Department of Mental Health and
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THE ROLE OF INTERNATIONAL HUMAN RIGHTS IN NATIONAL MENTAL HEALTH LEGISLATION

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By

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Introduction

Over the last half century, the importance of human rights has been recognized progressively by the international community, commencing with the adoption of the Universal Declaration of Human Rights in 1948 and followed periodically by human rights conventions which more specifically address certain aspects of human rights. At present, no convention addresses the special concerns of individuals with disabilities or the subgroup of people with mental disabilities. On November 28, 2001, however, the United Nations General Assembly adopted a resolution calling for the creation of an Ad Hoc Committee "to consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities...."[3] Encouraged by "the increasing interest of the international community in the promotion and protection of the rights and dignity of persons with disabilities," the United Nations General Assembly acted out of concern for the "disadvantaged and vulnerable situation faced by six hundred million persons with disabilities around the world…." Thus, the General Assembly's action responds to "the need to advance in the elaboration of an international instrument."[4]

It is not yet certain that the United Nations will adopt an international convention on the rights of people with disabilities, and even if it does so, governments will have to ratify a convention before it becomes legally binding. This process is likely to take years. Until that time, governments are under an obligation to abide by the requirements of existing international human rights conventions and customary international law. The adoption of domestic legislation that conforms to the requirements of international standards is one of the most important ways governments can meet their obligations to people with mental disabilities under existing international human rights law. This document provides a broad overview of some of the most important protections that now exist under international human rights law for people with mental disabilities. Every government should review its domestic legislation against the standards articulated in international human rights law, especially to the extent that such legislation affects the exercise of power and discretion by each government and its agents with regard to people with mental disabilities.

The United Nations has appointed three Special Rapporteurs on Human Rights and Disability who have found that people with mental disabilities experience some of the harshest conditions of living that exist in any society.[5] Some of this is the by-product of economic

[3] G.A. Res. 56/119, 28 November 2001, UN Doc. A/C.3/56/L.67/Rev.1, para. 1.

[4] *Id.* at preamble.

[5] The current Special Reporter on Disability is Bengt Lindqvist, appointed by the Economic and Social Council to monitor the implementation of the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities. *See* UN Economic and Social Council Resolution 2000/10, UN Doc. No. E/RES/2000/10., 27 July 2001. Lindqvist's

marginalization. Much of the hardship experienced by people with mental disabilities, however, is caused by discrimination and the absence of legal protections against improper and abusive treatment. 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.

People with mental disabilities are often denied opportunities to receive an education, to work, or to enjoy the benefits of public services or other accommodations. 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. 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.

In a number of countries, there are no domestic laws that address the support, care or treatment of people with mental disabilities or that ensure people have an opportunity to participate fully in the community. Notwithstanding the absence of a specialized convention on the rights of people with mental or physical disabilities, there is in fact a growing body of international human rights law that requires governments to take action in these areas.

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report is available on the web at <http://www.un.org/esa/socdev/enable/dismsre1.htm>. As part of the Decade for Disabled Persons from 1983 to 1992, the UN Human Rights Commission appointed two special rapporteurs, Leandro Despouy and Erica-Irene Daes. United Nations, Economic and Social Council, Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, HUMAN RIGHTS AND DISABILITY, U.N. Doc. E/CN.4/Sub.2/1991/31 (prepared by Leandro Despouy) [hereinafter Despouy Report]. United Nations, Economic and Social Council, Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, PRINCIPLES, GUIDELINES, AND GUARANTEES FOR THE PROTECTION OF PERSONS DETAINED ON GROUNDS OF MENTAL ILL-HEALTH OR SUFFERING FROM MENTAL DISORDER, U.N. Doc. E/CN.4/Sub.2/1983/17 (prepared by Erica-Irene Daes)[hereinafter Daes Report]. Independent non-governmental organizations have also documented human rights abuses in a number of countries. *See, e.g.* Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: MEXICO (2000), Mental Disability Rights International, CHILDREN IN RUSSIA'S INSTITUTIONS: HUMAN RIGHTS AND OPPORTUNITIES FOR REFORM (1999), Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: HUNGARY (1997), Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: URUGUAY (1995). *SEE:* AMNESTY INTERNATIONAL URGENT ACTION ON BULGARIA AT HTTP://WWW.AMNESTY.ORG]. *See ALSO* LOS DERECHOS HUMANOS DE LAS PERSONAS CON DISCAPACIDAD (compiled by Rodrigo Jimenez, 1996).

The requirements of international human rights law should be a major consideration in any legislation concerning people with mental disabilities[6] or regulating mental health and social service systems. Article 1 of the Universal Declaration of Human Rights, adopted by the United Nations in 1948, provides that "all people are free and equal in rights and dignity"[7] – establishing that people with mental disabilities are protected by human rights law by virtue of their basic humanity. The United Nations adopted the Universal Declaration of Human Rights as:

> a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance....[8]

While the Universal Declaration of Human Rights establishes a fundamental set of human rights that applies to all nations, the UN drafted two international human rights conventions to promote

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[6]The term "mental disabilities" is a broad term that includes people with disabilities caused by a mental disorder (such as people with a diagnosis of mental illness or with intellectual or developmental disabilities). Since many people are subject to discrimination based upon the improper perception that they have a current or past mental disorder, a well-crafted mental disability rights law will also protect people who have no disability or mental illness. Thus, the term "mental disability" in this document refers to any person who may be subject to discrimination on the basis of a perception that he or she is disabled or subject to a mental disorder. The document refers to individuals with mental disabilities because some of the most important rights under international law are enshrined in international instruments as disability rights. For example, the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities (StRe) refers to people with disabilities. Under the StRE "[t]he term 'disability' summarizes a great number of different functional limitations occurring in any population...People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature." Annex to UN General Assembly Resolution 48/96, 20 December 1993, Introduction, para. 17. The United Nations Committee on Economic, Social, and Cultural Rights, established to interpret the International Covenant on Economic, Social, and Cultural Rights (ICESCR), adopted this approach in General Comment No. 5, UN Doc. E/1993/22, 11th Sess., 9 December 1994, par. 3. The current WHO definition of disability, the second edition of the International Classification of Disabilities (or ICD 2) can be found on the web. World Health Organization, *International Classification of Functioning & Disability* (visited Jan. 22, 2002), <http://www.who.int/m/topics/icf/en/index.html>.

[7] G.A. Res. 217A (III), UN Doc.A/810 at 17 (1948).

[8]*Id.* at preamble.

the implementation and oversight of the rights it established. The two core UN human rights conventions are the International Covenant on Civil and Political Rights (ICCPR)[9] and the International Covenant on Economic, Social, and Cultural Rights (ICESCR).[10] Together with the Universal Declaration of Human Rights, they make up what is known as the "International Bill of Rights."[11]

Over the last half century, a number of additional human rights conventions (also known as treaties, covenants, or pacts) have been drafted and have been widely ratified by countries around the world. In Africa,[12] the Americas,[13] and Europe,[14] regional human rights conventions

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[9] G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No.16) 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, *entered into force* 23 Mar. 1976.

[10] G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No.16) 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, *entered into force* 3 Jan. 1976.

[11] "The International Bill of Human Rights comprises the most authoritative and comprehensive prescription of human rights obligations that governments undertake in joining the U.N." David Weissbrodt, Joan Fitzpatrick, and Frank Newman, INTERNATIONAL HUMAN RIGHTS: LAW, POLICY, AND PROCESS 9 (3d edition, 2001). *See generally, The International Bill of Rights* (Louis Henkin, ed., 1981) (a collection of essays describing the history, interpretation, and application of the International Bill of Rights).

[12] African Charter on Human and Peoples' Rights, adopted 27 June 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), *entered into force* 21 Oct. 1986. In addition to the general protections under the convention, the African Charter is the only one of the three regional conventions that explicitly creates special protections for people with disabilities. Article 18(4) of the African Charter states that "the disabled also have the right to special measures of protection in keeping with their physical and moral needs."

[13]American Convention on Human Rights, adopted 22 Nov. 1969, O.A.S. Treaty Series No. 36, 1144 U.N.T.S. 222, *entered into force* 3 Sept. 1953, *reprinted in* Basic Documents Pertaining to Human Rights in the Inter-American System, OEA/Ser.L.V./II.82 doc.6 rev.1 at 25 (1992).

[14]European Convention for the Protection of Human Rights and Fundamental Freedoms, 213 U.N.T.S. 222, *entered into force* 3 Sept 1953. (hereinafter ECHR) The ECHR is a convention of the Council of Europe, made up of 43 countries in Eastern as well as Western Europe. The Council of Europe recently adopted the 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, 4, April, 1997. This convention includes a right to informed consent for people with mental disabilities that is stronger than the MI Principles adopted by the UN General Assembly. *See* Council of Europe, *Convention for the*

have been established. The European and Inter-American regional systems are particularly important because they have the most highly developed mechanisms for implementation.[15]

In addition to regional human rights systems, a number of specialized conventions have been established through the United Nations to provide the detailed and specific provisions needed to protect the rights of people who may be particularly vulnerable to discrimination and abuse – including women,[16] children,[17] workers,[18] and people subject to custody or detention.[19] Politically, specialized conventions are important because they draw regular attention to the concerns of marginalized populations who may be overlooked by the mainstream human rights system.

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 (visited Jan. 22, 2002) <http://conventions.coe.int/treaty/en/treaties/html/164.htm>.

The Treaty of Amsterdam also creates a new area of rights that can be regulated by the European Union (EU). While the Treaty of Amsterdam does not itself protect against discrimination, it opens up a new area of international disability rights law that can develop within the EU. *See* Gerard Quinn, *The Human Rights of People with Disabilities under European Union Law*, *in* THE EU AND HUMAN RIGHTS 281 (Philip Alston, ed., 1999).

[15] For an overview of the operation of the European system of human rights and its application to people with mental disabilities, *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). *See also* T.W. Harding, The Application of the European Convention of Human Rights to the Field of Psychiatry, 12 Int'l J. L. & Psychiatry 245 (1989).

[16] 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* 3 Sept. 1981. (hereinafter CEDAW).

[17] International 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* 2 Sept. 1990. (hereinafter CRC)

[18] Convention Concerning Discrimination in Respect of Employment and Occupation, (ILO No. 111), 362 U.N.T.S. 131, *entered into force* 15 June 1960; Convention Concerning Vocational Rehabilitation and Employment (Disabled Persons)(ILO No. 159), *entered into force* 20 June, 1983; Convention Concerning Vocational Guidance and Vocational Training in the Development of Human Resources (ILO No.142), *entered into force* 19 July 1977.

[19] Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, G.A. Res. 39/46, annex, 39 U.N. GAOR Supp. (No. 51) at 197, U.N. Doc. A/39/51 (1984), *entered into force* June 26, 1987.

While international human rights law has grown tremendously over the last thirty years, the development of international law to protect specifically the rights of people with mental disabilities has been relatively slow and limited. Human rights oversight bodies that monitor the mainstream conventions and establish reporting guidelines have dedicated little attention to the rights of people with mental disabilities.[20] The lack of language that pertains specifically to people with mental disabilities in the International Bill of Rights and other mainstream conventions has long hampered the application of these conventions to people with mental disabilities. As a practical matter governments that have ratified the International Bill of Rights, as well as activists and mental health professionals, simply do not know what the specific requirements of international conventions are as they apply to people with mental disabilities.

In recent years, there have been a number of important developments that greatly aid the application of convention-based rights. In 1991, the United Nations General Assembly adopted the "Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care" (the MI Principles).[21] As this document will describe, the MI Principles are a non-binding UN General Assembly resolution, but they can be used as a guide to the interpretation of related provisions of international human rights conventions.[22]

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[20] Philip Alston, a member of the UN Committee on Economic, Social, and Cultural Rights mandated by the ICESCR to oversee the implementation of the convention, has stated that "[i]nternational human rights forums have been generally unresponsive to the situation and specific needs of persons with disabilities." Philip Alston, *Disability and the International Covenant on Economic, Social and Cultural Rights, in* Theresia Degener, "Disabled Persons and Human Rights: The Legal Framework" *in* HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN RIGHTS INSTRUMENTS 94 (Theresia Degener and Yolan Koster-Dreese, eds., 1995).

[21] G.A. Res. 46/119, 46 U.N. GAOR Supp. (No. 49) Annex at 188-192, U.N. Doc. A/46/49 (1991).

[22]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) (describing the use of the MI Principles as a guide to the interpretation of related provisions of human rights conventions). The Inter-American Commission on Human Rights adopted this analysis in the case of *Victor Rosario Congo*, the first case on the rights of a person with mental illness under the American Convention. *The Case of Victor Rosario Congo,* Inter-American Commission on Human Rights Report 29/99, Case 11,427, Ecuador, adopted in Sess. 1424, OEA/Ser/L.V/II.) Doc. 26, March 9, 1999, para. 54. *See* Fn.79 and accompanying text, *infra*. General Comment 5, *supra* n.6, recognizes the importance of the MI Principles and uses it as a guide to the requirements of certain provisions of the ICESCR.

In 1993, the World Conference on Human Rights meeting in Vienna reemphasized the fact that people with mental and physical disabilities are protected by international human rights law and that governments must establish domestic legislation to realize these rights. In what has come to be known as the "Vienna Declaration," the World Conference declared that "all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities."[23] The Vienna Declaration goes on to state:

> The World Conference on Human Rights calls on Governments, where necessary, to adopt or adjust legislation to ensure access to these (life, welfare, education, work, living independently and active participation in all aspects of society) and other rights for disabled persons.

Pursuant to the recommendations of the World Conference on Human Rights, the United Nations General Assembly adopted a new resolution, the "Standard Rules on Equalization of Opportunities for Persons with Disabilities" ("Standard Rules"). The Standard Rules are a revolutionary new international instrument because they establish citizen participation by people with disabilities as an internationally recognized human right. To realize this right, governments "*are under an obligation*" to provide opportunities for people with disabilities, and organizations made up of people with disabilities, to be involved in drafting new legislation on matters that affect them.[24] The Standard Rules call on every country to engage in a national planning process to bring legislation, policies, and programs into conformity with international human rights standards.[25]

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[23] Vienna Declaration and Program of Action, World Conference on Human Rights, Vienna, 14-25 June 1993, U.N. Doc A/CONF.157/24, para. 63.

[24] Standard Rule 15(1)(emphasis added). The Rule states in full:

> National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as the ongoing evaluation of that legislation.

The term "organizations of persons with disabilities" refers to organizations made up of and controlled by people with disabilities themselves. The role of such organizations in government is described further in Rule 18. Rule 15 provides additional guidance to governments in the legislative reform process, recommending that existing legislation be reviewed to incorporate disability rights principles and that specialized new legislation be adopted where necessary. *See* Rule 15 (2-4).

The United Nations established a monitoring mechanism "to further the effective implementation of the rules"[26] and authorized the establishment of a Special Rapporteur to report to the UN Commission on Social Development regarding the implementation of the Standard Rules.[27] The current Special Rapporteur on Disability is Bengt Lindqvist of Sweden.[28]

While the MI Principles and the Standard Rules provide detailed guidance to legislators as to the requirements of international human rights law, the fundamental obligations of governments are established by the international human rights conventions. Human rights conventions require governments to report regularly on the legislation they adopt and the policies they establish to implement the provisions of conventions. Until recently, few governments have reported on the steps taken to ensure realization of the rights of people with mental or physical disabilities. As part of the World Program of Action Concerning Disabled Persons in the 1980's, the UN General Assembly called on all "States parties to the International Covenants on Human Rights [to] pay due attention, in their reports, to the application of the Covenants to the situation of disabled persons."[29]

After years of neglect, the UN Human Rights Commission, the UN General Assembly and international human rights oversight bodies have taken a stand on the need for all governments to enforce human rights conventions with respect to people with disabilities. In April 2000, noting the continuing dearth of reporting on the rights of people with disabilities, the UN Human Rights Commission adopted resolution 2000/51.[30] In the resolution, the Commission "urges Governments to cover fully the question of the human rights of persons with disabilities in complying with the reporting obligations under the relevant United Nations instruments." The Commission has invited the UN High Commissioner on Human Rights, in cooperation with the Special Rapporteur on Disability "to examine measures to strengthen the protection and

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[25] "States should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status." *Id.*, Rule 14.

[26] *Id.* at Part IV, ¶ 1.

[27] *Id.* at Part IV, ¶ 2.

[28] Lindqvist's term was extended by the UN Economic and Social Council for one more year through 2002. Resolution 2000/10, 27 July 2001, *supra* note 5.

[29] World Program of Action, UN doc. A/37/52 (3 December 1982) at 9. The UN General Assembly specifically called on countries to report on the enforcement of the rights of people with disabilities under the ICCPR and the ICESCR.

[30] Human Rights Commission, E/CN.4/RES/2000/51, ¶ 13.

monitoring of the human rights of persons with disabilities....”[31] The United Nations General Assembly will take these recommendations into consideration through the work of the Ad Hoc Committee that is considering proposals for a convention on the rights of people with disabilities.[32]

With the adoption of the MI Principles and the Standard Rules in 1990 and the recent attention to convention-based rights, human rights standards for people with mental disabilities are evolving rapidly through the United Nations human rights systems. Even if a new convention is not adopted, the rapid growth in attention to the human rights of people with mental disabilities suggests that new standards may be adopted in the near future that will further facilitate the enforcement of human rights under existing international conventions.

This document will review international human rights law to provide a resource to legislators, policy-makers, mental health professionals and activists about government obligations that should be reflected in domestic mental health and disability rights legislation. The document will review a few of the most important convention-based rights and United Nations human rights standards, such as the MI Principles and the Standard Rules. It will describe how these standards can be used as a guide to the requirements of international human rights conventions.

This document will concentrate primarily on the requirements of the International Bill of Rights (the Universal Declaration of Human Rights, ICCPR and the ICESCR). The Universal Declaration is the most widely respected human rights instrument and is considered by many scholars to be binding customary international law in all nations.[33] The ICCPR and the ICESCR are conventions that may be ratified by every member of the United Nations – and they have been ratified by the great majority of governments.[34] The document will draw on jurisprudence in the European and American systems of human rights where it can help to clarify the requirements of the International Bill of Rights.

