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INTER - AMERICAN COMMISSION ON HUMAN RIGHTS
COMISIÓN INTERAMERICANA DE DERECHOS HUMANOS
COMISSÃO INTERAMERICANA DE DIREITOS HUMANOS
COMMISSION INTERAMÉRICAINE DES DROITS DE L'HOMME

FAX ORIGINAL

ORGANIZATION OF AMERICAN STATES
WASHINGTON, D.C. 20006 U.S.A.

000488

24 de octubre de 2005

Ref.: *Caso "Damião Ximenes"*

Señor Secretario:

Tengo el honor de dirigirme a usted, en nombre de la Comisión Interamericana de Derechos Humanos, con el objeto de remitirle peritaje rendido por el señor Eric Rosenthal ante notario público. La traducción de dicho documento al portugués se le enviará a la brevedad.

Aprovecho la oportunidad para reiterarle las muestras de mi consideración más distinguida.

Santiago Canton
Secretario Ejecutivo

Señor
Pablo Saavedra Alessandri, Secretario
Corte Interamericana de Derechos Humanos
Apartado 6906-1000
San José, Costa Rica

Anexo

HORA DE RECEPCIÓN OCT. 25. 7:50AM

Affidavit of Eric Rosenthal

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To the Inter-American Court of Human Rights

In the case of Damiao Ximenes Lópes

October 21, 2005 ~~DRAFT~~

In city of Washington D.C., on October 20, 2005, I, Eric Rosenthal, a lawyer, whose business address is 1156 15th St., NW, Suite 1001, Washington, D.C., 2005, and holder passport no. 016685600, issued by the United States, with expiration date of May 1, 2011, provide through this declaration before a Notary Public, expert work for the case of Damião Ximenes Lopes, that is at this moment before the Inter-American Court of Human Rights, of which I have seen the corresponding legal filing. In relation to this matter, the expert work provided will refer to the international standards for the treatment of people with mental disabilities and the application of these standards to the mentioned case

I provide this work as an international expert on the subject of human rights of the people with mental disabilities. I received a BA with honors from the University of Chicago in 1985, and I received his law degree *cum laude* from the Georgetown University Law Center in 1992. I am the founder of Mental Disability Rights International (MDRI), an advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. I have served as MDRI's Executive Director since 1993. On behalf of MDRI, I conducted investigations in psychiatric institutions, facilities for people with intellectual and other disabilities, prisons, and orphanages in more than twenty countries. I am the primary co-author of human rights reports on conditions of people with mental disabilities in Uruguay (1995), Hungary (1997), Russia (1999), Kosovo (2002), Peru (2004), and Turkey (2005).[1] In 2005, I was elected Vice President of the United States International Council on Disability (USICD), the US affiliate of Rehabilitation International and Disabled Persons International. I have served as a consultant to the World Health Organization (WHO), UNICEF, the UN Special Rapporteur on Disability, and the US National Council on Disability.

I have published and lectured extensively on the rights of people with mental disabilities. I was commissioned by WHO to write the 2002 monograph "The Role of International Human Rights in National Mental Health Legislation."[2] This monograph

[1] All reports are available on the MDRI website at www.MDRI.org

[2] WHO, THE ROLE OF INTERNATIONAL HUMAN RIGHTS IN NATIONAL MENTAL HEALTH LEGISLATION (2001), *available at* (http://www.who.int/mental_health/resources/policy_services/en/) (also available on the web in other UN languages). *this monograph reprinted in modified form as* Eric Rosenthal & Clarence Sundram, International Human Rights in Mental Health Legislation, 21 NY L. School J. Int'l & Comp. L. 469, 469-79

was translated by WHO into six languages and is disseminated on the WHO website. On behalf of the US National Council on Disability, I co-authored a report on discrimination in US foreign policy, leading to federal legislation requiring US foreign assistance programs to respond to the concerns of people with disabilities worldwide.[3]

I solemnly declare that I will perform this expert work in all honor and conscience. The methodology to be followed will be to call-back (repeat) the questions asked by Inter-American Commission of Human Rights on the subject matter, and then to provided the answers.

