION FOR DISABLED PEOPLE, (2003) *available at* http://www.dpi.org/en/resources/pdfs/03-04-09-1_Position_Paper_Draft3.pdf (last visited Oct. 18, 2003).

¹¹⁰ The Working Group on the draft Optional Protocol to the ICESCR is scheduled to have its first meeting beginning on February 23, 2004. In fact, it was argued almost a decade ago “...that the time is ripe for a fundamental change of policy” regarding the position that economic, social and cultural rights are not appropriate for an individual complaints procedure. See Philip Alston, *Establishing a Right to Petition Under the Covenant on Economic, Social and Cultural Rights*, in COLLECTED COURSES OF THE ACADEMY OF EUROPEAN LAW, Vol. IV, Book 2, 107, 115 (1995).

¹¹¹ As discussed by Bodansky with respect to reporting obligations in environmental regimes, the use of an ad hoc team of experts rather than a single commission or committee could allow for more in-depth review. See Daniel Bodansky, *Reporting Obligations in Environmental Regimes: Lessons for Human Rights Supervision*, in THE FUTURE OF UN HUMAN RIGHTS TREATY MONITORING 361 (Philip Alston and J. Crawford, eds., 2000).

¹¹² Quinn and Degener, *supra* note 28 at 297.

¹¹² DRAFT CONVENTION ON THE FUNDAMENTAL RIGHTS OF PERSONS WITH DISABILITIES, *available at* http://www.dpi.org/en/resources/topics/convention/06-13-03_Denmark_Draft.htm (last visited Oct. 18, 2003) [emphasis added]. There is no reason why the idea of representation of disabled persons on the monitoring body should not be equally applicable to national tribunals that govern decisions relating to disability. In Ontario,

VI. Conclusion

Though there are detailed international human rights mechanisms that are applicable to persons with mental disabilities, in practice these persons face major impediments to protections respecting the sanctity of bodily and psychic integrity. They are subjected to discrimination and degrading abuses of their rights on a daily basis.

A disability-specific Convention would serve to fill a glaring omission in the international framework, in addition to providing beneficial effects via the very treaty-making process itself. However, in order to reach its full potential, any such Convention must reject the traditional medical-model of disability and adopt a reformulation of disability as a social construct, thus reflecting a rights-based paradigm. While the social theory of disability has been widely accepted in respect of other forms of disability, the medical-model still governs mental disability. While the complete prohibition on forced treatment and committal advocated by particular NGOs is unrealistic, certain provisions/principles will ensure that the proposed Convention promotes a rights-based model. Namely, forced treatment interventions should be limited to the rarest of occasions and incapacity findings should recognize varying degrees of capacity. Previously expressed wishes regarding treatment must be respected and individuals who are the subject of forced treatment should be provided with alternatives to antipsychotic medications. It should not be presumed that chemical treatment modalities represent the only viable path.

The proposed Convention should also limit forced psychiatric confinement to the rare situations where it can be clearly established that the individual, as a result of a mental disability, is either at risk of serious bodily harm to her/himself or others. Individuals subjected to such detention should have the right to administrative or judicial review in a timely manner. Further, a physician's determination of

Canada, the Consent and Capacity Board ("the Board") typically sits as a panel of three (one lawyer member, one psychiatrist member and one lay member). There is no requirement that persons with disabilities be represented. While some may argue that the composition of an administrative review tribunal should reflect the principle of neutrality, the presence of a psychiatrist member demonstrates that the Board should also reflect a degree of expertise. Indeed, the expertise of the Board is a factor that courts rely on in giving deference to Board decisions on appeal. See *I.T. v.L.L. (a.k.a. C.) and T.C.* (1999) 46 O.R. (3d) 284 (Ont. C.A.). It should also be noted that while lawyer members of the Board are permitted to sit alone, there is no statutory requirement that they have experience before the Board prior to their appointments, or that they practice in the fields of administrative law or any form of

“dangerousness” leading to a forced psychiatric admission should not result in the automatic finding that an individual is also incapable of consenting to treatment or managing finances, and thus an accompanying loss of further rights. These key provisions, and this article’s recommendations respecting monitoring and the link between the failure to reasonably accommodate and discrimination, should not be sacrificed by drafters, lest any future Convention be rendered a hollow mechanism that serves only to perpetuate the problems it seeks to ameliorate.

litigation. Thus, lawyer members sitting alone need not have any experience or training in tribunal procedure or evidence. See Health Care Consent Act, 1996, S.O. c. 2, Sch. A, ss. 73(2) (1996).