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[31] *Id.* ¶ 31.

[32] G.A. Res 56/119, *supra* note 3.

[33] Mark W. Janis, An Introduction to International Law 177 (1988).

[34] U.N. Doc A/56/117. *See* <http://www.unhchr.ch/huridocda/huridoca.nsf/(Symbol)/A.56.178.En?Opendocument> for a list of countries that have ratified the covenants. Governments may also ratify these conventions with reservations. Reservations are recognized by the Vienna Convention on the Law of Treaties as a way governments can limit their legal obligations when they ratify a particular convention. U.N. Doc. A/CONF.39/7 (1969), art. 2(1)(d). Reservations must be taken into account in examining the international legal obligations of each country.

This document demonstrates the process legislators and activists can use to interpret international human rights law to ensure that domestic legislation is in conformity with international human rights standards and convention-based obligations. This document is not intended to be a comprehensive compilation of all rights recognized under international law. Due to space limitations, many important dimensions and aspects of the rights of people with disabilities, including the right to education, vocational training, work, sexual expression, parental rights, etc., have not been included in this document. While many of the rights described in this document apply to people who are detained in jails or prisons, this document is not specifically focused on the rights of people in the criminal justice system. This document also does not address the very important subject of people with mental disabilities who are criminal defendants.[35] While this document will describe the right to citizen participation under the Standard Rules, it does not provide a fully exhaustive analysis of the political rights of people with mental disabilities under article 25 of the ICCPR.[36]

In addition to conducting a thorough review of the major international human rights standards relating to people with disabilities, legislators, policy-makers and non-governmental activists working to draft new legislation should examine the specific requirements of each convention their particular government has ratified, including regional human rights conventions.[37]

I. A Guide to the Use of International Human Rights Law

There are a number of important legal differences between international human rights conventions, such as the ICCPR and the ICESCR, and UN General Assembly resolutions, such as the MI Principles and the Standard Rules. Conventions fall into the category of "hard" international law and General Assembly resolutions fall into the category of "soft" law. Soft law instruments in the human rights field are also referred to as international human rights "standards." Soft law is considered "non-binding" and hard law is considered "binding." This

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[35] *See* Dr. Theresia Degener, *International Disability Law – A New Legal Subject on the Rise*, 18 Berkeley J. Int'l L. 180, 193 – 194 (1999); Gerard Quinn, *Civil Commitment and the Right to Treatment under the European Convention on Human Rights*, 5 Harv. Hum. Rts. J. 1 (1992); *See* Amita Dhanda, LEGAL ORDER AND MENTAL DISORDER (2000); *See* Michael L. Perlin, LAW AND MENTAL DISABILITY (1994) for a treatment of many of these issues within the U.S. legal system.

[36] *See* Gerard Quinn, *The International Covenant on Civil and Political Rights*, *in* HUMAN RIGHTS AND DISABLED PERSONS 90 (Theresia Degener and Yolan Koster-Dreese, eds., 1995) (describing the political rights of people with disabilities under article 25 of the ICCPR).

[37] *See supra* notes 12-14 and accompanying text.

section will examine some of the rules for interpretation as to what constitutes soft and hard law, and it will describe some of the implications of what it means to be binding international law.

While this document focuses primarily on conventions, it is important to note that there are two main sources of binding international human rights law - customary international law and conventions.[38] Customary international law is made up of legal principles so widely accepted by governments and legal scholars as binding that they need not even be written legal principles.[39] The concept that a government must protect against torture or inhuman and degrading treatment, for example, is widely considered to be customary international law. Over time, soft law principles that become widely accepted can "harden" into binding international law. The "Universal Declaration of Human Rights" (UDHR) is the best example of a soft law (it was adopted in 1948 as a non-binding UN General Assembly Resolution) that is widely considered to have become binding, customary international law.[40]

In such a new area of law as the rights of people with mental disabilities, consensus has not yet developed as to the obligations of governments. Thus, it is unlikely that many rights that apply specifically to people with disabilities have developed into customary international law. However, core principles of customary law – such as the right to life and the concept of non-discrimination – apply to people with disabilities as they do to all other human beings.

The other source of hard international law is convention-based law (conventions can also be referred to as treaties, pacts, or charters).[41] The UN Charter is perhaps the most important treaty since it establishes the framework for the United Nations and commits member States to promote universal respect for human rights.[42] Unlike General Assembly Resolutions, treaties are

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[38] Janis, *supra* note 33 at 36. Most scholars accept the principle that human rights conventions constitute the most authoritative source of international law, above customary law. However, customary law can be used to interpret human rights conventions. *Id.* At 10-11.

[39] "In the human rights field widespread acceptance of treaties, declarations, resolutions, and other instruments has become a key source of evidence of state practice as well as *opinion* juris (the accompanying sense of legal obligation) in creating binding law." Weissbrodt, Fitzpatrick & Newman, *supra* n.11 at 22.

[40] UDHR, *supra* note 3.

[41] Mark W. Janis, AN INTRODUCTION TO INTERNATIONAL LAW 9 (1988). Terms such as pacts, protocols, accords, or charters may also designate conventions or treaties.

[42] U.N.CHARTER arts. 55-56. Article 103 of the UN Charter establishes that "[i]n the event of a conflict between the obligations of the Members of the United Nations under the present Charter and their obligations under any other international agreement, their obligation under the present Charter shall prevail."

binding on governments (known as States Parties) that ratify them.[43] As noted above, the UN General Assembly adopted resolution 56/119 in November 2001 calling for the creation of an Ad Hoc Committee to consider proposals for a new convention on the rights of people with disabilities.[44]

A. Human Rights Conventions

Because the most specific human rights instruments relating to mental health and disability are non-binding resolutions rather than binding conventions, there is a widespread misconception that legislation to protect people with mental disabilities or regulate the operation of mental health and social service systems is subject only to the domestic discretion of governments. This is not the case. Governments are under an *obligation*, under international human rights law, to ensure that government policies and practices conform to binding international human rights law. As the Vienna Declaration reaffirms, people with mental disabilities are protected by the same human rights law that protects all other individuals – including the provisions of binding human rights conventions. International human rights law creates a number of broad protections that provide important rights to people with mental disabilities. This document will review a few of those, including: (1) the right to the highest attainable standard of physical and mental health; (2) protections against discrimination (3) protections against torture, inhuman, or degrading treatment; (4) protections against arbitrary detention. This section also describes the obligation to "ensure and respect" human rights law, including the creation of safeguards for rights enforcement.

1. International enforcement and oversight of conventions

Within the regional human rights systems of Africa, the Americas and Europe, there is a highly developed system for enforcing human rights conventions. Individuals can bring complaints against governments in commissions or courts established under these conventions, and these bodies can arrange friendly settlements or issue binding decisions. There is now an

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[43] In some countries, international law is automatically enforceable in the same way as domestic legislation through their own court systems. Countries that treat international conventions in this manner are said to have a system of "monism." In most countries, however, domestic legislation must be adopted to implement international law. The more common mechanism for domestic enforcement is called "dualism." Janis, *supra* n.33 at 71.

[44] There have past been attempts to obtain political support for a specialized convention on the rights of people with disabilities. In the past, these efforts lacked sufficient political support within the United Nations. One initiative was rejected by the UN in 1987. UN Doc. A/C.3/42/SR.13 (1987) *See discussion in* Degener, *Disabled Persons and Human Rights, IN* HUMAN RIGHTS AND DISABLED PERSONS, *supra* note 20 at 12.

extensive body of case law on the rights of people with mental disabilities under the ECHR,[45] and the first case of a person with a mental disability has recently been decided under the American Convention. Cases decided by the regional conventions are binding only within the human rights system created by the respective convention. However, these decisions can be useful in the interpretation of similar protections in other conventions. While this document focuses primarily on the International Bill of Rights, it will refer to cases from the European and American human rights systems that may help shed light on the meaning of the UN conventions.

Even where no international enforcement mechanism is available, many human rights conventions create a system for international monitoring. The major UN conventions, including the ICCPR and the ICESCR, create treaty-based supervisory bodies. Governments that ratify conventions agree to report regularly on the steps that they have taken to implement the convention – through changes in legislation, policy, or practice. Non-governmental organizations can also submit information for review by oversight bodies. Oversight bodies review both the official and non-governmental reports and publish their findings, which may include a determination that governments have not met their international obligations under the convention. The international oversight and reporting process thus provides an opportunity to educate the public about a specialized area of rights. This process can also be a powerful way to pressure governments to realize convention-based rights.

2. Interpretative Guidelines

One of the most important sources of interpretation of human rights conventions is the guidelines, known as General Comments, produced by human rights oversight bodies (also referred to as treaty-based committees) to guide governments in the preparation of their official reports. General comments are non-binding, but they represent the official view as to the proper interpretation of the convention by the human rights oversight body. There have only been very limited General Comments on the rights of people with mental disabilities adopted by treaty-based committees.

In 1996, the Committee on Economic, Social, and Cultural Rights adopted General Comment 5,[46] detailing the application of the International Covenant on Economic, Social, and

[45] *See* Lawrence O. Gostin, *Human Rights of Persons with Mental Disabilities*, 23 INT'L J. L. PSYCHIATRY 125 (2000); Margaret G. Wachenfeld, THE HUMAN RIGHTS OF THE MENTALLY ILL IN EUROPE (1992); T.W. Harding, *The Application of the European Convention of Human Rights to the Field of Psychiatry* 12 INT'L J. L. PSYCHIATRY 245 (1989).

[46] Committee on Economic, Social, and Cultural Rights (Eleventh session, 1994), *Persons with Disabilities*, 9 December 1994, General Comment 5.

Cultural Rights (ICESCR) with regard to people with mental and physical disabilities.[47] As part of General Comment 5, the Committee recognized the MI Principles, the Standard Rules, and the UN's Guidelines for National Coordinating Committees as instruments established by the international community to "ensure the full range of human rights for persons with disabilities."[48] General Comment 5 singles out the Standard Rules as "a particularly valuable reference guide in identifying more precisely the relevant obligations of States under the Covenant."[49]

In 2000, the Committee further elaborated on the right to the highest attainable standard of health.[50] In General Comment 14, the Committee specified the general and specific legal obligations of States in implementing Article 12 (the right to the highest attainable standard of physical and mental health) of the ICESCR.

The Committee on the Elimination of All Forms of Discrimination Against Women has also issued a general recommendation pertaining to the rights of women with disabilities.[51] This recommendation calls on governments to improve their reporting on the enforcement of the rights of women with disabilities under the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

The UN Human Rights Committee, established to monitor the International Covenant on Civil and Political Rights (the ICCPR), has yet to issue a general comment specifically on the rights of people with mental disabilities. It has issued General Comment 18 that defines the protection against discrimination against people with disabilities under article 26.[52] In its comments on Article 7, it specifies that the protection against "torture...cruel, inhuman or degrading treatment" applies to "medical institutions, whether public or private." In order to demonstrate compliance with Article 7, all governments that have ratified the ICCPR:

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[47] For a background on the development of General Comment 5, see Philip Alston, *Disability and the International Covenant on Economic, Social and Cultural Rights in* HUMAN RIGHTS AND DISABLED PERSONS, *supra* note 20 at 100-102.

[48] General Comment 5, *supra* note 46, ¶.7.

[49] *Id.*

[50] General Comment No. 14 (2000)(E/C.12/2000/4) on the right to the highest attainable standard of health (art. 12 of the International Covenant on Economic, Social and Cultural Rights), adopted by the Committee on Economic, Social and Cultural Rights at its twenty-second session in April/May 2000.

[51] U.N. Doc. (CEDAW) C/L.8/Add. 18.

[52] UN Human Rights Committee, General Comment 18, Non-Discrimination, UN Official Records Suppl. No. 40 (A/45/40), pp.173-175 [check this cite]. General Comment 18 is also found in the UN Manual on Human Rights Reporting (1997). *See* UNHCR, UN Manual on Human Rights Reporting (visited Jan. 22, 2002) <http://www.unhchr.ch/pdf/manual_hrr.pdf >.

should further address the conditions and procedures for providing medical and particularly psychiatric care. Information should be provided on detention in psychiatric hospitals, on measures taken to prevent abuses in this field, on appeals available to persons interned in a psychiatric institution and on any complaints registered during the reporting period.

3. Obligation to Enforce Conventions

When a government ratifies a convention, it agrees to implement the convention's terms according to a series of obligations or enforcement mechanisms established within the convention. Every convention has an enforcement provision, and different conventions create different kinds of obligations on States Parties. Since countries are States Parties to some of the conventions and not others, it is necessary to examine the conventions ratified by a particular country in order to examine that country's obligations under international human rights law.[53] This said, there is a widespread recognition that all internationally recognized human rights are ultimately indivisible and interrelated.[54] Thus, the breakdown of rights under different conventions is, at some level, artificial. While keeping in mind the related nature of different rights, it is important for legislators and activists to understand the different implementation requirements of each convention.

There are two types of enforcement requirements created in the two conventions that make up the International Bill of Rights, the International Covenant on Economic and Social Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR). The International Bill of Rights was drafted immediately following the Second World War when the international community was divided by the beginning of the Cold War. While the division of rights between these two conventions is increasingly viewed as artificial, the split between the conventions reflects the ideological divide at the time they were drafted. As a relic of this period, we are left with two different types of enforcement requirements for the rights established under the two international conventions.[55] The two types of obligations can be described as an "obligation of outcome" and an "obligation to take action."

a. Obligation of outcome

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[53] *See supra* note 34.

[54] *See supra* note 23 and accompanying text.

[55] In addition, many later international conventions also follow the pattern established by the ICCPR and the ICESCR. The European Convention on Human Rights (ECHR) and the American Convention create obligations roughly similar to the ICCPR. The American Convention, however, includes a section on economic and social rights very similar to the ICESCR.

Article 2(1) of the ICCPR requires governments to "respect and ensure" the enforcement of human rights under the covenant. This clause has been characterized as an "obligation of result" because it requires governments not only to "respect" rights as a matter of law,[56] but to "give effect" to these rights, i.e. to "ensure" their enforcement.[57] Article 2 requires governments to "adopt such laws or other measures as may be necessary to give effect to the rights recognized in the Present Covenant." Under article 3(a), States Parties must "ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy." By establishing enforceable rights and remedies, rights are "brought from the lofty plane of international principles to enforceable law in concrete cases."[58]

b. Obligation to take action/Progressive realization

In recognition that economic and social rights are more likely to require the investment of resources and to require government planning, the ICESCR creates a requirement of progressive realization.[59] The ICESCR creates immediate obligations on governments to begin planning ("to undertake to take steps") to bring about the full enforcement of the rights recognized under the ICESCR.[60] This includes "particularly the adoption of legislative measures" to bring about the implementation of the ICESCR. The ICESCR may require governments to reform social and medical policies to bring about reform of rights under the covenant. Part II below describes further the obligation of progressive enforcement as it applies to the obligation to protect the "highest attainable standard of physical and mental health."

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[56]ICCPR, Article 2(2) states that "each State Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such legislative or other measures as may be necessary to give effect to the rights recognized in the present Covenant."

[57] Oscar Schachter, *The Obligation to Implement the Covenant in Domestic Law*, *in* THE INTERNATIONAL BILL OF RIGHTS 311 (Louis Henkin, ed., 1981).

[58] *Id.* at 331.

[59]Article 2(1) of the ICESCR states that "[e]ach State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."

[60]*See* Philip Alston & Gerard Quinn, *The Nature and Scope of States Parties' Obligations Under the International Covenant on Economic, Social and Cultural Rights* 9 Hum. Rts. Q. 156, 159 (1987). (describing the immediate obligations created under article 2(1) the ICESCR).

While the ICESCR has been characterized as establishing an obligation of action rather than an obligation of outcome, there are aspects of the ICESCR which also create immediate obligations on States Parties to the convention. For example, the principle of non-discrimination has immediate effect – i.e., the individual's right to enjoy all the benefits of the ICESCR on an equal basis is effective immediately, as is the obligation of the State not to discriminate. Governments are also under an immediate obligation to "take steps toward the full realization of article 12," including moving as expeditiously as possible to adopt appropriate legislation and begin national planning.[61] These steps "must be deliberate, concrete and targeted towards the full realization of the right to health."[62] Furthermore, there are "core concepts" in Article 12 of the ICESCR, which are non-derogable, for which a State party cannot, under any circumstances whatsoever, justify its non-compliance.[63]

c. Indivisibility of rights

Despite the significant differences between legal obligations created under the ICCPR and the ICESCR, there is a growing recognition that the division between these two sets of rights is often artificial. Indeed, the World Conference on Human Rights declared in Vienna in 1993 that "[a]ll rights are universal, indivisible, interdependent and interrelated."[64]

It is a common misconception that the rights of people with mental disabilities are particularly linked with "economic and social" rights because many of their concerns relate to human rights in mental health care systems. As the analysis below will describe, the rights established in the ICCPR are as relevant to people with mental disabilities as the rights established under the ICESCR. More important, many of the same abuses violate *both* the ICCPR and the ICESCR. The closer one examines any given right, the more it is clear the rights under the covenants are overlapping and mutually reinforcing. For example, a government may be under an obligation to create community-based services for people with mental disabilities under the ICESCR. The failure to create community-based services is likely to lead to "arbitrary detention" in psychiatric facilities under the ICCPR.

While the two UN conventions that are part of the International Bill of Rights are divided into two sets of rights, it is important to note that some other human rights instruments do not make such a distinction. The most important such instrument is the Universal Declaration of Human Rights (UDHR) which preceded the ICCPR and the ICESCR. More recent conventions, such as the Convention on the Rights of the Child (CRC) also contain both types of rights. Similarly, different provisions of the MI Principles and the Standard Rules can be seen to fall

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[61] *Id.* ¶¶ 30 and 43.
[62] *Id.*
[63] General Comment 14, ¶ 47.

[64] Vienna Declaration, *supra* note 23, ¶ 5.

within the ambit of rights protected by either the ICCPR or the ICESCR or – very often – both covenants. While this document examines the specific protections under the two different covenants, it is important to keep in mind the relationship between the different sets of rights.