Questions #1 and #2

Are people with mental disabilities victims of prejudice, stigma and other cultural factors and adverse practices? Do you consider that persons with mental disabilities are particularly vulnerable to discrimination, the arbitrary restriction of personal liberty, inhuman and degrading treatment and to other human rights violations?

People with mental disabilities are subject to extreme prejudice and stigma, and they constitute a group that is especially vulnerable to human rights violations in every country around the world.[4] Four different United Nations Special *Rapporteurs* on human rights have found that people with mental disabilities experience some of the most pervasive forms of discrimination and harshest conditions of living of any vulnerable group in society.[5] Independent non-governmental organizations have documented

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[3] National Council on Disability, FOREIGN POLICY AND DISABILITY: LEGISLATIVE STRATEGIES AND CIVIL RIGHTS PROTECTIONS TO ENSURE INCLUSION OF PEOPLE WITH DISABILITIES (2003)

[4] World Health Organization, WHO RESOURCE BOOK ON MENTAL HEALTH, HUMAN RIGHTS AND LEGISLATION (2005) (describing the context of mental health legislation and the need to overcome widespread stigma against people with mental disabilities). *See also* UN Economic and Social Council Resolution 2000/10, UN Doc. No. E/RES/2000/10, 27 July 2001. The problem of stigma and its relationship to economic marginalization and discrimination has been extensively documented in the United States. *See* Department of Health and Human Services, MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL (1999).

[5] The most important recent report is by UN Special *Rapporteur* on Health and Human Rights Paul Hunt, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Commission on Human Rights, 61st sess., Item 10, E/CN.4/2005/51 (February 11, 2005) [hereinafter the "Hunt Report"]. There is also a specialized *rapporteur* on disability. The report from the previous UN Special *Rapporteur* on Disability Bengt Lindqvist, is available 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

pervasive human rights violations against this population in the Americas[6] and other parts of the world.[7]

The adverse practices violating the rights of people with mental disabilities follow similar patters throughout the world. This includes people with a diagnosis of mental illness, such as psychosis, as well as people with intellectual disabilities, such as mental retardation. While the needs of people with mental illness and people with intellectual disabilities are very different, these populations are often confused and are often lumped together in institutions. They are subject to many of the same forms of stigma and discrimination. Except where distinctions are otherwise noted, this affidavit will refer broadly to people with mental disabilities and is intended to include the full range of populations.

People with mental disabilities are arbitrarily and unnecessarily segregated from society in closed psychiatric facilities. In the absence of any due process or independent review, large numbers of people with mental disabilities are detained arbitrarily in violation of internationally accepted human rights standards.

People detained in closed institutions are subjected to extreme forms of inhuman and degrading treatment or torture. According to UN Special Rapporteur on Health and Human Rights Paul Hunt:

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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].

[6] *See* Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: PERU (2004); Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: MEXICO (2000); Mental Disability Rights International, HUMAN RIGHTS & MENTAL HEALTH: URUGUAY (1995) LOS DERECHOS HUMANOS DE LAS PERSONAS CON DISCAPACIDAD (compiled by Rodrigo Jimenez, 1996) Reports by Mental Disability Rights International are available on the web at www.MDRI.org.

[7] *See* Mental Disability Rights International, BEHIND CLOSED DOORS: HUMAN RIGHTS ABUSES AT PSYCHIATRIC FACILITIES, ORPHANAGES AND REHABILITATION CENTERS OF TURKEY (2005); 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); AMNESTY INTERNATIONAL URGENT ACTION ON BULGARIA AT HTTP://WWW.AMNESTY.ORG.