4. Universality of Rights

The Universal Declaration of Human Rights (UDHR) establishes human rights law as "a common standard of achievement for all peoples and all nations."[65] Despite the widespread acceptance of the UDHR as the cornerstone of international human rights law, there has often been a perceived tension between the regional, cultural, and economic differences among different countries and the universality of human rights. The Vienna Declaration made clear that while "national and regional particularities and various historical, cultural and religious backgrounds must be borne in mind, it is the duty of States, regardless of their political, economic and cultural systems, to promote and protect all human rights and fundamental freedoms."[66]

The major UN human rights standards on disability rights do recognize the need to respect cultural differences. The MI Principles recognize the right of every person receiving mental health care "to treatment suited to his or her cultural background."[67] The right to informed consent includes the right to information about treatment "in a form and language understood by the patient."[68] People receiving mental health treatment have a similar right to be informed of their rights in their own language.[69] While the MI Principles are sensitive to cultural and linguistic differences, there is nothing to indicate that any right they recognize can be limited or abridged in any society on the grounds of culture and tradition.[70]

One of the most powerful protections for community and culture is the respect for self-determination and individual choice embodied in the MI Principles and the Standard Rules. By recognizing and respecting the right of people who receive treatment to be involved in mental

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[65] UDHR, *preamble.*

[66] *Id.*

[67] *See supra* note 21, Principle 7(3).

[68] *Id.* at Principle 11(2).

[69] *Id.* at Principle 12(1).

[70] The MI Principles contain a "general limitation clause" which states that "The exercise of the rights set forth in these Principles may be subject only to such limitations as are prescribed by law and are necessary to protect the health or safety of the person concerned or of others, or otherwise protect public safety, order, health or morals or the fundamental rights and freedoms of others." Thus, limitations upon these principles cannot be arbitrary or ad hoc or applied by practices of clinicians on the front lines of the service system, or as part of culture and tradition, but need to be carefully thought out and enacted in legislation, and even then, they are limited to narrow justifications.

health system planning and program implementation, the Standard Rules provide the most effective protection against the delivery of culturally inappropriate mental health services.

Finally, it is important to recognize that the lack of economic resources in any country is not a reason to limit any of the rights established by human rights conventions or standards, including the MI Principles or the Standard Rules. "While development facilitates the enjoyment of all rights," the Vienna Declaration notes that "the lack of development may not be invoked to justify the abridgement of internationally recognized human rights."[71]

B. Major UN Human Rights Standards

In the absence of a specialized convention, it is necessary to look to soft law standards to understand the specific rights of people with mental and physical disabilities. Due to its specificity and detail, soft law can provide the most practical guidance for legislators in the mental health field.[72] The detailed provisions of specialized soft law standards are particularly useful as a guide to the requirements of the broad, general terms of mainstream human rights conventions, such as the ICCPR and the ICESCR.[73]

The following is a brief review of the most important UN human rights standards relating to people with mental disabilities. It is beyond the purview of this document to review these standards in their entirety, and there is no substitute for a review of the full text of each of these standards as part of any legislative drafting project in the mental health or mental disability area.

1. Declaration on the Rights of Mentally Retarded Persons

In 1971, the UN General Assembly adopted the "Declaration on the Rights of Mentally Retarded Persons"[74] (MR Declaration). The MR Declaration is in many ways dated. For

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[71] Vienna Declaration, *supra* note 23, ¶ 10.

[72] For an overall description of the use of soft law standards in the development of domestic legislation, *see* Jiri Toman, *Quasi-Legal Standards and Guidelines for Protecting Human Rights, in* Guide to International Human Rights Practice 192-210 (Hurst Hannum, ed., second edition, 1992).

[73] As Jiri Toman describes, "The quasi-legal nature of these international standards should not obscure the fact that they often interpret and implement fundamental human rights – the right to be free from torture, to receive a fair trial, to have the assistance of legal counsel, and other related rights. In this sense, they might be viewed as the international equivalent of administrative regulation, whose implementation will ensure that basic rights are effectively guaranteed." *Id.* at 208.

[74] G.A. Res. 2856 (XXVI), 26 U.N. GAOR Supp. No. 29 at 99, U.N. Doc. A/8429 (1971) (MR Declaration). *See* Stanley S. Herr, *Rights of Disabled Persons: International Principles and American Experiences*, 12 Colum. Rts. Rev. 1 (1980) (reviewing content and implications of the MR Declaration).

example, the very term “mental retardation” is now widely viewed as derogatory, and the major international advocacy organization for people with intellectual disabilities, Inclusion International, opposes this terminology (this document will use the more current term “intellectual disability”). Despite its limitations, the declaration does establish some important rights. The person with intellectual disability has “the same rights as other human beings”[75] which cannot be restricted without due process that “must contain proper legal safeguards against every form of abuse.”[76]

The MR Declaration protects against the common practice in some countries of stripping away a person’s rights through a finding of mental incompetence or by placing people with an intellectual disability under guardianship for a lifetime without due process. Instead of relying simply on a medical diagnosis, the MR declaration provides every person with an intellectual disability a right to an evaluation of his or her “social capability” by a “qualified expert.” Any determination of incompetence must be reviewed periodically, and an individual whose rights have been limited has a right to appeal to a court.

The MR Declaration recognizes a right to community integration and inclusion in society by establishing that “the mentally retarded person *should* live with his own family or with foster parents and participate in different forms of community life.”[77] The MR Declaration permits institutionalization if it should “become necessary,” a vague standard that could easily be clarified in domestic legislation. Yet this standard may evolve into a mandate for community integration as more and more countries develop community-based services and support systems that permit the full social inclusion of people with even the most severe intellectual disabilities. In societies where most or all people with intellectual disabilities live in the community, it should rarely if ever be necessary to place a person in an institution.

2. Principles for the Protection of Persons with Mental Illness

In 1991, the MI Principles established minimum human rights standards of practice in the mental health field. The MI Principles have been recognized as “the most complete standards for the protection of the rights of persons with mental disability at the international level.”[78] The MI

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[75] MR Declaration, ¶ 1 (“The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.”).

[76] *Id.* ¶ 7.

[77] *Id.* ¶ 4 (emphasis added).

[78] *The Case of Victor Rosario Congo,* Inter-American Commission on Human Rights Report 29/99, Case 11,427, Ecuador, adopted in Sess. 1424, OEA/Ser/L.V/II.) Doc. 26, March 9, 1999, para. 54. The Inter-American Commission went on to say that “[t]hese Principles serve as a guide to States in the design and or reform of mental health systems and are of utmost utility in evaluating the practice of existing systems. Mental Health Principle 23 establishes that each State must adopt the legislative, judicial, administrative, educational and other measures that

Principles have been used by international oversight and enforcement bodies as an authoritative interpretation of the requirements of the ICESCR[79] and the American Convention on Human Rights.

The MI Principles have served as model mental health legislation and many countries, such as Mexico, Hungary, Costa Rica, Portugal and Australia, have incorporated the MI Principles in whole or in part into their own domestic laws.[80] Other countries such as Nicaragua and Costa Rica have used the MI Principles as a guide in the redesign of their mental health policies. The MI Principles establish standards for treatment and living conditions within psychiatric institutions, and they create protections against arbitrary detention in such facilities.[81] These principles apply broadly to persons with mental illness, whether or not they are in psychiatric facilities, and they apply to all persons admitted to a mental health facility, whether or not they are diagnosed as mentally ill.[82] These provisions are important because, in many countries, long-term mental health facilities often serve as repositories for people who have no history of mental illness, or no current mental illness, but who remain in the institution due to the lack of other community facilities or services to meet their needs. The MI Principles recognize that "[e]very person with a mental illness shall have the right to live and work, as far as possible, in the community."[83] The MI Principles have major implications for the structure of mental health systems since they recognize that "[e]very patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives."[84]

The MI Principles protect a broad array of rights within institutions, including protections against "harm, including unjustified medication, abuse by other patients, staff or others..."[85] They require the establishment of monitoring and inspection of facilities to ensure compliance with the Principles.[86] The MI Principles require treatment "based on an individually prescribed plan,"[87] and they require that "the treatment of every patient shall be directed towards preserving and

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may be necessary to implement them." *Id.* at note 8, *citing* Rosenthal & Rubenstein, *supra* note 22.

[79] UN Committee on Economic, Social, and Cultural Rights, General Comment 5, *supra* n.6 para. 21 (using MI Principle 13(3) as an interpretation of the ICESCR Articles 6-8 on rights relating to work). The importance of the MI Principles are noted more generally at para. 7.

[80] Norma Oficial Mexicana, NOM-025-SSA2-1994 Para lea prestacion de servicios de salud en unidades de atencion integral hospitalaria medico-psiquiatrica. (Official Mexican Law, NOM-0250SSA2-1994 For the provision of health services in integrated hospital attention, medical-psychiatric units. Hereinafter the Mexican mental health law).

[81] *See supra* n.21, Principles 15-18.

[82] Id. at Definitions, Principle 24.

[83] *Id.* at Principle 3.

[84] *Id.* at Principle 7(1).

[85] *Id.* at Principle 8(2).

[86] *Id.* at Principle 22.

[87] *Id.* at Principle 9(1).

enhancing personal autonomy."[88] The MI Principles establish substantive standards and procedural protections against arbitrary detention in a psychiatric facility.

3. Standard Rules

As a product of the Vienna Declaration's call for increased attention to the human rights of people with disabilities, the United Nations General Assembly in 1993 adopted the "Standard Rules on Equalization of Opportunities for People with Disabilities" (Standard Rules). The Standard Rules have major implications for the very process of developing mental health legislation because they recognize the right of people with mental disabilities – and by extension organizations made up of people with disabilities – to participate in national planning for mental health and social service system reforms needed to bring countries in line with international human rights standards:

> National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation. (Rule 15)

General Comment No. 5 recognizes that the Standard Rules on Equalization of Opportunities for Persons with Disabilities should be used as a guide to the requirements of the ICESCR. There is no more fundamental principle in the Standard Rules than the recognition of the right of people with mental and physical disabilities to participate fully in matters that affect them.[89] This specifically includes a right of people with disabilities to be included in a public process of legislative drafting.[90] Governments are required to review legislation regularly and to establish national planning committees, and these committees must include representation of people with disabilities.[91]

The Vienna Declaration similarly identifies the right of people with disabilities to "active participation in all aspects of society" as one of the specific rights established under

[88] *Id.* at Principle 9(4).

[89] "States should involve organizations of persons with disabilities in all decision-making relating to plans and programs concerning persons with disabilities or affecting their economic and social status." StRE, *supra* note 6, Rule 14(2).

[90] *Id.* at Rule 15(1).

[91] *Id.* at Rule 17.

international law.

What is intended by the Standard Rules is not token representation of one or two individuals on large committees made up of professionals and government officials, but a meaningful voice and participation in the process of developing legislation and monitoring its implementation. In the process of reviewing domestic legislation dealing with mental health, States should involve organizations of persons with mental illness and their families in the formulation of legislation, identification of their needs, resources, safeguards, and monitoring of services and supports.

It may be the case in some States that such organizations of persons with disabilities do not exist or do not have the capacity to play the role envisioned in the Standard Rules. In such cases, the Standard Rules provide that "States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy." (Rule 18)

To implement their right to participate, people with disabilities, their family members, and community allies and advocates should be included in all aspects of planning, design, implementation and evaluation of services, supports and human rights oversight programs. The right to participation by key stakeholders should be recognized as a matter of law. Governments should support the formation of such NGO groups and provide for their training to be effective advocates in performing these roles. The active participation of primary users of services and their families is not only useful in the policy formulation and legislative development process but can be invaluable in the design and operation of the service system itself.

The Standard Rules' recognition of the right of people with disabilities to engage in the process of legislative and policy development, ironically, raises doubts about the very process the United Nations has used to develop international standards relating to people with mental disabilities.[92] UN Special Rapporteur on Disability Bengt Lindqvist is in the process of

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[92] The organization recognized by the UN Special Rapporteur on Disability as representing people with psychiatric disabilities, known as the World Network of Users and Survivors of Psychiatry, has called into question the MI Principles because of the lack of stakeholder participation in their drafting. At their first world convention held in Vancouver in July 2001, the World Network adopted an alternative statement of rights that they have proposed as a replacement for the MI Principles. World Network of Users and Survivors of Psychiatry, Human RIGHTS POSITION PAPER, adopted at the WNUSP General Assembly in Vancouver, Canada, August 2001. The organization Disabled People's International (DPI) is the only organization of people with disabilities that commented on the draft of the MI Principles. DPI's comments were not incorporated into the final draft of the MI Principles. Commission on Human Rights, *Written statement submitted by Disabled People's International, a non-governmental organization in consultative status*, UN Doc. E/CN.4/Sub.2/1988/NGO/27 (31

developing draft revisions of the Standard Rules, and he will soon propose that the UN General Assembly revise these standards.[93]

C. Soft Law as an Evolving Standard

When they are well-drafted and reflect a broad international consensus, non-binding human rights standards can serve as models for domestic legislation. Where international consensus is still developing, one of the important qualities of soft law is that it can be modified and amended. This requires a new resolution of the UN General Assembly, which is much easier than having each country ratify an amendment to a convention. Thus, soft law is particularly appropriate for areas of law that are rapidly evolving and in which international consensus may further develop. Soft law standards are often improved over time, and they may serve as a draft of what eventually becomes an international human rights convention.[94]

This is particularly important in such a new area as international mental health and disability rights. The UN Human Rights Commission has called for the strengthening of human rights standards, and UN Special Rapporteur Bengt Lindqvist is in the process of drafting proposed revisions to some of the major human rights standards affecting people with mental disabilities. Activists from many countries have criticized the MI Principles for providing fewer protections than exist under many domestic legal systems.

One limitation of human rights standards is that they may provide fewer protections than existing international human rights conventions. As always, the right established in the convention takes precedence over the standard. The MI Principles themselves recognize that "[t]here shall be no restriction upon or derogation from any existing rights of patients, including rights recognized in applicable international or domestic law, on the pretext that these Principles do not recognize such rights or that they recognize them to a lesser extent."[95] This document notes a few instances in which the MI Principles provide more limited protections than do human rights conventions.

August 1988). *See* Theresia Degener, *Disabled Persons and Human Rights: The Legal Framework, in* HUMAN RIGHTS AND DISABLED PERSONS, *supra* n.20 at 27 (reviewing a number of the critiques of the MI Principles).

[93] The proposed revision of the Standard Rules will provide some new protections to people with mental disabilities that make up for some of the weaknesses of the MI Principles, including a proposed recognition of the right to refuse treatment. Personal communication with Bengt Lindqvist, December 2001.

[94] *Id.* at 209.

[95] *See supra* note 21, Principle 25.

As these difficulties illustrate, UN human rights standards should not necessarily be viewed as model laws – but as minimum standards necessary to protect basic rights. Human rights standards may be incorporated directly into domestic law wherever legislators and activists find them to be a useful guideline. However, these standards should be checked against the requirements of related human rights conventions and existing domestic law. Where human rights conventions or existing domestic law provides greater protections, the convention or domestic law should govern. Where there is no specific law on point (or existing law provides fewer protections), governments should look to human rights standards as a non-binding but persuasive source of authority as to what international human rights law requires. As described by Henry Steel, chairman of the working group that prepared the MI Principles for the Human Rights Commission, the MI Principles "represent the minimum United Nations standards for the protection of fundamental freedoms and human and legal rights of persons with mental illness."[96] This principle also applies to other key human rights standards as described below.

D. Technical and Professional Standards

In addition to UN General Assembly resolutions, a broad array of technical guidelines and policy statements has been adopted by UN agencies, world conferences, and professional groups meeting under UN auspices. These resolutions can be a valuable source of interpretation of international human rights conventions. In the hierarchy of legal authority, technical or professional standards are of lesser importance in the interpretation of UN conventions than the resolutions of the UN General Assembly because the General Assembly is specifically authorized by the UN Charter to assist in the development of international law.

One of the most important of technical standards, the "Declaration of Caracas," was adopted as a resolution by legislators, mental health professionals, human rights leaders and disability activists convened by the Pan American Health Organization (PAHO).[97] The Declaration of Caracas has major implications for the structure of mental health services, finding

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[96] United Nations, Economic and Social Council, Commission on Human Rights, Human Rights and Scientific and Technological Developments, REPORT OF THE WORKING GROUP ON THE PRINCIPLES FOR THE PROTECTION OF PERSONS WITH MENTAL ILLNESS AND FOR THE IMPROVEMENT OF MENTAL HEALTH CARE, UN Doc. E/CN.4/1991//39 (prepared by Henry Steel). Leandro Despouy, Special Rapporteur on Human Rights and Disability, reaffirmed this viewpoint in his report to the UN Human Rights Commission. United Nations, Economic and Social Council, Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, HUMAN RIGHTS AND DISABILITY, UN Doc. E/CN.4/Sub.2/1991/31 (prepared by Leandro Despouy) [Despouy Report].

[97] *See* Itzhak Levav, Helena Restrepo and Carlyl Guerra de Macedo, *The Restructuring of Psychiatric Care in Latin America: A New Policy for Mental Health Services*, 15 J. Pub. Health and Policy 71 (1994).

that exclusive reliance on in-patient treatment in a psychiatric hospital "isolates patients from their natural environment...generating greater disability." The Declaration establishes a critical link between mental health services and human rights by concluding that such outmoded mental health services "imperil the human and civil rights of patients."[98] The Declaration calls on governments to use national legislation to order the restructuring of services where necessary.[99]

PAHO has demonstrated how a UN technical agency can make great strides in collaborating with human rights oversight bodies to promote human rights. PAHO has provided technical assistance to the Inter-American Commission on Human Rights in conducting *in loco* visits to psychiatric facilities as part of its monitoring of governments' compliance with the American Convention on Human Rights. This collaboration has led to the adoption of recommendations for further action by governments to promote rights under the American Convention.[100]

In 1990, the UN Secretariat convened a group of experts to draft the "Guidelines for the Establishment and Development of National Coordinating Committees on Disability or Similar Bodies"[101] (Guidelines for National Coordinating Committees). In 1996, WHO adopted "Mental Health Care Law: Ten Basic Principles" as a further interpretation of the MI Principles.[102] WHO also adopted the Guidelines for the Promotion of Human Rights of Persons with Mental Disorders," a tool that can be used to interpret the MI Principles, evaluate human rights conditions in institutions, and draft mental health legislation.[103] In 1994, the World Conference on Special Needs Education adopted "The Salamanca Statement and Framework for Action on Special Needs Education" affirming the right to integrated education for children with mental disabilities.[104] The Salamanca Declaration is of particular importance in implementing the World Declaration on Education for All (WDEA) and enforcing the right to education established under the ICESCR.

II. Highest Attainable Standard of Physical and Mental Health

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[98]*Id.* at 83, *preamble*, ¶ 2.

[99]*Id.* at Article 4.

[100] Inter-American Commission on Human Rights, Recommendation for the Promotion and Protection of the Rights of the Mentally Ill, 28 February 2001.

[101] A/C.3/46/4, annex I.

[102] WHO/MNH/MIND/96.9

[103] WHO/MNH/MND/95.4

[104] *See* Degener, HUMAN RIGHTS AND DISABLED PERSONS, *supra* note 20 at 31.

Article 12 of the ICESCR establishes "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." The Constitution of the World Health Organization (WHO), adopted in 1946, first enunciated a right to health and mandated WHO to promote that right.[105] The language of Article 12 mirrors the language of WHO's constitution:

> The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions.

While Article 12 is often referred to conveniently as the "right to health," the "word 'attainable' makes clear that States Parties are not required to guarantee that all citizens be healthy -- an absurd proposition."[106] Instead, Article 12 has been interpreted as an obligation on governments to take specific steps to protect and promote health.[107] The right to health can be viewed both as a "positive" right to government action or services necessary to maximize health and as a "negative" right to protection against unhealthy or dangerous conditions.[108] As described by the Committee on Economic, Social and Cultural Rights (CESC) in General Comment 14:

> The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference such as the right to be free from torture, non-consensual treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.[109]

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[105] World Health Organization, Q&A ON HUMAN RIGHTS, *supra* note 55 at 10.

[106] Virginia A. Leary, *Implications of a Right to Health, in* HUMAN RIGHTS IN THE TWENTY-FIRST CENTURY: A GLOBAL CHALLENGE 485 (1993).

[107] As stated by the UN High Commissioner on Human Rights, Mary Robinson, "The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public health authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time. To ensure that this happens is the challenge facing both the human rights community and public health professionals." World Health Organization, Q&A on Health and Human Rights, *supra* note 55 at 12.

[108] *Id.* at 486. CESC *General Comment 14* states that "the right to health contains both freedoms and entitlements."

[109] CESC General Comment 14, *supra* note 46, ¶ 8.

General Comment 14 also establishes that the right to health is "related to and dependent upon the realization of other human rights as contained in the International Bill of Rights...."[110] Thus, while this document examines rights under the ICCPR in different sections, it is important to recognize that implementation of the full range of human rights is essential in order to guarantee the right to health.

The right to health care also extends to the right of access to the "underlying determinants of health..."[111] This includes access to:

> adequate sanitation, an adequate supply of safe food, nutrition, housing, healthy occupational and environmental conditions, and access to health-related education and information, including sexual and reproductive health. A further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels.[112]

For further elaboration of the ICESCR's requirements, General Comment 14 recognizes the MI Principles as a guide to State obligations under the convention, particularly with respect to protections against improper coercive treatment.[113] General Comment 5 of the Economic, Social and Cultural Rights Committee states that UN human rights standards - such as the MI Principles and the Standard Rules – can be used for guidance. Indeed, General Comment 5 makes clear that under Article 12 of the ICESCR, governments are required to provide health care services "in such a way that the persons concerned are able to maintain full respect for their rights and dignity."[114]

The concept of progressive realization under the ICESCR recognizes that resources are not limitless, and governments cannot be expected to do more than to make the best of available resources. However, certain elements of the right to health are immediate, including the obligation to guarantee protections against discrimination.[115]

A. Access to Appropriate and Professional Services

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[110] *Id*. ¶. 3.

[111] *Id.* ¶ 11. *See also* discussion in World Health Organization, Q&A on Health and Human Rights, *supra* n.20 at 10.

[112] CESC General Comment 14, ¶ 11.

[113] *Id.* ¶ 34.

[114] General Comment 5, s*upra* note 6, ¶ 34.

[115] General Comment 14, ¶ 30.

The right to the highest attainable standard of mental health under Article 12 entails a right on the part of people with mental disabilities to services that are (a) available (b) accessible (c) acceptable and of (d) appropriate and good quality.[116] To be appropriately available, services must be provided in "sufficient quantity" by "trained medical and professional personnel."[117] The concept of accessibility goes beyond physical access – it also requires that services be affordable and available in a non-discriminatory manner.[118] The requirement that services be "acceptable" means that they must be provided in a manner that is culturally appropriate and respectful of medical ethics.[119] For services to be of appropriate quality, they must also be culturally acceptable, medically appropriate, and provided in a safe and clean environment.[120]

General Comment 5 adds some specific content to the right to health, specifying that it includes a right of access to rehabilitation services.[121] The MI Principles elaborate extensively on the availability, accessibility, acceptability, and quality of services, providing an example of internationally accepted standards. Under the MI Principles, "[a]ll persons have the right to the best available mental health care, which shall be part of the health and social care system."[122] MI Principle 14 requires qualified staff in sufficient numbers.

Principle 4 requires that "a determination that a person has a mental illness shall be made in accordance with internationally accepted medical standards." Thus, domestic legislation will need to incorporate standard diagnostic processes and standards such as those contained in the Diagnostic and Statistical Manual of the American Psychiatric Association[123] or the International Classification of Diseases[124] as well as address the qualifications of persons who make a determination of mental illness. These Principles implicate the relatively brief and informal

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[116] *Id.* ¶ 12.

[117] *Id.* ¶ 12 (a).

[118] *Id.* ¶ 12 (b).

[119] *Id.* ¶ 12(c).

[120] *Id.* at ¶ 12(d).

[121] General Comment 5, s*upra* note 6, ¶ 34.

[122] *See supra* note 21, Principle 1(1).

[123] American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, DSM-IV (1994).

[124] World Health Organization, ICD-10 Classification of Mental and Behavioral Disorders: Clinical Descriptions and Diagnostic Guidelines (1993).

process of evaluation of patients that exists in many countries, which results in the diagnosis of mental illness which can have severe and lasting consequences for the individual's health and liberty.

Principle 13 provides for rights and conditions in mental health facilities to enable them to meet the needs of patients, while principle 14 provides specifically for resources including

> "(a) qualified medical and other appropriate professional staff in sufficient numbers and with adequate space to provide each patient with privacy and a program of appropriate and active therapy;
>
> (b) diagnostic and therapeutic equipment for the patient;
>
> (c) appropriate professional care; and
>
> (d) adequate, regular and comprehensive treatment including supplies of medication."

General Comment 14 on the ICESCR, paragraph 43, makes it clear that the core obligations of States includes the provision of essential drugs, as outlined under the WHO Action Programme on Essential Drugs.[125]

1. **Right to individualized treatment**

The principle that people with mental disabilities have a right to individualized treatment is emphasized throughout the MI Principles. Principle 9(2) states that "[t]he treatment and care of every patient shall be based on an individually prescribed plan discussed with the patient, reviewed regularly, revised as necessary and provided by professional staff." MI Principle 8 recognizes that, within health care systems, a person with mental disabilities "shall have the right to receive such health and social care as is appropriate to his or her health needs." Medication "shall meet the best health needs of the patient...."[126] In addition to treatment that is individualized to meet a particular person's health needs, the treatment of every person must also be "suited to his or her cultural background."[127]

The right to individualized treatment entails an obligation on governments to provide professional services tailored to individual needs (a) in the best judgment of professionals but also (b) respecting the preferences of the individual receiving services. Thus, one of the goals and requirements of individualized treatment is respect for individual choice in treatment. This is a key principle underlying the right to informed consent to treatment as established in Principle 11.

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[125] General Comment 14, ¶ 47.
[126] *Id., see also* note 21, MI Principle 10(1).
[127] General Comment 14, ¶ 47*, see also* note 21, MI Principle 7(3).

These principles address issues that are commonly found in institutions for people with mental disabilities. Due to shortages of professional staff and other resources, institutions may not be able to provide any treatment at all, or may be reduced to providing the same treatment or medications to all patients regardless of their diagnosis or individual need.

2. **Right to rehabilitation and treatment that enhances autonomy**

Both the MR Declaration and the MI Principles recognize that all treatment must be directed toward the enhancement of the autonomy and skills of each individual. The MR declaration recognizes a right of each person to the medical care, therapy, education, and training "as will enable him to develop his ability and maximum potential"[128] and "to care and treatment in accordance with the same standards as other ill persons." MI Principle 9(4) recognizes that "[t]he treatment of every patient shall be directed towards preserving and enhancing personal autonomy." The more generic UN Declaration of the Rights of Disabled Persons adopted in 1975[129] also recognizes the importance of self-reliance and social integration.[130]

The profound importance of this principle – and the fact that it applies to "every patient" – cannot be overemphasized. Throughout the world, people are placed in custodial facilities where the mental health or social services system functions to keep a person alive but essentially gives up on the hope that a person has any potential to develop his or her skills or return to the community. This danger is particularly great for people with the most severe mental disabilities, who are often relegated to the "back wards" of psychiatric institutions or facilities for people with intellectual disabilities. Sociologists have observed that, over time, individuals placed in institutions who are not challenged to use the social skills that they have upon placement inevitably lose those skills and establish an "institutionalized" mentality. By recognizing a right of every person to treatment that preserves or enhances his or her skills or develops maximum

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[128] MR Declaration, *supra* note 75, ¶ 2.

[129] G.A. Res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975).

[130] *Id.*

> "5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.
>
> 6. Disabled persons have the right to medical, psychological and functional treatment…and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration."

potential, the MI Principles and the MR Declaration raise expectations to a level that cannot be met by custodial care alone.

General Comment 5 makes clear that these rights are core principles under the ICESCR. The UN Economic, Social and Cultural Rights Committee interprets the right to health under the ICESCR to place great emphasis on promoting individual independence and social integration. General Comment 5 states that "the right to physical and mental health ... implies the right to have access to, and benefit from, those medical and social services...which enable persons with disabilities to become independent, prevent further disabilities and support their social integration."[131] Thus, in providing rehabilitation, General Comment 5 quotes the Standard Rules to state that rehabilitation services should be designed to enable individuals "to reach and sustain their optimum level of independence and functioning."[132]

B. Right to Independence and Social Integration

The rights to independence and social integration do not stop at the walls of the institution but clearly suggest the right to assistance in becoming free of reliance on mental health services. The right to social services that promote independence and social integration has major implications regarding the way mental health systems are structured -- clearly favoring community-based services over services within the closed environment of institutions. The MI Principles elaborate on both these concepts of independence.

1. Right to least restrictive services

The MI Principles have a number of provisions that promote the right to individual independence and autonomy within mental health care treatment. Under MI Principle 9(1), every individual "shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others." The right to treatment in the least restrictive environment is reinforced by the principle 9(4) requirement that "[t]he treatment of every patient shall be directed towards preserving and enhancing personal autonomy."

The principle that treatment should be the least restrictive possible is built into protections against such practices as physical restraints or involuntary seclusion. Principle 11(11) states that such practices should be used "only when it is the only means available to prevent immediate or imminent harm to the patient or others." Principle 11(11) contains a number of procedural safeguards against abuse, such as the requirement that each use of restraints or seclusion be recorded in the patient's record, along with an explanation of the

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[131] General Comment 5, *supra* note 6, ¶ 34.

[132] *Id.*, *citing* StRE, Rule 3.

"reasons for them and their nature and extent...." The "personal representative" of the patient should be informed promptly of any use of physical restraint or seclusion.

Consistent with the philosophy of individualized decision-making that is built into these Principles, decisions about restraint and seclusion must also be individualized and cannot be a condition of confinement applicable to all residents of a ward, for example, simply by virtue of their being placed there.

Recognition of the right to the least restrictive services is also built into the MI Principles' commitment standards. The MI Principles permit involuntary detention to prevent against "serious deterioration" in a person's medical condition. However, involuntary treatment for this purpose can only be justified if "appropriate treatment ...can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative."[133] Thus, if a person can receive appropriate treatment in the community, involuntary commitment could not be justified on these grounds.

2. Right to community-based services

In addition to recognizing the right to independence within mental health services, MI Principle 3 recognizes that "[e]very person with a mental illness shall have the right to live and work, as far as possible, in the community." It is important to note that MI Principle 3 is a right to community integration (or "social independence") that is not linked to whether or not a person receives mental health treatment. The MI Principles also recognize the right to community-based services and support systems necessary to promote this right. MI Principle 7(1) states that "[e]very patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives."

In many countries, the absence of adequate community programs and services for persons with mental illness leads to an unnecessary reliance on institutions to provide care and treatment. Admission to these facilities is usually necessitated not so much by the clinical condition of the patient but by the absence of any other alternative. Once in the institution, the same lack of community alternatives serves to retain patients in the institution long after their psychiatric condition has stabilized and they could function in the community if adequate services and supports were available. This common condition, in which patients who no longer clinically require this level of service occupy institutional beds, also makes mental health care inaccessible to many who need it because the available beds are full. In some institutions, long-term patients are confined for whom there are no bona fide diagnoses of mental illness but who remain simply due to an absence of other alternatives. The doctrine of the least restrictive environment is meaningless unless States take affirmative steps to create less restrictive alternatives in the community to meet a range of needs that can be predicted.

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[133] *See supra* note 21, Principle 16(1)(b).

As General Comment 14 to the ICESCR recognizes, States can address the need for a range of community services needed to serve people with mental disabilities in their planning and budget development processes. "Such steps must be deliberate, concrete and targeted towards the full realization of the right to health."[134]

3. Children's right to services that promote community integration

The Convention on the Rights of the Child (CRC) provides the strongest convention-based statement of the right to services that promote community integration.[135] While the right to grow up in a family or a family-like environment is emphasized throughout the CRC,[136] Article 23 on the rights of children with disabilities particularly emphasizes these rights. Article 23(3) requires that service systems be:

> designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's receiving the fullest possible social integration and individual development.

The Convention on the Rights of the Child (CRC) has been ratified even more widely than has the ICESCR. While services that support community integration can be viewed as an expression of children's right to health, the right to services that support community integration stands on its own as an independent right in any country that has ratified the CRC. Special protections are thus required in domestic legislation to ensure the community integration of children with disabilities.

C. Informed consent and the right to refuse treatment

MI Principle 11 establishes that "no treatment shall be given to a patient without his or her informed consent...." Implicit in the formulation of Principle 11 is the concept of a right to refuse treatment since a person may choose to withhold consent. The MI Principles have been

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[134] General Comment 14, ¶ 30.

[135] *See* Eric Rosenthal, Elizabeth Bauer, Mary Hayden, Andrea Holley, *Implementing the Right to Community Integration for Children with Disabilities in Russia: A Human Rights Framework for International Action*, 4 HEALTH AND HUMAN RIGHTS 83, 85 (1999) (describing the right to community integration for children under international human rights law).

[136] *See supra* note 17 at Preamble.

criticized for the lack of a more explicit and affirmative statement of the right to refuse treatment.[137]

The Principles further protect the patient's autonomy by creating a due process procedure before a patient can be determined to lack legal capacity, thus empowering a personal representative to represent the patient's interest or exercise the patient's rights. Principle 1 (6) provides:

> Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue shall be entitled to be represented by a counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by the person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceeding represent a mental health facility or its personnel and shall not represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest..."

As discussed in the section on guardianship below, the common practice in many countries of permitting family members to consent on behalf of the patient, without any formal process for determining the legal incapacity of the patient consistent with these requirements, violates the human rights of dignity and autonomy as recognized in the Universal Declaration of Human Rights as elaborated upon in these Principles.

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[137] For a detailed analysis and critique of the right to refuse treatment under the MI Principles, *see* Caroline Gendrau, 20 INT J LAW PSYCHIATRY 259, 267 (1997)(suggesting that MI Principle 11 creates more limitations on individual rights than protections). One of the main concerns raised by Disabled People's International on the draft of the MI Principles was the lack of stronger protection of the right to refuse treatment. *Written statement submitted by Disabled People's International*, *supra* note 93, *citing* E/CN.4/Sub.2/1988/66). The World Network of Users and Survivors of Psychiatry has also singled out Principle 11 as the source of its major concerns about the MI Principles. "The World Network of Users and Survivors of Psychiatry (WNUSP) supports most of the Principles but has grave concerns about Principle 16 – Involuntary Admission and Principle 11, paragraphs 6 to 16 – Consent to treatment." 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*, unpublished statement submitted to the UN Commission on Human Rights, 9 February 2000. Copies of statements by the WNUSP can be obtained by contacting the organization directly at law.dk@get2net.dk.

MI Principle 11 recognizes the core principle that "no treatment shall be given" without informed consent, but there are a number of major exceptions to this right. Under MI Principle 11(6), involuntary treatment may be ordered by an "independent authority" in the case of a person who has been detained in an institution involuntarily. The independent authority must find that the "patient lacks the capacity to give or withhold informed consent" and that treatment is "in the best interest of the patient's health needs." One weakness of the MI Principles is that they do not define what would constitute an "independent authority", nor do they provide procedural protections for people whose decisions may be over-ruled by this body.

The major limiting factor on the involuntary treatment that can be provided under MI Principle 11(6) is that it applies only to individuals subject to involuntary detention (and there are a number of other protections against involuntary detention under MI Principles 15-18). In emergency cases, however, involuntary treatment may be ordered for individuals who have not been involuntarily detained. Under MI Principle 11(8), a "qualified mental health practitioner" may order involuntary treatment if he or she determines that treatment is "urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons," for example, and consequently, the right to refuse treatment can be limited. Even under these circumstances, however, "such treatment shall not be prolonged beyond the period that is strictly necessary for this purpose."[138]

As described in parts IV and V of this document, there are probably stronger protections for the right to refuse treatment as part of the protection against inhuman and degrading treatment under Article 7 of the ICCPR. The protection against treatment without consent in the area of human experimentation is clearly greater under Article 7 of the ICCPR than it is under the MI Principles.[139]

A meeting of disability rights experts convened by UN Special Rapporteur Bengt Lindqvist at AlmΔsa, Sweden in November 2000, pursuant to UN Human Rights Commission Resolution 2000/51 to recommend improvements in international human rights protections, has called into question whether Principle 11 may violate the anti-discrimination provision of international human rights conventions.[140] The conference members adopted a resolution finding

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[138] *See supra* note 21, Principle 11(8).