> The Special Rapporteur has received numerous accounts of the long-term inappropriate institutionalization of persons with mental disabilities in psychiatric hospitals and other institutions where they have been subjected to human rights abuses, including: rape and sexual abuse by other users or staff; forced sterilizations; being chained to soiled beds for long periods of time, and in some cases, being held inside cages; violence and torture; the administration of treatment without informed consent; unmodified use (i.e. without anesthesia or muscle relaxants) of electro-convulsive therapy (ECT); grossly inadequate sanitation; and a lack of food [8]

As described in the Pan American Health Organization's Declaration of Caracas, the exclusive reliance on psychiatric hospital "isolates patients from their natural environment... generating greater social disability."[9] Paul Hunt states that:

> Decisions to isolate or segregate persons with mental disabilities, including through unnecessary institutionalization, are inherently discriminatory and contrary to the right of community integration enshrined in international standards. Segregation and isolation in itself can also entrench stigma surrounding mental disability.[10]

Throughout the world, the experience of modern mental health systems has demonstrated that the vast majority of people with mental disabilities can be provided treatment in a safe and dignified matter in the community.[11] In addition, modern mental health programs have demonstrated that people with a diagnosis of mental illness can make responsible choices about their own treatment and other basic life decisions. As described by Paul Hunt:

> People once thought incapable of making decisions for themselves have shattered stereotypes by showing that they are capable of living independently if provided with appropriate legal protections and supportive services. Moreover, many people once thought permanently or inherently limited by a diagnosis of major mental illness have demonstrated that full recovery is possible.[12]

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[8] Hunt Report, *supra* note 5, para. 9.

[9] Pan American Health Organization, *Declaration of Caracas, preamble*, para. 2.

[10] Hunt Report, *supra* note 5, para. 54

[11] *Id.* para. 15.

[12] *Id.*

Very often, paternalistic laws with the stated purposes of protecting people with mental disabilities may hurt them by denying them the ability to make important choices about their lives. The practice of legal guardianship, for example, can be easily misused. The Montreal Declaration on Intellectual Disabilities, adopted by the Pan American Health Organization in 2004, starts with the preamble that it is "[m]indful that persons with intellectual disabilities have often been excluded from decisions about their human rights, health and well-being, and that guardianship laws have historically been sued to deny persons with intellectual disabilities their right to make decisions."[13] The Montreal Declaration thus sets forth standards to ensure that "[p]ersons with intellectual disabilities have the same right as other people to make decisions about their lives."[14]

Question #3 Are there special international human rights standards related to people with mental disabilities? If so, to what do you attribute the creation of these specific standards on the subject?

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 only developed in recent years. The lack of language that pertains specifically to people with mental disabilities in international human rights covenants has long hampered the application of these conventions to people with mental disabilities.

The primary reason for the lack of attention to these issues relates to the very fact that people with mental disabilities have been so stigmatized and subject to discrimination around the world. As a result of this marginalization, people with mental disabilities have not had the resources or the recognition they need to form advocacy organizations to speak out for their own rights at the national or international level.

In recent years, United Nations, the Organization of American States (OAS), the Pan American Health Organization, and non-governmental organizations have brought world attention to the concerns of people with mental disabilities, there has been a corresponding development in legal standards. The most dramatic recent development has been the decision by the United Nations General Assembly to begin work drafting a new UN Convention on the Rights of People with Disabilities.[15] These specific standards have been developed as a result of the recognition of the pervasive stigma and discrimination faced by people with mental disabilities, and their position of vulnerability within this context.

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[13] Pan American Health Organization, *The Montreal Declaration on Intellectual Disabilities, preamble* (October 6, 2004).

[14] *Id.*, section 6.

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

The Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (*herein after the* American Convention on Disability) is the first international human rights convention specifically dedicated to the international human rights of people with disabilities.[16] The American Convention on Disability represents a valuable commitment on the part of governments throughout the Americas to ensure that people with disabilities should have the same rights as all others.

Despite the lack of specific language on people with disabilities or mental disorders in the American Convention and other general human rights treaties, it has become widely recognized that people with mental disabilities are protected by the main international human rights conventions that protect all other individuals. In 1993, the World Conference on Human Rights meeting in Vienna declared that people with mental and physical disabilities are protected by existing international human rights conventions. 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."[17]

Question #4 What are, on the level of the Organization of American States as well as the United Nations, the principle treaties, declarations, and other instruments that have been ratified relating to the human rights of people with mental disabilities?

The American Convention on Disability is the only specialized international human rights treaty relating to people with mental or physical disabilities. Article 23 of the UN Convention on the Rights of the Child provides specific recognition of the rights of children with disabilities. The two main UN human right treaties that make up the International Bill of Rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic Social And Cultural Rights (ICESCR) do not specifically mention the rights of people with disabilities, but general comments on both those conventions are available to guide in their interpretation with regard to people with mental disabilities.[18]

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[16] AG/RES 1608 (XXIX-0/99), 29th Sess of the General Assembly; opened for signature 7 June 1999, entered into force 14 September 2001.

[17] 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.

[18] *See* Rosenthal & Rubenstein, *supra* note 2, at 481-2 (describing the general comments on the ICCPR and the ICESCR relating to people with mental disabilities).

The American Convention on Human Rights provides the most important protections relating to the rights of people with mental disabilities in the Americas.[19] The Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social, and Cultural Rights (the Protocol of San Salvador), establishes a right to the health under article 10.[20]

The European Convention on Human Rights (hereinafter ECHR) provides many rights similar to those protected by the American Convention. Over the last thirty years, a body of case law on the rights of people with mental disabilities has developed in the ECHR that can be valuable in interpreting similar protections under the American Convention.[21] The European Committee for the Prevention of Torture has adopted an evolving set of detailed standards on conditions in psychiatric institutions needed to protect against violations of the European Convention for the Prevention of Torture.[22]

The United Nations General Assembly has adopted a number of different resolutions on the rights of people with mental disabilities. The "Declaration on the Rights of Mentally Retarded Persons"[23] (MR Declaration) was adopted in 1971. In 1991, the General Assembly adopted the "Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health" (the "MI Principles").[24]

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[19] *See discussion in* WHO (2002), *supra* note 1 at 5 and Rosenthal & Sundram, *supra* note 1, at 241 (describing the application of the American Convention and core UN human rights conventions to protect the basic rights of people with mental disabilities).

[20] Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, Nov. 17, 1988, O.A.S.T.S. No. 69 (1988), 28 I.L.M. 156 (1989), *entered into force* Nov. 16, 1999 [hereinafter the Protocol of San Salvador].

[21] *Id.*

[22] European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, *The CPT Standards. "Substantive" sections of the CPT's General Reports*, CPT/Inf/E (2002) 1 Rev 2003 [hereinafter *The CPT Standards*] available at http://www.cpt.coe.int/en/documents/eng-standards.doc.

[23] 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).

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

The MI Principles are the most comprehensive human rights standard with regard to mental health treatment practices,[25] and they have been used by UN bodies as a guide to the interpretation of convention-based rights.[26] There have been important developments in international law since the adoption of MI Principles, however, that render the MI Principles somewhat dated. The United Nations "Standard Rules on Equalization of Opportunities for Persons with Disabilities," adopted in 1993, is the broadest and perhaps most influential UN disability rights resolution. The Standard Rules are significant because they call for the full community integration and participation in society of all people with disabilities.

The 2005 report by UN Special *Rapporteur* for Health and Human Rights, Paul Hunt, on *The right of everyone to the enjoyment of the highest attainable standard of physical and mental health* with its focus on "Mental Disability and the Right to Health" constitutes the most up-to-date international standard that reflects the rapid evolution of the international disability rights field. Paul Hunt has called for stronger protections than are recognized under the MI Principles in some specific areas, such as the right to refuse treatment for people detained in psychiatric institutions.[27]

In recent years, the Pan American Health Organization organized two meetings of legal experts, mental health professionals, and people with disabilities to establish human rights norms for people with mental disabilities in the Americas. The first of these meetings resulted in the adoption of the *Declaration of Caracas* in November 1990.[28] The *Declaration of Caracas* identifies practices that "imperil the human and civil rights of patients," including the improper detention of people in psychiatric facilities that "isolate[] patients from their natural environment... generating greater social disability."[29] On October 6 2004, a meeting organized by PAHO resulted in the adoption

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[25] 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).