[139] *See supra* note 9 and accompanying text.

[140] Report of a Seminar on Human Rights and Disability Held at Almasa Conference Centre, Stockholm, Sweden, (Marcia Rioux, ed. 2000). While this meeting included representatives of the six major international disability groups, this group of experts should not be confused with the UN Panel of Experts authorized by the UN General Assembly to advise the Special Rapporteur. The report of the conference does not make specific reference to the resolution adopted by the experts at the meeting.

that any law is "inherently suspect" as a form of discrimination if it permits coercive treatment for individuals with disabilities and not all other people. This is an issue that has yet to receive additional attention by international human rights oversight bodies. This may be further addressed in Special Rapporteur Lindqvist's proposed revision of the Standard Rules.

D. Protection of Human Dignity

The mandate of General Comment 5 that health services should be provided in such a way as to protect the "rights and dignity" of individuals with disabilities places a broad range of rights within institutions within the ambit of the right to health. The right to dignity is protected under the International Covenant on Civil and Political Rights (ICCPR) as well (see Section IV below), reflecting the central importance of the concept of human dignity as a cornerstone from which all other rights proceed. As Article I of the Universal Declaration of Human Rights proclaims, "All human beings are born free and equal in dignity and rights."[141]

While the protection of all rights should be considered linked with a respect for an individual's dignity, there are a number of specific rights within mental health services that are particularly essential to this principle. Perhaps the most important aspect of human dignity is the right to be treated as an individual, and this recognition permeates the MI Principles.[142] MI Principle 13(2) recognizes that "[t]he environment and living conditions in mental health facilities shall be as close as possible to those of the normal life of persons of similar age" including facilities for education, leisure, "active occupation," and "vocational rehabilitation measures to promote reintegration in the community."[143] MI Principle 13(1) (b) recognizes the right of people within mental health facilities to privacy - perhaps the most widely violated right of people in institutions.[144] As part of this right, the MI Principle 13 recognizes a right to "uncensored private communications" with the outside world. This includes freedom to receive visitors as well as access to telephones, newspapers, radio and television.[145]

III. Non-Discrimination

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[141] UDHR, *preamble.*

[142] *See e.g.,* MI Principle 9, *supra* note 21.

[143] *Id.* at Principle 13 (2).

[144] The ICCPR also protects the right to privacy. Article 17 states that "no one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence...."

[145] See *supra* note 21, Principle 13(1).

A fundamental human rights obligation that cuts across all areas of mental health legislation is the protection against discrimination. This right, which is recognized both in the UN Charter itself (articles 55-56) and the Universal Declaration of Human Rights, which protects "everyone," is further protected under the ICESCR and the ICCPR and it is recognized by the major UN human rights standards concerning people with mental or physical disabilities.

The concept of non-discrimination is closely linked with the concept of equality stated in Article 1 of the Universal Declaration of Human Rights: "[a]ll human beings are born free and equal in dignity and rights."[146] The protection against discrimination is, first and foremost, a promise that people with disabilities will enjoy the same legal rights as all other individuals.[147] Article 26 of the ICCPR establishes that:

> All persons are equal before the law and are entitled without any discrimination to equal protection from the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, color, sex...or other status.[148]

As the Vienna Declaration makes clear, "or other status" includes mental or physical disabilities. The United Nations Committee on Economic, Social, and Cultural Rights has made clear that the protection against discrimination on the basis of "other status" under article 2(2) of the ICESCR "clearly applies to discrimination on the grounds of disability."[149] It is important to note that, unlike many of the "positive rights" created by the ICESCR, which are subject to "progressive realization," non-discrimination on the basis of disability is an obligation that is effective immediately.[150] In the context of health care, the Human Rights Committee has emphasized a

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[146] The link between equality and non-discrimination has been described as "the dominant single theme of the Covenant [on Civil and Political Rights." B.G. Ramcharan, *Equality and Non-Discrimination in* THE INTERNATIONAL BILL OF RIGHTS, HENKIN, ED., *supra* n.13 at 246-269, 246. *See also discussion in* Aart Hendricks, *supra* n.167 at 45-53 (discussing the difference between "formal" and "material" equality and non-discrimination).

[147] *Id.* at 254.

[148] *See also* UDHR, Articles 2 &7.

[149] General Comment 5, s*upra* note 6, ¶ 5.

[150] General Comment 14, ¶ 30 provides:
While the Covenant provides for progressive realization and acknowledges the constraints due to the limits of available resources, it also imposes on States parties various obligations which are of immediate effect. States parties have immediate obligations in relation to the right to health, such as the guarantee that the right will be

positive right to access services.[151] Examples of the negative right to protections against discrimination include protections against restrictions on marriage and raising children, forced sterilization,[152] exclusion from employment, using mental illness as grounds for divorce, limitations on voting rights, and other limitations on civil rights.

Some conventions, such as the European Convention, protect only against discrimination in the exercise of rights guaranteed under the convention itself.[153] Article 26 of the ICCPR protects against discrimination in any area of law.[154] The UN Human Rights Committee, established by the ICCPR to assist in the interpretation of the convention, defines discrimination as "any distinction, exclusion, restriction, or preference....which has the *purpose or effect* of nullifying or impairing the recognition or enjoyment or exercise by all persons on an equal footing, of all rights and freedoms."[155]

Thus, protections against discrimination under international law go much further than simply outlawing laws that explicitly or purposefully exclude or deny opportunities to people

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exercised without discrimination of any kind (art. 2.2) and the obligation to take steps (art. 2.1) towards the full realization of article 12. Such steps must be deliberate, concrete and targeted towards the full realization of the right to health.

[151] As part of the right to access health services, the principle of non-discrimination means that "health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds. *Id.* ¶ 12(b).

[152] Principle 11 of the MI Principles provides that "Sterilization shall never be carried out as a treatment for mental illness."

[153]Article 14 of the European Convention provides that "[t]he enjoyment of the rights and freedoms *set forth in this Convention* shall be secured without discrimination on any ground...." (italics added). Article 2(1) of the ICCPR and Article 2(2) of the ICESCR have similar protections.

[154] United Nations Office of the High Commissioner for Human Rights, MANUAL ON HUMAN RIGHTS REPORTING 197 (1997), HR/PUB 91/1 (Rev.1), ¶ 7. at 255.

[155] UN Human Rights Committee, General Comment No. 18, ¶ 7 (emphasis added). Note that the MI Principles incorporate almost the exact words of this definition of discrimination into Principle 1(4). This is one indication that the drafters of the MI Principles intended principle 1 to help interpret Article 26 of the ICCPR. General Comment 5 of the UN Committee on Economic, Social, and Cultural Rights uses almost the same definition, but also includes language that creates even broader rights, such as the right to reasonable accommodation. General Comment 5, *supra* note 6, ¶ 15.

with disabilities. Legislation that has the *effect* of denying rights and freedoms is discriminatory, as well. As the UN Committee on Economic, Social, and Cultural Rights has observed, the problem of discrimination goes well beyond that:

> Both *de jure* and *de facto* discrimination against persons with disabilities have a long history and take various forms. They range from invidious discrimination, such as the denial of educational opportunities, to more 'subtle' forms of discrimination, such as segregation and isolation achieved through the imposition of physical and social barriers....The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.[156]

Thus, the Committee states that "[i]n order to remedy past and present discrimination, and to deter future discrimination, comprehensive anti-discrimination legislation in relation to disability would seem to be indispensable in virtually all States Parties."[157]

A. Affirmative Action and Reasonable Accommodation

Both the ICCPR and the ICESCR have been interpreted to require more than equality under the law; they require special efforts to ensure that individuals can enjoy the benefits of equal protections.[158] As described below, both the ICCPR and the ICESCR have been interpreted to require "affirmative action." The Economic and Social Committee has gone even further than the Human Rights Committee by including in its definition of discrimination under the ICESCR the "denial of *reasonable accommodation* based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights."[159]

1. Affirmative Action

For people with mental or physical disabilities, the protection against discrimination would be of limited value if it only meant that people situated similarly are treated equally.[160] In addition to outlawing explicit discrimination, domestic mental health law is an important tool

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[156] *Id.* ¶ 15.

[157] *Id.* ¶ 16.

[158] *See* Aart Hendicks, *supra* note 20 at 56.

[159] General Comment 5, *supra* note 6, ¶ 15.

[160] *See* discussion in Aart Hendriks, *The Significance of Equality and Non-Discrimination… in* HUMAN RIGHTS & DISABLED PERSONS, *supra* note 20 at 40.

needed to bring about the equality promised by the ICCPR. The UN Human Rights Committee makes clear that Article 14 "does not mean identical treatment in every instance."[161] Under the ICCPR, special protections or "affirmative action" is permissible – and at times required – to bring about equal protection under the law.[162] The MI Principles also affirm that, in the context of mental health care, "[s]pecial measures to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed discriminatory."[163] The Standard Rules also support the idea that resources may be needed in order to protect equal rights:

> The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunities for participation.[164]

2. Reasonable accommodation

While General Comment 5 recognizes the right to reasonable accommodation under the ICESCR, it does not provide further definition of this right. The principle of reasonable accommodation was established as part of United States anti-discrimination in the Rehabilitation Act of 1973, and it is now incorporated into the Americans with Disabilities Act.[165] The concept

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[161]General Comment 18(37), ¶ 8, *in* UN MANUAL ON HUMAN RIGHTS REPORTING, *supra* n.154 at 253.

[162] The Human Rights Committee states that "affirmative action" may at times be required under the convention:

> The Committee also wishes to point out that the principle of equality sometimes requires States Parties to take affirmative action in order to diminish or eliminate conditions which cause or help perpetuate discrimination prohibited by the Covenant. For example, in a State where the general conditions of a certain part of the population prevent or impair their enjoyment of human rights, the State should take specific action to correct those conditions. Such action may involve granting for a time to the part of the population concerned certain preferential treatment in specific matters as compared with the rest of the population. However, as long as such action is needed to correct discrimination in fact, it is a case of legitimate differentiation under the Covenant. *Id.* at 254.

[163] *See supra* note 21, Principle 1(4).

[164] Standard Rules, ¶ 25.

[165] ADA Title I, Section 12111 (B) states that "[t]he term 'reasonable accommodation' may include (A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities and (B) job restructuring, part-time or modified work schedules,

has had great influence on the development of legislation in other countries.[166] Reasonable accommodation has been defined in US law as "providing or modifying devices, services, or facilities, or changing practices or procedures in order to match a particular person with a particular program or activity."[167]

In the employment context, a person with a mental disability could, for example, receive reasonable accommodation by being allowed to adjust his or her work schedule to take time off to see a psychotherapist or to arrive late in the morning and make up the time later in the day. The accommodation would only be required if it still allows the individual to perform the "essential functions" of his or her job. An accommodation would not be considered "reasonable" if it places "undue financial and administrative burden" on an employer or if it requires "a fundamental alteration in the nature" of a program.[168] US law is obviously not an authoritative interpretation of the ICESCR's protection of the right to reasonable accommodation, but the growing jurisprudence in the countries that have adopted similar legislation provides extensive guidance that can be used to develop effective protections.[169]

International human rights law creates direct legal obligation only on governments and not on private actors although governments can be required to adopt legislation that protects vulnerable populations even in the private sphere.[170] Thus, the right to reasonable

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reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment of modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities."

[166] *See discussion in* Aart Hendricks, *The Significance of Equality and non-Discrimination*, in HUMAN RIGHTS AND DISABLED PERSONS, 40, (Degener and Koster-Dreese eds. 1995), *supra* note 20 at 58.

[167] Robert Burgdorf, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES, 122 United States Commission on Civil Rights, Publication No. 81 (1983).

[168] *Southeastern Community College v. Davis*, 442 U.S. 379, (1979).

[169] For a practical discussion on the right to reasonable accommodations for people with mental disabilities, *see* Robert M. Levy and Leonard S. Rubenstein, THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES 159 (1996).

[170] *See* discussion in Ramcharan, *supra* note147 at 261-3. One member of the Human Rights Committee observed that "article 26 could not be interpreted as referring only to public acts. It must cover the internal system of a country and the authorities who decided who could work, occupy land, and so forth. If the State owned all housing and was the sole employer then its provisions applied to the State. In a different system, however, with private housing and numerous private employers, it was the latter who must be prevented from practicing

accommodation under the ICESCR is at its strongest in the area of public accommodations, particularly where they impact on the right to health. Public programs that allow non-disabled people to live in the community and avoid institutionalization may, for example, need to be crafted so that they meet the needs of individuals with mental disabilities. If a government creates a foster care program for all children, a child with a mental disability could make a claim for reasonable accommodation to ensure that he or she could benefit from the program. For example, reasonable accommodation might mean the provision of counseling to the parents on the needs of a child with a mental disability or an additional payment to a family to cover respite care.

B. Rule of Proportionality & Due Process Protections

International human rights law has developed rules to determine which distinctions are legitimate and which constitute unlawful discrimination. The UN Human Rights Committee has stated that a distinction is justified "if the criteria for ... differentiation are *reasonable and objective* and if the aim is to achieve a purpose which is *legitimate*."[171]

Even though Article 14 of the European Convention contains a more limited scope of protections than Article 26 of the ICCPR, the case law under the European Convention provides useful guidance in the further interpretation of the convention's requirements. In the *Belgian Linguistic* case, the European Court pointed out that "[a] difference of treatment in the exercise of a right ...must not only pursue a legitimate aim: Article 14 is likewise violated when it is clearly established that there is no reasonable relationship of proportionality between the means employed and the aim sought to be realized."[172] A restriction is not considered proportionate if a less restrictive alternative can be shown to be equally effective.[173] When a right must be restricted, the principle of proportionality may require governments to use appropriate due process.[174] This may include judicial safeguards, such as a hearing or a guarantee of independent and impartial decision-making.[175]

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discrimination." Tarnopolsky, UN Doc. CCPR/C/SR.170, ¶ 82 (1979), *as cited in* Ramcharan at 262. In General Comment 14 on the right to health, "the Committee stresses the need to ensure that not only the public health sector but also private providers of health services and facilities comply with the principle of non-discrimination in relation to persons with disabilities." General Comment 14, para. 26.

[171]General Comment No. 18, ¶ 7 (emphasis added).

[172]*Belgian Linguistics Case* (1979-80) 1 EHRR 241.

[173] *Campbell v. UK* (1993) 14 EHRR 137.

[174] *W. v. UK* (1988) 10 EHRR 29.

[175] *See* discussion in Keir Starmer, EUROPEAN HUMAN RIGHTS LAW 147 & 175 (1999).

The principle of proportionality is similar to the approach taken in the Siracusa Principles for the derogation of rights. The Siracusa Principles create the outside parameters for the protection against discrimination – setting forth a rule for the extreme cases where the right to protection against discrimination can be derogated. The Siracusa Principles would permit a derogation of the protection against discrimination if the limitation were "strictly necessary" for a legitimate objective of public interest – provided that there were not less restrictive way for that objective to be met.[176]

C. Applications of Protection Against Discrimination in Mental Health Law

Protections against discrimination impact all areas of government practice. As the Human Rights Committee has stated, "[t]he impact of the right contained in Article 26 may extend also to any legislative measure in domestic law...."[177] While protections against discrimination in education, employment, housing, or access to public services may be the most common areas where anti-discrimination laws are needed, it is also important to examine the implications of anti-discrimination law for areas of mental health practice in which people with mental disabilities are treated differently from other individuals.

1. The Right to Community Integration

The protection against discrimination has major implications for the broadest legal framework in which mental health systems operate. Throughout the world, outmoded mental health systems provide services within the segregated environment of closed institutional wards for people with mental disabilities who would be capable of living in the community if services and support systems were located there. General Comment No. 5 recognizes that the right to community integration - including the right to medical and social services to permit people to participate fully in the community - is needed to protect people with disabilities against discrimination under the ICESCR. While there is no specific language about this in the general comments of the ICCPR, the identification of segregated services as a form of discrimination under the ICESCR may indicate that the ICCPR provides similar protections.[178]

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[176] *See infra* note 220 and accompanying text discussing the Siracusa Principles.

[177] General Comment 20(44), ¶ 2, *in* UN MANUAL ON REPORTING, *supra* note155 at 255.

[178] *See* Gerard Quinn, *The International Covenant on Civil and Political Rights*, *in* HUMAN RIGHTS AND DISABLED PERSONS 84 (Theresia Degener and Yolan Koster-Dreese, eds., 1995).

This is an area in which law is continuing to evolve, and US anti-discrimination may serve as a model in other countries. In *Olmstead v. L.C.*,[179] the United States Supreme Court has interpreted the Americans with Disabilities Act of 1990 [180] and its implementing regulations, which oblige States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[181] In doing so, the Supreme Court ruled that it is discrimination to deny people with disabilities services in the most appropriate integrated setting.

The Court stated that "[u]njustified isolation . . . is properly regarded as discrimination based on disability." It observed first, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Secondly, the Court found that institutional confinement severely curtails opportunities for participation in everyday activities, such as family and social activities, work and educational options, economic independence and cultural enrichment. To remedy this type of discrimination, the Court stated that the ADA requires states to serve individuals with disabilities in community settings rather than in segregated institutions when this is appropriate and reasonable in light of certain factors.

If the reasoning of the US Supreme Court were to be adopted in interpreting the non-discrimination provisions of the ICESCR and ICCPR, there would be major implications for the tens of thousands of people with mental disabilities who are confined in institutions throughout the world without a current clinical justification for their segregation from society. The disability rights experts convened by UN Special Rapporteur Bengt Lindqvist in November 2000 discussed this matter and supported this principle.[182] The experts concluded that mental health services provided in an exclusively segregated environment are "inherently suspect as a form of discrimination" under international human rights law.

2. Improper guardianship as discrimination

The use of guardianship, as practiced in many countries of the world,[183] can be a form of discrimination under international human rights law. In theory, guardianship is used to protect individuals who are unable to look out for their own interests. In practice, guardianship may

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[179] 527 U.S. 581 (1999).

[180] 42 U.S.C. §12101 (2000).

[181] 28 C.F.R. §35.130(d) (2000).

[182] *See supra* note141 (discussing the conference at Almasa, Sweden in November 2000).

[183] *See, e.g.* MDRI, Human Rights & Mental Health: Hungary at 58; MDRI, Human Rights & Mental Health: Mexico at 34.

improperly strip people of their right to make some of the most important and basic decisions about their life. It is a common practice in many countries for individuals with a psychiatric diagnosis or mental retardation to be considered "mentally incompetent" without any form of legal process. Where legal process is used, an individual with limited disabilities (as well as many practical abilities) may be placed under "plenary guardianship" -- and stripped of all rights to make choices about his or her life. In some countries, guardianship procedures have been used to circumvent laws that would protect against improper involuntary detention in a psychiatric facility. Once a family member or the director of a psychiatric facility is declared an individual's guardian, he or she may "voluntarily" commit a person to a psychiatric facility -- without ever asking that person what he or she really wants and, in fact, over the active objection of the person. Without due process protections for the review of that decision, guardianship can be used to commit a person to an institution for life.

MI Principle 1, which protects against discrimination on the basis of mental illness, specifies that:

> Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an *independent and impartial tribunal established by domestic law.* The person whose capacity is at issue shall be entitled to be represented by counsel. MI Principle 1(6) (italics added).

In addition to providing a right to legal counsel, MI Principle 1(6) provides detailed provisions to ensure that these rights are effective, including the right to payment for such counsel if an individual lacks resources. MI Principle 1(6) requires there be protections against a conflict of interest between the individual and the mental health facility or its personnel. Thus, "counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue...." MI Principle 1(6) also provides a right to the periodic review of any decision regarding capacity "at reasonable intervals prescribed by domestic law" and provides a right to appeal this decision to a higher court.

There are many safeguards to protect against the improper use of guardianship developed under the domestic laws of many countries that the MI Principles do not mention. The lack of any mention in the MI Principles does not mean that human rights law does not create additional obligations in this area. In many countries, courts are required to limit the power of guardians to only those subjects or areas in which a person is shown to truly lack legal competence. These laws strive to enable individuals with mental disabilities, who cannot necessarily make all decisions about themselves, to nevertheless retain the opportunity to make most decisions. This matter has not yet been tested by international courts, but the principle of "proportionality" under international discrimination law would seem to require a close relationship between any limitation on a person's legal rights and his or her actual ability to make decisions about himself or herself with regard to a specific activity.

IV. Inhuman & Degrading Treatment

The Article 7 protection in the ICCPR against "inhuman and degrading treatment" is one of the most important protections under international human rights law for people with mental disabilities. Article 7 reads in full:

> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

Article 7 is such an important part of the ICCPR, it is designated as one of the provisions that is "non-derogable" – it can never be limited even under conditions of national emergency.[184] It is notable that the first sentence of Article 7 is a verbatim repetition of Article 5 of the UDHR, which is widely considered to be binding, customary international law. Thus, the protection against torture or inhuman and degrading treatment is applicable even to countries that have not ratified the ICCPR.

Article 7 of the ICCPR requires governments to establish protections that would prevent unnecessary physical or mental suffering. [185] While Article 7 as a whole is non-derogable, there is an important distinction between "torture" and "inhuman and degrading treatment" under this provision of the ICCPR. For an action to constitute torture, pain and suffering must be inflicted upon a person by a government authority (or some person acting under government authority) for some unlawful purpose. [186] While "intent" plays some role in determining whether a practice

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[184] *See supra* note 9, Art. 4(2). The UN Human Rights Committee states that "Article 7 allows no limitation. The Committee reaffirms that, even in situations of public emergency such as those referred to in Article 4 of this Covenant, no derogation from the provision of Article 7 is allowed and its provisions must remain in force...[N]o justification or extenuating circumstances may be invoked to excuse a violation of Article 7 for any reasons..." General Comment 20(44), para. 3, *in* UN MANUAL ON REPORTING, *supra* note 155 at 196.

[185]General Comment 20(44) states that "Article 7 relates not only to acts that cause physical pain but also to acts that cause mental suffering to the victim." *See also* Manual on Reporting, *supra* note155 at 196, ¶ 5.

[186] In The Greek Case, the European Commission stated, "The word 'torture' is often used to describe inhuman treatment which has a purpose, such as the obtaining of information or confession, or the infliction of punishment, and it is generally an aggravated form of inhuman treatment." 12 Y.B. Eur. Conv. On H.R. 186 (1969) (Eur. Comm'n on H.R.) Even though their

constitutes inhuman and degrading treatment, this is not required to demonstrate a violation of Article 7. This distinction is extremely important when looking at the application of Article 7 requirements to the treatment of people in psychiatric hospitals or social institutions. The vast majority of mental health professionals, staff or administrative authorities would not intentionally cause harm or great suffering to an individual, but a broad range of practices may cause suffering or an affront to an individual's dignity. Mistreatment as a result of neglect or failure to take precautions to prevent or stop abuse is common. Often neglect may be due to a lack of resources or staff. [187] The linkage between the protection of individuals in medical research and the protections against torture and inhuman treatment in the language of the ICCPR is an indication that this protection was not intended to be limited to politically-motivated actions by government authorities but is also applicable to medical or scientific practices.[188]

The recent case of *Price v. United Kingdom*, decided by the European Court of Human Rights in July 2001, demonstrates the application of the protection against inhuman and degrading treatment to people with disabilities.[189] Ms. Price is a woman with a physical

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decisions technically apply only to the European Convention of Human Rights, the European Court and Commission of Human Rights have had a great deal of influence on the developing the understanding of the prohibition against torture and inhuman treatment.

[187] For example, a significant subset of people with mental disabilities also suffers from seizure disorders. The institutions in which they are confined may not have access to adequate seizure medications to provide them prophylactically, and patients may suffer seizures which cause them great harm, including death. The institutions may not have the facilities to perform regular blood level monitoring for patients on seizure medication or those receiving lithium for treatment of manic depressive illness. Patients may receive either too little medication to achieve therapeutic benefit or too much, causing toxicity.

[188]*See* Eric Rosenthal, *The International Covenant on Civil and Political Rights and the Rights of Research Subjects, in* ETHICS IN NEUROBIOLOGICAL RESEARCH WITH HUMAN SUBJECTS 265, 266 (Adil E. Shamoo, ed., 1997). At the time the covenants were being drafted in 1948, the horrors of the Holocaust were still fresh. As legal experts met to draft the covenants, Nazi doctors who had used people in concentration camps as "guinea pigs" in dangerous and often fatal experiments were being tried at Nuremberg. Seeing the dangers of unlimited medical authority without any regulation or control, the authors of the ICCPR linked the principle of individual choice with the most basic human rights protections in the convention. S. Perley, S. Fluss. Z. Bankowski, and F. Simon, *The Nuremberg Code: An International Overview*, *in* THE NUREMBERG CODE: HUMAN RIGHTS IN HUMAN EXPERIMENTATION 153 (George J. Annas and Michael A. Grodin eds. 1992).

[189] *Price v. United Kingdom,* Application No. 3394/96, 10 July 2001. The European Court of Human Rights considered the case under Article 3 of the European Convention. Article 3, like Article 7 of the ICCPR, states that "[n]o one shall be subjected to torture or to inhuman or

disability who uses a wheelchair (she is described by the Court as "four-limb deficient" and "suffers from problems with her kidneys").[190] During a civil proceeding she was placed in jail for seven days for contempt of court. The cell in which she was placed was not adapted for a person with a disability, and so she was forced to sleep in her wheelchair. Emergency buttons and light switches were out of her reach, and the toilet was not accessible. When she was finally given access to a toilet, she was left there for hours and undressed in front of male guards.

The European Court found that this treatment constituted degrading treatment under the Convention. The Court noted that "ill-treatment must attain a minimum level of severity if it is to fall within the scope of" the convention. Even though there had been no intent to cause harm to this woman, the failure to accommodate her needs caused her great suffering. The Court stated that: "In considering whether treatment is "degrading" within the meaning of [the Convention] one of the factors the Court will take into account is the question whether its object was to humiliate or debase the person concerned although the absence of any such purpose cannot conclusively rule out a finding of violation…."[191] In this case, the court found degrading treatment in violation of the covenant, even though it found "no evidence in this case of any positive intention to humiliate or debase the applicant."

In recent years, the UN Human Rights Committee has taken a strong stand on the application of Article 7 of the ICCPR to all people in detention, including individuals in psychiatric facilities. General Comment 20(44) states that Article 7 "is complemented by the positive requirements of Article 10, paragraph 1 of the Covenant, which stipulates that 'All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.'" In addition, the Human Rights Committee has stated that "[i]t is appropriate to emphasize ... that Article 7 protects, in particular, children, pupils, and patients in teaching and medical institutions."[192] The UN Manual on reporting points out that "Article 7 protects not only detainees from ill-treatment by public authorities or by persons acting outside or without any official authority but also in general any person. This point is of particular relevance in situations concerning ... patients in ... medical institutions, whether public or private."

When governments report on their actions to implement Article 7, the UN Human Rights Committee encourages governments to "address the conditions and procedures for providing

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degrading treatment or punishment." While the interpretation of the European Court is binding only under the European Convention, its decisions are influential in the understanding of similar provisions of the ICCPR.

[190] *Id.* ¶ 7.

[191] Id. ¶ 24.

[192] General Comment 20(44), ¶ 5, *IN* UN MANUAL ON REPORTING, *supra* note155 at 197.

medical and particularly psychiatric care. Information should be provided on detention in psychiatric hospitals, on measures to prevent abuses in this field, on appeals available to persons interned in a psychiatric institution and on any complaints registered during the reporting period." By calling on governments to report on conditions in psychiatric facilities, appeals processes, and complaint procedures, the UN Human Rights Committee makes clear that government legislation and practice in these matters raise fundamental human rights concerns protected by Article 7 of the Covenant. Legislation is needed to define the expected standard of care and to protect against mistreatment. In order to protect these rights, governments must not only establish legislation that prohibits abuses but also must ensure the enforcement of these laws.[193] Legislation may need to be enacted to create safeguards, such as systems for inspection or independent monitoring. Systems for investigating complaints must also be established as part of domestic legislation.[194]

A. Extra vigilance required in mental health and disability cases

There is a high threshold for an affront to individual dignity or the amount of suffering needed for a practice to rise to the level of inhuman and degrading treatment in violation of Article 7. While the European Court has been open to the possibility of finding inhuman and degrading treatment in institutions, there is a long line of cases in which the Court found that the amount of suffering caused by poor conditions did not meet the standard required by the Convention.[195] However, the European Court did establish the principle that special scrutiny is required in the case of people detained in psychiatric facilities. In *Herzcegfalvy v. Austria*, the Court observed that, "[t]he position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with." [196]

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[193] General Comment 20(44) states that "States Parties should indicate how their legal system effectively guarantees the immediate termination of all acts prohibited by Article 7 as well as appropriate redress." *Id.* ¶ 14.

[194] "[T]he right to lodge complaints against maltreatment prohibited by Article 7 must be recognized in the domestic law." *Id.*

[195] One scholar who reviewed the European Court's decisions in 2000, before the *Price* case was decided, observed that "[t]he Strasbourg authorities have been so deferential in their Article 3 jurisprudence that the Commission or Court has never found that the conditions in a mental hospital were so inhuman and degrading as to breach Article 3. Yet, severe maltreatment, neglect, or humiliation of patients, or placing them in punitive or unsafe environments should give rise to an Article 3 claim." Lawrence Gostin, *Human Rights of Persons with Mental Disabilities*, 23 International Journal of Law & Psychiatry 125, 152 (2000).

[196] Judgment of 24 September 1993, 244 Eur. Ct. H.R. (ser. A), ¶ 82, 15 E.H.R.R. 437 (1993).

The case of Victor Rosario Congo – the first case regarding the rights of a person with a mental disability issued by the Inter-American Commission on Human Rights – builds on the approach adopted by the European Court in *Herczegfalvy*, demonstrating the importance of looking at the particular vulnerability of people with mental disabilities subject to detention. In this case, a 48 year-old man in Ecuador was placed in detention at a Social Rehabilitation Center on September 12, 1990 after he was charged in a criminal case. He appeared depressed, unresponsive to questions by the guards, and "behaved in a way that suggested mental disorder."[197] Two days after his detention, when Congo did not respond to questions, a guard "shouted questions over and over at him, which clearly made him more demented…"[198] The guard later beat him and left a wound in his scalp. Congo received no medical treatment and was detained in an isolation cell naked and virtually *incommunicado.* A medical expert who interviewed Congo three weeks after his detention stated that he had developed psychiatric symptoms as a result of the trauma he experienced in detention.[199] On October 23, 1999, a judge ordered Congo transferred to a hospital where he could receive appropriate treatment. Both a psychiatric hospital and a general hospital refused to admit him. On October 25, 1999, Congo was transferred to another Social Rehabilitation Center, where he was found to be in a "critical state of health" due to severe dehydration. He was brought immediately to a hospital where he died of dehydration hours after he was admitted.[200]

The Inter-American Commission found that the government of Ecuador violated Congo's right to life and subjected him to inhuman and degrading treatment.[201] The Commission found that Congo did not die of the wound inflicted by the beating but because of dehydration that resulted from the lack of diligence to Congo's mental and physical health. Even though the government did not actively deprive Congo of food and water, it failed to take the care, including psychological care, necessary to ensure that Congo would be protected.

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[197] *See supra* note 79, at ¶ 7; *see also supra* text accompanying note 22.

[198] *Id.* ¶ 9.

[199] *Id.* ¶ 15.

[200] *Id.* ¶ 19.

[201] *Id.* ¶ 101.

The Commission's ruling on the violation of Congo's right to life[202] is not as striking as its analysis of whether Congo had been subjected to "inhuman and degrading" treatment.[203] For this analysis, the Commission "deems it pertinent to apply *special standards* to the determination of whether the provisions of the Convention have been complied with in cases involving persons suffering from mental illnesses."[204] The Commission states that the protection against inhuman and degrading treatment under the American Convention "must be interpreted in light of the" MI Principles.[205] The Commission notes that detention of a person in a small, isolated cell "can itself constitute inhumane treatment. [But]… when the person kept in isolation in a penitentiary institution has a mental disability, this could involve an even more serious violation of the State's obligation to protect the physical, mental and moral integrity of persons held under its custody."[206] The Commission found that placement in isolation itself constituted inhuman and degrading treatment and that "[t]his violation is aggravated by the fact that he was left in isolation unable to satisfy his basic needs."[207] The Commission found that detention "under deplorable conditions and without medical treatment" constituted an additional form of inhuman and degrading treatment.[208] Finally, the Commission noted that "the right to physical integrity is

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[202] The decision on the protection of the right to life is valuable to understanding the minimum protections required by the American Convention. The Commission stated that "international standards applicable establish that every detention center shall possess the services of at least one qualified physician, who must possess some psychiatric knowledge. This physician must be responsible for the physical and mental health of the inmates and must see those with health problems every day as well as those drawn to his attention." *Id.* ¶ 80. In this specific case, "[t]he measures needed for [Congo's] survival consisted in medical care to heal his physical injuries, and such vital ministrations as cleansing, food, and psychological attention to treat his depression and the psychosis characteristics" of his psychiatric syndrome. *Id.* ¶ 74. Congo was diagnosed with "Ganser's syndrome" a diagnosis of psychosis caused by detention.

[203] As the Inter-American Commission is constituted to enforce the American Convention, this case concerns the application of article 5 of the American Convention. The language and jurisprudence of this protection are very similar to the protections under article 7 of the ICCPR.

[204] *Id.* ¶ 53 (emphasis added). The Commission cites the European Court of Human Rights' decision in *Herczegfalvy v. Austria* for support of this proposition. Para. 54, *citing Herczegfalvy v. Austria*, September 12, 1994, at ¶ 82.

[205] *Id.* ¶ 54.

[206] *Id.* ¶ 58.

[207] *Id.* ¶ 59.

[208] *Id.* ¶ 66, *citing* the European Court of Human Rights in *Ashingdane v. United Kingdom,* Application No. 8225/78 93, 6 EHRR 50 (1984).

even more serious in the case of a person held in preventative detention, suffering a mental disease, and therefore in the custody of the State in a particularly vulnerable position."[209]

Since *Congo* was decided, the July 2001 decision of the European Court of Human Rights in *Price v. United Kingdom* demonstrates a marked step forward from its past cases in recognizing the special circumstances of individuals with disabilities. In finding that a woman detained in jail for seven days had been subject to degrading treatment after she was forced to sleep in a wheelchair and left without an accessible bathroom, the Court stressed the importance of context:

> The Court recalls that ill-treatment must attain a minimum level of severity if it is to fall within the scope of [the convention.] The assessment of this minimum level of severity is relative; it depends on all the circumstances of the case, such as the duration of treatment, its physical and mental effects and, in some cases, the sex, age, and state of health of the victim.

For people with mental disabilities detained for a long duration in state of great vulnerability, this emphasis on "all the circumstances of the case" is very important. A person suffering from distress that might cause him or her to seek mental health treatment may experience higher levels of suffering from a practice that might cause only minimal suffering to a person at another point in his or her life who can benefit from a full range of social and psychological support systems. For example, a woman hospitalized for Post Traumatic Stress Disorder following a sexual or physical assault may re-experience the trauma of the assault when subjected to physical restraint in a manner that another person does not. Recent decisions of the European Court and Inter-American Human Rights Commission suggest that the standard that applies for people with mental disabilities is rapidly evolving and that courts recognize that extra vigilance is required on the part of governments to protect against inhuman and degrading treatment of people with mental disabilities.[210]

The Human Rights Committee has followed a similar line of analysis in its explication of Article 7 of the ICCPR. While there is no specific definition of "torture, inhuman or degrading" treatment in the Covenant and "no sharp distinctions between the different kinds of punishment or treatment; the distinctions depend on the nature, purpose, and severity of the treatment applied."[211]

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[209] *Id.* ¶ 67.