[26] *See, e.g.*, the UN Committee on Economic, Social, and Cultural Rights has similarly used the MI Principles to interpret the International Covenant on Economic, Social, and Cultural Rights (ICESCR). 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.

[27] Hunt Report, para. 24.

[28] *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). This article provides helpful background and comments on the development of the Declaration of Caracas. The Declaration is reproduced in full as an appendix to this article.

[29] Declaration of Caracas, *preamble, para. 2.*

of the Montreal Declaration on Intellectual Disabilities. The Montreal Declaration is the most highly developed international standard on the rights of individuals with intellectual disabilities.

Question #5 In your opinion, what would be the importance of using international standards in the human rights of people with mental disabilities to interpret the American Convention on Human Rights?

In the absence of detailed language in the American Convention on the application of these general principles to the context of mental health treatment or psychiatric institutionalization, detailed international standards are valuable as a guide to interpreting how these rights apply to people with mental disabilities.[30] The international standards provide clarity and guidance to judicial bodies and the application of general principles, and they put governments on notice as to the nature of their human rights obligations. International standards also represent consensus among governments and mental health professionals as to what constitutes the minimum acceptable level of treatment practices. Incorporation of international standards in the interpretation of the American Convention would further the overarching goal of viewing human rights as "universal", consistent with the Universal Declaration of Human Rights' goal of having a "common standard" of human rights protection.

Given their level of detail, The MI Principles are particularly useful as a guide to the interpretation of the American Convention with regard to the rights of people with mental disabilities.[31]

#6 In relation to the specific case of Mr. Damiao Ximenes Lopes, could you indicate which are the international standards applicable to a person with psychosis that refuses to take the medicines that have been prescribed?

International human rights law recognizes that individuals with mental disorders or mental disabilities detained in a psychiatric institution, such as Mr. Ximenes Lópes, have a right to informed consent and a corresponding right to refuse treatment.

Under international law, there are circumstances in which coercive treatment can be applied – as in a medical emergency where such treatment is deemed by qualified medical authority to be necessary to prevent against "immediate or imminent harm." Coercive treatment may be justified under limited circumstances in a non-emergency

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[30] 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).

[31] *Id* (describing the use of the MI Principles as a guide to the interpretation of related provisions of human rights conventions).

situation, but only after review by an independent authority determines that such treatment is in the interest of the patient's health.

There are no indications in the record that a qualified medical authority determined that an imminent or immediate risk existed. Nor is there any information in the record about any form of independent review. In the absence of such protections, Mr. Ximenes Lópes had the right to refuse treatment. Any effort at coercive treatment violated international human rights law.

As background to this discussion, it is important to understand that people with mental illness, including psychosis, are not necessarily dangerous to themselves or others. Indeed, research has demonstrated that people with mental illness are often less dangerous than the population at large.[32] The common perception that people with mental illness are dangerous is the kind of common misperception based on stigma that human rights laws are developed to protect against.[33] Indeed, the behavior of people with mental disabilities may be interpreted as being "aggressive" simply because this behavior is unusual or not understood.

The most detailed international standards on the right to refuse treatment are contained in the MI Principles. The MI Principles recognize the right of a psychiatric patient to "informed consent" about his or her treatment – and this right is not limited simply because a person has a mental disorder or psychosis.[34] Informed consent entails a right to "disclosure to the patient of adequate and understandable information in a form and language understood by the patient" on such issues as diagnosis, types of proposed treatment, alternative treatments (including less intrusive treatments) available, and "possible pain or discomfort, risks and side-effects of the proposed treatment."[35] The right to informed consent inherently entails a converse right to refuse or stop treatment at any time.[36]

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[32] John Monahan and Jean Arnold, *Violence By People With Mental Illness: A Consensus Statement By Advocates and Researchers*, 19(4) PSYCHIATRIC REHABILITATION JOURNAL 1996; American Psychiatric Association, FACT SHEET: VIOLENCE AND MENTAL ILLNESS, Washington, DC (1994).