[210] It is an accepted rule of interpretation that the ECHR is a "living instrument" subject to "dynamic interpretation" in light of "present day conditions." *See* Starmer, *supra* note176 at 160.

[211] *Id.* ¶ 4.

B. Applications

The MI Principles establish a broad array of minimum standards for treatment within psychiatric institutions, and as noted above, legislation to ensure the fulfillment of these standards may be needed to protect the right to health under the ICESCR. When the violation of these same standards causes great suffering or personal degradation, these practices should also be seen as a violation of Article 7 of the ICCPR and Article 5 of the UDHR. When individuals detained in institutions are kept in unhygienic conditions, for example, such treatment is not only unhealthy but also causes physical and mental suffering and degradation. The threshold of suffering required to prove an Article 7 violation is high, and so not every violation of the MI Principles will constitute a violation of the ICCPR. However, the obligation on the part of governments to prevent inhuman and degrading treatment is much greater than the obligation to protect the right to health – indeed, whether or not a State has ratified the ICCPR, it is bound by the identical language of Article 5 of the UDHR. Whereas the ICESCR recognizes that governments have constraints on their budgets and that "progressive realization" of the right to health may take place over time, the ICCPR requires immediate enforcement for every individual. The lack of financial or professional resources is not an excuse for inhuman and degrading treatment. Governments are thus required to provide adequate funding for the basics needed to protect against suffering that can be caused by a lack of food, clothing, proper staffing at an institution, protection of basic hygiene, and provision of an environment that is respectful of individual dignity.

The exact contours of Article 7 requirements with regard to basic conditions of living in institutions have not yet been fully tested, and consequently, it is not clear to what extent the MI Principles would have to be violated before they could be considered to cause inhuman or degrading treatment. One scholar has suggested, "a deliberate policy to treat persons with disabilities under separate arrangements simply for the sake of administrative convenience might amount to second class citizenship and is thus at least arguably 'degrading' as per art. 7."[212]

There are some clinicians who believe in the use of aversive therapy in which a variety of noxious or painful stimuli are deliberately applied to an individual in order to change or extinguish a behavior that is believed to be harmful or undesirable. The aversives used can include being sprayed with pepper, receiving jolts of electricity, deep muscle pinches, slaps, being placed in sensory deprivation chambers, wearing "white noise" helmets, and so on. In some cases, the application of aversive procedures can be frequent and unrelenting and may very well be experienced by the recipient as inhuman and degrading.

Whether or not these examples are ultimately found by international oversight bodies to be inherently degrading, a number of provisions of the MI Principles regarding the rights of

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[212] Gerard Quinn, *The International Covenant on Civil and Political Rights, in* HUMAN RIGHTS AND DISABLED PERSONS 84 (Theresia Degener and Yolan Koster-Dreese, eds., 1995).

people in psychiatric facilities can be seen as an essential part of the Article 7 protection of the ICCPR, including:

1. Neglect and inhuman or degrading conditions of living

Under MI Principle 13, "[t]he environment and living conditions in mental health facilities shall be as close as possible to those of normal life of persons of similar age…." This includes facilities for leisure, education, and vocational rehabilitation. The MI Principles recognize a right to freedom of communication, a right to receive visitors in private, "and freedom of access to postal and telephone services and to newspapers, radio, and television." MI Principle 8(1) requires that "[e]very patient shall have the right to receive such health and social care as is appropriate to his or her health needs and is entitled to care and treatment in accordance with the same standards as other ill persons." In order to make this possible, Principle 14(1) requires that resources should be provided to ensure "[q]ualified medical and other appropriate professional staff in sufficient numbers and with adequate space to provide each patient with privacy and a programme of appropriate and active therapy."

The provision of a safe and hygienic environment is not only a matter of physical health but also critical to a person's overall mental health and well-being. Any individual who is forced to subject himself or herself to unsafe or unsanitary conditions just to be able to receive mental health treatment or social support should be protected against the suffering and degradation that such conditions may cause. Some institutions may lack adequate food and clothing for all the residents; may be unable to provide adequate heat or warm clothing in the winter, leading to illness or death of residents; and may lack adequate health care and facilities to prevent the spread of contagious diseases. The shortage of staff may lead to practices in which patients are forced to perform institution maintenance labor without pay or in exchange for minor privileges. Not only may such practices constitute inhuman and degrading treatment in violation of Article 7 of the ICCPR, but also they may violate Article 7 of the ICESCR and Article 23 (the right to work) of the UDHR.[213]

MI Principle 13(2) specifically requires conditions to be age appropriate. It is common in institutions for adults with mental disabilities to be limited to activities that would be completely inappropriate to people of their age in society at large. Adults may be given children's toys or activities or may be left to repetitive tasks that they find mind numbingly boring. More

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[213] The International Covenant on Economic, Social and Cultural Rights, Article 7 recognizes the "right of everyone to the enjoyment of just and favorable conditions of work which ensure, in particular:

(a) Remuneration which provides all workers, as a minimum, with: (i) fair wages and equal remuneration for work of equal value without distinction of any kind…. *See supra* note 21, Principle 13 (3)(4).

pervasively, adults in institutions often spend their days without any purposeful activity at all. The absence of opportunities to engage in normal adult activities contributes to a progressive deterioration of their functioning abilities and a loss of skills. On a single occasion, it is hard to imagine these practices amounting to inhuman and degrading treatment. Over the course of months or years without a break or a chance to engage in appropriate leisure or educational activities, such practices could easily become inhuman and degrading. The Human Rights Committee has stated that the duration of a particular practice is one factor that will be taken into consideration in the determination as to whether treatment is inhuman and degrading. Individuals who are involuntarily detained, or who are forced to live in such conditions for more than a very short period of time, would be subject to heightened protections.

2. Protection from Harm

As noted above, Article 7 of the ICESCR also includes a right to protections against practices that pose a direct threat to the health of an individual. In this sense, the right to health under the ICESCR is closely linked with the protection of the "right to life" under Article 6 of the ICCPR - which requires governments to protect against conditions that might threaten an individual's life. Both rights entail a "negative" protection against government action that might threaten life or health and a "positive" protection on the part of government to take specific steps to protect life and health.[214]

The MI Principles provide a number of important provisions that elaborate on this aspect of the right to health. Under MI Principle 8, "[e]very patient shall be protected from harm, including unjustified medication, abuse by other patients, staff, or others, or acts causing mental distress or physical discomfort." Principle 8 is very important because it makes clear that improper medical or psychiatric treatment constitutes a form of prohibited "harm" similar to abuse by other staff or patients. Safeguards against abuse are thus an essential part of enforcing the right to health.

There are several implications of the individual's right to protection from harm for the obligations of governments and their agents. While all harm is probably not preventable, much of it is foreseeable and therefore requires attention. For example, in institutions serving people with mental disabilities, reasonable efforts ought to be made in the diagnostic and individual treatment planning process to separate violent individuals from the more vulnerable, to provide adequate supervision to prevent physical and sexual assaults between patients, and to train staff adequately

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[214] The UN Human Rights Committee, established by the ICCPR to interpret the convention, states that "the right to life has been too often narrowly interpreted. The expression 'inherent right to life' cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures." General Comment on Article 6, Report of the Human Right Committee, 37th Sess., A/37/40 at 93-94. *See* discussion in Leary, *supra* note107 at 487.

to equip them with the skills needed for the work required.[215] The practices in some institutions of delegating staff duties to patient "trustees" and empowering them to discipline other patients create a grave risk of abuse that violates MI Principle 8.

3. Medical and scientific experimentation

As noted above, the second clause of Article 7 of the ICCPR states that "no one shall be subjected without his free consent to medical or scientific experimentation." It is very unusual that the ICCPR would contain such specific language, and it is clear that the drafters of the convention intended to link the protection against torture, inhuman and degrading treatment with protections against coercive and potentially dangerous medical practices.

The United Nations Human Rights Committee interprets Article 7 very strictly with regard to its protection of voluntary consent. When a person is subject to any form of detention, General Comment 20(44) of the United Nations Human Rights Committee interprets the ICCPR to ban *any* experimentation on individuals unable to consent if the experiment poses a hazard to their health.[216] This provision recognizes that the inherently coercive environment of the institution compromises the voluntariness of any consent. The Ethical Principles for Medical Research Involving Human Subjects of the World Medical Association Declaration of Helsinki further addresses the limited conditions under which such research may be conducted. Principle 24 provides that research subjects who are legally incompetent or physically or mentally incapable of giving consent should not be included in research unless the research is necessary to promote the health of the population represented and this research cannot instead be performed on legally competent persons.[217]

This provision of Article 7 is of great significance and widespread applicability. It has been a common and customary practice in many countries to use residents of institutions in

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[215] See, Clarence J. Sundram, *Strategies to Prevent Patient Abuse in Public Institutions*, NEW ENGLAND JOURNAL OF HUMAN SERVICES, Vol. VI, Issue 2, 1986; Clarence J. Sundram, *Obstacles to Reducing Patient Abuse in Public Institutions*, HOSPITAL & COMMUNITY PSYCHIATRY, Vol. 35, No. 3, pp. 238-243 (March 1984).

[216]General Comment 20(44) states that "Article 7 expressly prohibits medical or scientific experimentation without the free consent of the person concerned. . . The Committee also observes that special protection in regard to such experiments is necessary in the case of persons not capable of giving valid consent and in particular those under any form of detention or imprisonment. Such persons should not be subjected to any medical or scientific experimentation that may be detrimental to their health." UN MANUAL ON HUMAN RIGHTS REPORTING, *supra* note155 at 197, ¶ 7.

[217] The World Medical Association, Inc., *World Medical Association Declaration of Helsinki: The Ethical Principles for Medical Research Involving Human Subjects* (visited Jan. 22, 2002) < http://www.wma.net/e/policy/17-c_e.html >.

scientific experimentation that requires the use of human subjects.[218] This is especially true in the area of experimentation involving new medications. Some of the drug trials may involve medications that are potentially beneficial to the patients recruited for the trial; but others may involve medications of no direct benefit to the patient while also posing a significant degree of risk. At a minimum, Article 7 would require that before a patient is permitted to enroll in experimental treatment, a clinical determination must be made by a qualified professional that the patient is competent to consent and does in fact provide consent based on a full disclosure of the risks and benefits. Article 7 does not provide for surrogate consent to experimentation upon an individual not capable of informed consent,[219] and the concerns of the United Nations Human Rights Committee also argue strongly against consensual participation in non-therapeutic research due to the inherently coercive environment experienced by the institutionalized person.

However, this is another area in which the language of the MI Principles appears to offer a lesser degree of protection than that contained the ICCPR. Principle 11 states:
"Clinical trials and experimental treatment shall never be carried out on any patient without informed consent" but then proceeds to carve out an exception that swallows the rule by stating that "a patient who is unable to give informed consent may be admitted to a clinical trial or given experimental treatment, but only with the approval of a competent, independent review body specifically constituted for this purpose." There is no prohibition against non-therapeutic experimentation. Experience has demonstrated how limited this protection is.[220]

4. Protection from Coerced Treatment

While the second clause of Article 7 applies only to experimental treatment, the core protection against inhuman and degrading treatment in both the ICCPR and Article 5 of the UDHR may apply more generally to coercive treatment that is potentially dangerous or degrading. MI Principle 11 states that "no treatment shall be given to a patient without his or her informed consent..." but the MI Principles create many exceptions to this protection, and they do not recognize an affirmative right to refuse treatment. It is likely that Article 7 of the ICCPR provides greater protections. The exact protections of Article 7 with regard to non-experimental treatment have not been fully clarified by the UN Human Rights Committee, but coerced

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[218] Clarence J. Sundram, *In Harm's Way: Research Subjects Who Are Decisionally Impaired*, J. HEALTH CARE L. & POLICY, Vol. 1, 36-65 (1998)

[219] However, The Ethical Principles for Medical Research Involving Human Subjects of the World Medical Association Declaration of Helsinki do provide for surrogate consent in accordance with applicable law although they narrowly limit the types of permissible research. See Principles 24 and 26.

[220] *See* Sundram, *supra* note 220.

treatment would meet the general definition of inhuman and degrading treatment when it causes great suffering or degradation.

A particular treatment decision may be contrary to deeply held social, medical, political or religious values held by 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. Article 7's protections recognize the importance of mental as well as physical suffering and the context in which that suffering occurs.

5. Seclusion and Restraints

The seclusion and restraint of people in psychiatric facilities are common practices that may cause great degradation or suffering. In many countries, individuals may be placed in restraints at the discretion of ward staff with no standards to determine whether this is appropriate and no procedural protections against abuse. In a number of countries, human rights organizations have documented the detention of individuals in cages.[221] Some cages are built over beds such that an individual cannot stand up. Unable to go to the bathroom, people in cages may remain for hours or days covered in their own urine or feces. According to staff at one facility, authorities reported that many people were placed in cages in the evening or over the weekend when staff levels were insufficient. At one psychiatric facility, staff routinely locked everyone in their rooms at 3pm until the next morning because staffing levels were insufficient to monitor patients.

Some people are detained for long periods of time because staff members consider them "potentially" dangerous to themselves or others or because there are no professionals on staff who know how to provide appropriate treatment. At one facility, a human rights organization reported that it found a person with a history of alcoholism held in a cage for months at a time to prevent him from escaping the institution or finding alcohol. A human rights group reported that it observed an institution where children were strapped to beds, tied down to wheelchairs, or left for hours in straitjackets.[222] Staff at one facility explained that children who were self-abusive had to be kept in restraints almost all the time because of the lack of any form of treatment or professional assistance to control the problem of self-abuse.

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[221] *See, e.g.* Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: HUNGARY (1997). *See,* www.amnesty.org EUR 15/002/2001 for Bulgaria Action Alert.
[222] Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: MEXICO (2000).

The UN Human Rights Committee specifically mentions "prolonged solitary confinement" as a practice that may amount to a violation of Article 7.[223] The MI Principles state that "[p]hysical restraint or involuntary seclusion of a patient shall not be employed except in accordance with the officially approved procedures of the mental health facilities and only when it is the only means available to prevent *immediate or imminent harm* to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose."[224]

The MI Principles create a substantive standard that defines the purpose of seclusion or restraint (to protect against imminent harm) so as to limit these practices to a narrow set of circumstances. The use of physical restraints as a tool of administrative convenience or ward management is clearly prohibited. The MI Principles also prohibit the use of seclusion or restraints by psychiatric facilities that use these procedures because they are under-staffed and cannot supervise patients. In this circumstance, the use of restraints or seclusion is not the "only means available" to protect against harm – the provision of adequate staff to supervise or monitor patients would be a much more humane alternative. By limiting the time that restraints can be used to a period for which they are "strictly necessary" the MI Principles make clear that this is a form of crisis management only. If a person is very upset but calms down after a short time, that person would have to be released from seclusion or restraint.

The MI Principles require that "[a] patient who is restrained or secluded shall be kept under humane conditions and be under the care and close and regular supervision of qualified members of the staff." The fact that the MI Principles require close and regular supervision by qualified staff reinforces the fact that these practices should not be used in lieu of adequate staff since staff would have to be available to observe and monitor a person even if he or she were in seclusion or restraints. Any system of restraints that leaves a person covered in his or her own urine or feces or unable to stand up or move around freely for long periods of time would certainly be considered inhumane.

The MI Principles also create procedural protections to safeguard against abuse. They require that "[a]ll instances of physical restraint or involuntary seclusion, the reasons for them and their nature and extent shall be recorded in the patient's medical record." In addition, "[a] personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient."

6. Protection against Punishment

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[223] General Comment 22(40), *in* UN MANUAL ON REPORTING, *supra* note155, ¶ 6.

[224] *See supra* note 21, Principle 11(11) (emphasis added).

Like Article 7 of the ICCPR, Article 5 of the UDHR provides, "No one shall be subjected to torture or cruel, inhuman or degrading treatment or punishment."

It is an unfortunate reality that, on occasion, methods of treatment may also be used as forms of punishment. These include electro-convulsive therapy (ECT) and the most common form of psychiatric treatment, psychotropic medications. The use of "unmodified ECT" without anesthesia or muscle relaxants creates a serious risk of harm to patients, including fractures and other injuries. In some institutions, untrained and unsupervised ward staff have been known to use medications as a form of control over patients, to punish them for transgressions by sedating them to make them more manageable and reduce the demands upon limited staff to provide supervision or offer therapeutic programs.

Principle 10 prohibits the use of medication as a punishment or for the convenience of others. This reinforces the core concepts in the Principles of professional treatment, diagnosis in accordance with internationally accepted standards, adequate professional staff, individualized treatment and the use of medications for diagnostic and therapeutic purposes only. Thus, Principle 10 and the related protection against the unjustified use of medication in Principle 8(2) bring the protection in the ICCPR and the UDHR into the mental health facility.

7. Right to privacy

One of the most pervasive violations of human rights in psychiatric facilities is the violation of the right to privacy. People may be forced to live for years in dormitory-like wards where they are never able to have a moment of solitude. They may have no secure place in which to place their personal possessions or their clothing. They may have no privacy when bathing or toileting. Institutions may resort to convenient but degrading practices like "gang showers" in which groups of patients are stripped naked and hosed down. Even when they have a single or double room, staff or other patients may be able to violate their personal space. Intimate meetings with friends, family, or even a spouse may be restricted. Communication with family or friends is often monitored, and letters are opened.

MI Principle 13(1) protects the right to privacy, freedom of communication, and private visits. The right to privacy is also protected as a right in and of itself under Article 12 of the UDHR and Article 17 of the ICCPR, which states that "[n]o one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence..." Article 17 specifies that "[e]veryone has the right to the protection of the law against such interference...."

V. Liberty & Security of the Person

Article 9 of the ICCPR establishes that "[e]veryone has the right to liberty and security of the person. No one shall be subjected to arbitrary...detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law." UDHR Articles 3 and 9 provide similar protections.

Article 9 requires governments to adopt legislation to protect against arbitrary detention in psychiatric facilities. The MI Principles contain detailed guidelines that are helpful in interpreting the protections against improper detention in a psychiatric facility. The MI Principles establish both substantive standards and procedural protections necessary to protect against arbitrary detention in a psychiatric facility. An extensive body of case law from the European system of human rights interpreting the protection against arbitrary detention under the European Convention establishes a number of additional rights that may be greater than those established under the MI Principles. While this body of case law is binding only in countries that have ratified the European Convention, it may provide useful guidance in understanding the requirements of the ICCPR.

Unlike the Article 7 protection against inhuman and degrading treatment that is non-derogable, protections established under Article 9 are subject to limitation under very specific circumstances. The "Siracusa Principles" set forth internationally accepted standards for the derogation of certain rights.[225] The MI Principles protections against improper civil commitment to a psychiatric facility mirror many of the Siracusa Principles. Consistent with the MI Principles, the Siracusa Principles emphasize key policy goals that should be incorporated into mental health legislation. Any limitation of a person's right to be free from detention must be "strictly necessary" to achieve a legitimate public objective – such as public safety.[226] In addition, there must be "no less intrusive or restrictive means available" to meet the same objective. Thus, the Siracusa Principles underscore the fact that any involuntary psychiatric commitment should be a last resort, used only after all the options for appropriate community treatment and support have been explored.

A. Psychiatric commitment - substantive standards

The MI Principles limit involuntary commitment to a psychiatric facility to people who have been diagnosed with a mental illness "in accordance with internationally accepted medical

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[225] The Siracusa Principles require that any limitation of rights meet the following five criteria:
1) The restriction is provided for and carried out in accordance with the law;
2) The restriction is in the interest of a legitimate object of general interest;
3) The restriction is strictly necessary in a democratic society to achieve the objective;
4) There are no less intrusive and restrictive means available to reach the same objective;
5) The restriction is not drafted or imposed arbitrarily, *i.e.* in an unreasonable or otherwise discriminatory manner.

[226] MI Principle 9 recognizes that "[e]very patient shall have the right to be treated in the least restrictive environment" and MI Principle 15(1) recognizes that "every effort shall be made to avoid involuntary admission."

standards."[227] On account of this mental illness a person must be found to meet one of two additional criteria. The first criterion is that the person must present a "serious likelihood of immediate or imminent harm to that person or other persons…." Principle 16(1) (a).

Alternatively, a person can be subject to involuntary commitment if his or "judgment is impaired" and "failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition or will prevent the giving of appropriate treatment that can only be given by admission to a mental health facility…." This second criterion for commitment is much broader than the first, and it creates a risk of opening up psychiatric commitment to anyone who is determined to "need treatment." Thus, it is extremely important that the second criterion is linked with the "principle of the least restrictive alternative," *i.e.* – a person cannot be involuntarily committed unless he or she could not receive appropriate services in the community.

The substantive standards established by the MI Principles are not as strong as those in many parts of the world where involuntary commitment is limited to the first criterion -- dangerousness to self or others.[228] The fact that a more narrow criterion has been proven successful in parts of the world casts doubt as to whether commitment for "appropriate treatment" is *ever* "strictly necessary" as would be required by the Siracusa Principles. No international oversight body has yet ruled on this specific question. Of course, the failure to develop any community-based treatment and support services may create the "necessity" for commitment, rendering the doctrine of Least Restrictive Alternative utterly meaningless in this context. Clearly, the MI Principles contemplate the availability of alternatives to institutional placement and reasoned consideration of such alternatives prior to an involuntary commitment decision.

B. Psychiatric commitment - procedural protections

The MI Principles permit detention for a "short period" which must be specified by domestic law "for observation and preliminary treatment pending review" by an independent body.[229] Any involuntary commitment after this time can only be ordered by "a judicial or other independent and impartial body established by domestic law in accordance with procedures laid down by domestic law." The review body determines whether the individual subject to detention

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[227] *See supra* note 21, Principle 4(1).

[228] The second criterion for commitment based on need for treatment is even more deferential to medical judgment than the standard proposed by the American Psychiatric Association. *See* Clifford D. Stromberg & Alan Stone, *A Model Law on Civil Commitment of the Mentally Ill*, 20 HARV. J. ON LEG. 275, 280 (1983).

[229] *See supra* note 21, Principle 16(2).

meets the substantive criteria discussed above. Thus, the determination as to whether the person should be committed, while initially a medical or psychiatric determination, is ultimately subject to judicial review to ensure that the determination is consistent with legal standards. The review body shall have at its disposal one or more qualified mental health practitioners, but they must also be independent of the institution seeking to commit the individual.[230] A person subject to involuntary commitment "shall have the right to appeal to a higher court…."[231]

Individuals subject to involuntary commitment have a right "to choose and appoint counsel to represent the patient as such, including representation in any complaint procedure or appeal."[232] This counsel shall be provided without payment if the individual lacks resources to pay. Where necessary, the government should also provide the assistance of an interpreter.[233] A person subject to commitment proceedings and his or her personal representative or counsel have the right to "attend, participate and be heard personally in any hearing."[234] The individual or counsel can request an independent mental health report and may present "oral, written or other evidence…."[235] The MI Principles also set forth procedures for making a patient's records available to the patient or counsel.[236]

People subject to involuntary civil commitment have a right to periodic review of their case. Under MI Principle 17(3), domestic law must set forth "reasonable intervals" for review, and the review must be conducted by the review body. At a periodic review, the same rights should apply as in the original commitment.

C. Guidance from the European Human Rights System

Jurisprudence from the European Court of Human Rights demonstrates how similar many of the provisions of the MI Principles are to the requirements of convention-based law. In some cases,

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[230] *Id.* at Principle 17(1).

[231] *Id.* at Principle 17(7).

[232] *Id.* at Principle 18(1).

[233] *Id.* at Principle 18(2).

[234] *Id.* at Principle 18(5).

[235] *Id.* at Principle 18(3).

[236] *Id.* at Principle 18(4). While the person subject to commitment has a general right of access to his or her records, this right may be limited where "disclosure to the patient would cause serious harm to the patient's health or put at risk the safety of others." As domestic law shall permit, records should be made available to counsel.

convention-based rights under the ICCPR or the European Convention on Human Rights (ECHR) may provide greater protections than do the MI Principles. There is a line of cases interpreting Article 5 of the ECHR, and these should be taken into account, particularly in countries that are also States Parties to the ECHR.[237] Cases interpreting the requirements of Article 5 may also be relevant to countries that are States Parties to the ICCPR outside Europe because the protections under Article 5 of the ECHR are similar – though not identical – to protections under Article 9 (the right to liberty and security of person) of the ICCPR.[238]

The line of cases established under article 5 of the ECHR helps clarify many points not specifically mentioned in the MI Principles. The European Court makes clear that improper placement in a psychiatric facility is governed by the protection against arbitrary detention – even if a person is occasionally permitted to leave the facility.[239] The MI Principles require review of any commitment within a "short period" established by law. In *E v. Norway,* the European Court of Human Rights has found that a delay of eight weeks violates the right to speedy review by a court,[240] and the judgment in the unpublished case of *Wassink v. Netherlands* would suggest that a three week delay would violate the convention.[241]

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[237] For a review of this case law, *see* Gostin, *supra* note 45 at 136-148 and Wachenfeld, *supra* note 45.

[238] Article 5(1) states that "No one shall be deprived of liberty save in the following cases and in accordance with a procedure prescribed by law." Article 5(1)(e) permits the "lawful detention of persons ... of unsound mind, alcoholic or drug addicts or vagrants." Article 5(2) protects the right of individuals to be informed of their reasons for arrest (which has been interpreted to include psychiatric detention), Article 5(4) provides a right to "speedy review" before an independent court or tribunal, and Article 5(5) provides a right to compensation for individuals who are improperly arrested or detained.

[239] In the case of *Ashingdane v. United Kingdom* the European Court of Human Rights found that an individual was "detained" in a psychiatric facility even though the patient was permitted to leave the facility on occasion. In this case, the Court found that the patient's "liberty, and not just his freedom of movement, has been circumscribed..." 93 Eur. Ct. H.R. (Ser. A), ¶ 42., 7 EHRR 528 (1985). The European Commission on Human Rights also stated that "a person detained in a psychiatric hospital would clearly still be regarded as 'deprived of his liberty' even if he was occasionally allowed to leave the hospital premises." *L v. Sweden,* App. No. 10801/84, Eur. Comm'n H.R., October 3, 1988 decision, ¶ 74, 61 Decisions & Reports 62, 73 (1988).

[240] Judgment on 29 August 1990, 181 Eur. Ct. H.R. (ser.A), ¶ 63 (1990).

[241] A/185–A Court (27 September 1993) (unreported) *as cited in* Starmer, *supra* note 176 at 500.

The landmark *Winterwerp v. Netherlands* case established that the European Convention provides individuals subject to commitment a right of "access to a court and the opportunity to be heard either in person or, where necessary, through some form of representation."[242] The affirmative right to a hearing is stronger than MI Principle 18(5), which never states that a hearing is required but recognizes the right to "be heard in any hearing."

The ECHR also provides more specific requirements regarding "access to a court."[243] MI Principle 17(1) requires review of any involuntary commitment by an "independent and impartial body" but mentions a right to a review by a court only when it refers to a right to "appeal" a decision by the review body.[244] The European Court has approved the use of an administrative body instead of a court as long as that body has a judicial character, provides procedural protections, and is independent from the parties in the case.[245] The European Court insists that the review body be part of a branch of government different from the psychiatric facility.[246] A person must still have a right to appeal a decision of such an administrative body to a court.[247]

The *Winterwerp* case also sets forth substantive standards for civil commitment. Mental disorder must be established by a mental health professional and must be sufficiently extreme to justify the deprivation of liberty. The Court does not try to define this level of mental disorder, recognizing that societal understanding of mental illness and its implications is continually evolving. More important, the Court makes clear that detention can only be justified as long as a mental disorder continues to persist at the level of severity originally required for involuntary commitment. This standard would suggest that the right to periodic review, established in the MI Principles, is also required by the ECHR. This view is supported by the European Court's 1993 decision in *Megyeri v. Germany,* which states that "where there is no automatic period of review of a judicial character" an individual subject to psychiatric commitment has a right "to

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[242] 33 Eur. Ct. H.R. (Ser. A) at 26 (1979).

[243] *Id., See also* review of case law in Starmer, *supra* note176 at 498.

[244] *See supra* note 21, Principle 17(7)

[245] *See* discussion in Gostin, *supra* note 45 at 145.

[246] *Id.*

[247]The Court has stated that "[w]here a decision depriving a person of his liberty is one taken by an administrative body, there is no doubt that Article 5(4) obliges the Contracting States to make available to the person detained a right to recourse by a court." *Versyp v. Belgium*, 12 ECHR (ser. A) ¶ 76, June 18, 1971.

take proceedings 'at reasonable intervals' before a court to put in issue the 'lawfulness' – within the meaning of the Convention – of his detention."[248]

VI. Safeguards

As is evident from history, including the reports of the Special Rapporteurs,[249] people with mental disabilities are vulnerable to abuse, neglect, mistreatment and exploitation, and especially so when they are confined in institutions. The reasons for these problems are legion and affect institutions in both developed and developing countries. They begin with the relatively low priority attached to services for people with mental disabilities, which restricts the range of options available to provide services in the community. This leads to over-reliance on institutions, which in turn leads to conditions that are often characterized by overcrowding, understaffing, and staff who are overwhelmed and poorly trained. This combination of circumstances often creates a culture of tolerance for harmful conditions and a high threshold for reporting and reacting to problems.

International human rights standards recognize the importance of a sense of security of the person. The Universal Declaration of Human Rights, Article 3 states that "Everyone has the right to life, liberty and security of person." This concept is captured more specifically in the MI Principles. Principle 8 (2) provides that "Every patient shall be protected from harm, including unjustified medication, abuse by other patients[,] staff or others or other acts causing mental distress or physical discomfort."

In designing safeguards, it is important that there be a conscious awareness of the hazards and risks to which people with mental disabilities are exposed, including an appreciation of sources of danger. This section lists some reasons why safeguards are necessary; discusses the various types of activities that provide a safety shield; and finally, suggests ways of developing an overall strategy of providing safeguards.

A. Dangers arising from impaired functioning.

Many people with mental disabilities in institutions suffer from some significant degree of impairment in their ability to look after their own self-interest. They depend upon others for assistance in many aspects of their lives. Some depend upon others for critical life functions or essential nursing care. Some may be unable to communicate their needs and wants. There may be a misunderstanding about their critical needs by people who make decisions on their behalf. Their expressed wishes may be overlooked or disregarded by others simply because of their disabilities. The nature of their disabilities makes them particularly vulnerable to physical and sexual abuse and exploitation. Their disabilities, which may affect their physical health, mental

[248] 15 EHRR 584, ¶ 22.

[249] *See supra* note 5.

competence and strength to protect themselves, also affect their ability to seek assistance when they are victimized. Their segregation in institutions may make it difficult for others to know of their plight. If they do complain, others may discount the truth or seriousness of their complaints due to their diagnostic label. Thus, not only are such individuals vulnerable to abuse and neglect but also they are handicapped by their disabilities and circumstances in seeking relief.

B. **Dangers arising from weaknesses in the service system.**

Despite the recent emphasis on articulating expectations in documents such as the MI Principles, the gulf between the aspirations and the reality of what is available is considerable. For many people served, the treatment, services and supports they need may simply not be available in the institution or anywhere else. The staff upon whom they rely for help may have low expectations of what is possible in their lives or may simply have insufficient concern for their needs. The result may be that significant needs of individuals are either unrecognized or neglected.

C. What types of safeguards are needed?

In designing safeguards, many dangers can be anticipated based on experience (e.g., that not all employees will be adequately trained, that some will not know what to do in an emergency, that some will neglect their duties, that some will steal money, exploit vulnerable people or be abusive, that well-intentioned actions will have perverse consequences, etc.). Safeguards can be implemented in advance to prevent, detect and minimize anticipated problems (*e.g.,* through adequate staffing, pre-employment screening, employee training and supervision, etc.).

However, safeguards themselves can fail (*e.g.,* notwithstanding employee training and supervision, mistakes can occur). Thus, there is a need for multiple and redundant safeguards that exist at different levels and that function independently from one another; if one fails, another may either prevent a problem or detect and correct it.

One of the real benefits of developing a community system is that it creates opportunities to rely to a considerable extent upon safeguards that occur *naturally* in the community and can become potent forces for protection. To the extent that services and supports are integrated into the community, the connections that individuals being served form with others who are not part of the service system become an important safeguard. These independent "eyes and ears" can alert the system to problems and foster prompt intervention to resolve them.

D. Recommendations.

In drafting domestic legislation, consistent with the requirements of the Standard Rules on Equalization of Opportunities for Persons with Disabilities,[250] States should involve organizations of primary consumers and their families in the process of identifying the specific types of safeguards and the manner in which they are to be implemented. Among the types of safeguards that ought to be considered are the following:

1. Promulgating a set of clearly stated rights that protect the person against unlimited discretion of custodians and service providers. Such a set of rights should be posted in each institution in prominent locations where patients can see them. The content of the rights should be included as part of the orientation for newly admitted patients.

2. Supporting the formation of NGOs of consumers, families and other advocates and empowering them to participate in the development of public policy, drafting legislation and regulations, and in monitoring the implementation of the public policy and legislation.

3. Encouraging open access to institutions by families and friends and NGOs involved in advocacy on behalf of people with mental disabilities. Specifically, the observation of institutional conditions by such groups should be incorporated into the process of periodic monitoring of the health and safety of residents by qualified professionals.

4. Building connections to community resources through rehabilitation and work programs that help preserve pre-existing skills of patients or develop the skills needed for community living.

5. Developing a process for professional and thorough investigations of reports of physical and sexual abuse and for monitoring and following up on serious injuries, including injuries of unknown origin, illnesses, and all deaths.

6. Creating a grievance/compliant process for patients and their families, which protects them against reprisals while assuring them fair and impartial investigations into their complaints. One model is to create an independent Ombudsman office with the responsibility for managing the grievance/complaint function and which also has access to all institutions and to any information needed to carry out oversight responsibilities.

7. Providing institutional residents with access to legal and non-legal advocates to assist them when other means of resolving their problems have proved unsuccessful.

VII. CONCLUSION

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[250] *See supra* p.7.

1. International human rights conventions (including the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) and customary international law (such as the Universal Declaration of Human Rights) create a broad range of obligations on governments with respect to people with mental disabilities. Human rights law requires protections against government intrusion upon individual freedom and autonomy, and it requires positive action to ensure services that are accessible and appropriate. In addition to protecting rights within institutions, human rights law provides a broad right to services that promote community integration.

2. Domestic legislation should ensure both *de jure* and *de facto* compliance with international human rights law. In addition to developing legislation that meets the requirements of international human rights law on paper, legislation can be used to reform policies and practices to bring mental health and social service systems into compliance with international standards. Comprehensive anti-discrimination legislation is also needed to protect people with mental disabilities in both the public and private spheres.

3. International human rights law provides substantial guidance to States in evaluating their current mental health laws and in the drafting of new laws. Non-binding UN General Assembly resolutions can, in some cases, be used as a detailed guide to the requirements of binding human rights conventions. Specialized UN General Assembly resolutions may not always provide protections as strong as those provided by human rights conventions, however, so it is important to refer directly to the requirements of human rights conventions ratified by the individual government in question and to the Universal Declaration of Human Rights.

4. As difficult as the task of updating domestic law to conform to the expectations in international law may be, the task of implementing these laws is likely to be an even greater challenge. A planning process will be needed to bring policies and practices into conformity with new legislation. With respect to obligations under the ICESCR that are subject to progressive realization, States need to develop a planning process that sets realistic targets for the use of available resources, both domestic and international, to fulfill the requirement of law.

5. States need to carefully consider the obligations under international law that are immediate and prioritize those domestic laws and practices that need prompt attention to realize the protections required by international law.

6. In the process of drafting legislation and planning for its implementation, States should heed the requirement of the Standard Rules on Equalization of Opportunities for Persons with Disabilities for the meaningful involvement of people with mental disabilities and their families in setting priorities, developing legislation and action

plans, and creating methods of monitoring their progress. Funds may need to be allocated to support the training and work of advocacy groups representing people with mental disabilities to ensure that these groups can participate effectively in the development of new legislation and policy development.