[33] WHO (2005), *supra* note 4, at 1. The US Surgeon General has observed: "Why is stigma so strong despite better public understanding of mental illness? The answer appears to be fear of violence: people with mental illness, especially those with psychosis, are perceived to be more violent than in the past." Department of Health and Human Services (1999), *supra* note 4, at 7, *citing* J. Phelan, *et al.* Public conceptions of mental illness in 1950 and 1996: Has sophistication increased? Paper presented at the meeting of the American Sociological Association, Toronto Ontario (August 1997).

[34] MI Principle 11(1).

[35] MI Principle 11(2).

[36] MI Principle 11(4).

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While recognizing the general right to refuse treatment, the MI Principles recognize many exceptions to this right. The right may be over-ridden when "a qualified mental health practitioner authorized by law determines that [treatment] is urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons."[37] While treatment may be provided under emergency situations, such "treatment shall not be prolonged beyond the period that is strictly necessary for this purpose."[38]

The MI Principles recognize that coercive treatment may be provided in a non-emergency situation for people who are detained as "involuntary patients."[39] This exception, however, only applies to people who are lawfully detained – a procedure which requires independent judicial review with appropriate due process protections.[40] In addition, a lawfully detained involuntary patient may only be forcibly treated after an additional review by an "independent authority."[41] The independent authority must find that "the patient lacks the capacity to give or withhold consent to the proposed plan of treatment or, if domestic legislation so provides, that, having regard to the patient's own safety or the safety of others, the patient unreasonably withholds such consent."[42] The independent authority must also determine that the "plan of treatment is in the best interest of the patient's health needs."

The exceptions to the right to refuse treatment under the MI Principles are broad, and they have been criticized for not providing stronger protections.[43] The European Committee for the Prevention of Torture (CPT) and the UN Special Rapporteur on Health and Human Rights requires stricter protections for the right to refuse treatment. The CPT has stated that "[psychiatric] patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of persons to a psychiatric establishment on an involuntary basis should not be construed as authorizing treatment without their consent."[44]

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[37] MI Principle 11(8).

[38] MI Principle 11(8)

[39] MI Principle 6(a).

[40] *See* MI Principles 16-18

[41] MI Principle 6(b) and (c)

[42] MI Principle 6(b)

[43] Rosenthal & Sundram, *supra* note 5 at 501 n.143 and accompanying text.

[44] *See* REPORT TO THE GOVERNMENT OF IRELAND ON THE VISIT TO IRELAND CARRIED OUT BY THE EUROPEAN COMMITTEE FOR THE PREVENTION OF TORTURE AND INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT (CPT) FROM 20 TO 28 MAY 2002, Publication Number CPT/Inf (2003) 36 *available at* http://hudoc.cpt.coe.int/cpt/SearchSdt/OriginalHtml.asp.

The profound importance of the right of a person to refuse treatment – particularly the use of psychotropic medications – cannot be overemphasized. It is also important to note why a person may choose to refuse psychotropic medications. What appears to be "aggression" may be a person's response coercive medication. Mental health professionals have observed that, when a psychiatric patient is given choice about medication, he or she is less likely to resist.[45] What may appear to be an irrational or aggressive act caused by mental illness may also be an effort to avoid the negative and potentially dangerous affects of the treatment.

Psychotropic drugs produce a wide variety of negative side effects that "can be a source of acute distress."[46] These side effects range from mildly unpleasant to extremely painful. Common side effects include dizziness, drowsiness, dry mouth and throat, stuffy nose, urinary retention, constipation, blurred vision, sexual dysfunction, and menstrual irregularity in women.[47] Psychotropic medications also have a major impact on thought and cognition, may limit a person's ability to respond to external stimuli.[48] Common motor disturbances include hand tremors, drooling, rigidity, stooped posture, blank stare, and a dulled facial expression.[49] Research indicates that 20% of people receiving certain psychotropic medications experience the parkinsonian-like effect of "akathesia," creating "a subjective feeling of muscular discomfort to an agitated, desperate, markedly dyphoric

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[45] Ronald J. Diamond, *Enhancing Medication Use in Schizophrenic Patients*, 44 J. Clinical Psychiatry 7, 13 (June 1983). By the same token, when psychotropic medications are taken voluntarily based on a therapeutic alliance formed between a patient and a mental health professional, they are likely to be more effective. One psychiatric researcher observed that, "[n]ot only is permitting limited refusal generally innocuous, but some definite gains may accrue from the accompanying negotiations" between doctor and patient. Paul S. Appelbaum and Thomas G. Gutheil, *Drug Refusal: A Study of Psychiatric Inpatients*, 137 Am J. Psychiatry 340, 345 (1980).

[46] Robert Levy and Leonard S. Rubenstein, THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES 112 (1996). *See also* World Health Organization, *Critical Questions in Clinical Pharmacology*, Treatment of Mental Disorders: A Review of Effectiveness 67 (Norman Sartorius, *et. al eds.*, 1993) (summarizing international research on the frequency of serious side-effects of common psychotropic medications); Dennis E. Cichon, The Right to "Just Say No": A History and Analysis of the Right to Refuse Antipsychotic Drugs 53 LA. L. REV. 283, 297 (1992) (describing the fact that side effects may be significant even when psychotropic medications are properly administered).

[47] *Id.* at 298; Robert M. Julien, A PRIMER ON DRUG ACTION 229 (1992)

[48] *Id.* at 229-30.

[49] *Id.* at 231.

pacing with hand-wringing and weeping."[50] Psychotropic medications may also produce tardive dyskenesia, an irreversible neurological impairment[51] that causes "involuntary, rhythmic, and often grotesque movements of the face, lips, tongue, fingers, hands, legs, and pelvis."[52] In some cases, psychotropic medications can cause causing permanent neurological damage or blood disorders leading to death.[53] A major recent study disputes commonly held beliefs that newer psychotropic medications are more effective and have fewer side-effects.[54]

The powerful sedative impact and strange appearance of people suffering from these side-effects can make it difficult for them to assimilate back into the community. Psychotropic medications may also limit a person's ability to express him or herself, a problem that can be particularly disturbing to a person attempting to respond to a psychiatric crisis.

Many psychotropic medications act as major sedatives, rendering a person even more dependent on an institution. 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. Because of psychotropic medications' sedative effects, they are often used by psychiatric facilities as a mechanism of control and patient management. In the absence of strict medical standards and oversight for their use, staff may intentionally use such treatment as a form of punishment.[55]

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[50] Alan F. Schatzbert & Jonothan O. Cole, MANUAL OF CLINICAL PHARMACOLOGY 95 (1986).

[51] WHO, *supra* note 46 at 309 (citing research showing that there is a 5% incidence per year of tardive dyskensia caused by antipsychotic medications). Dilip V. Jeste *et al. The Biology and Experimental Treatment of Tardive Dyskinesia and Other Related Movement Disorders*, in 8 AMERICAN HANDBOOK OF PSYCHIATRY 536 (Philip A. Berger & Keith H. Brodie eds., 2nd ed. 1986).

[52] Levy & Rubenstein, *supra* note 46, at 112.

[53] Cichon, supra note 46 at 298-99. Barry H. Guze & Laeis R. Baxter, *Neuroleptic Malignant Syndrome* 313 NEW ENG. J. MED. 163 (1985).

[54] Shankar Vedantam, *New Antipsychotic Drugs Criticized: Federal Study Finds No Benefit Over Older, Cheaper Drug*, The Washington Post A1 (September 20, 2005).

[55] MDRI recently documented the use of psychiatric treatment as punishment in Turkey. Turkish psychiatrists told MDRI that the lack of enforceable laws and standards created an environment in which treatment was liable to be used as a form of punishment. *See* MDRI (2005), *supra* note 7 at 23.

The UN Special Rapporteur on the Right to Health, Paul Hunt describes why strict protections are needed to protect the right to refuse treatment for people with mental disabilities:

> In the Special Rapporteur's experience, decisions to administer treatment without consent are often driven by inappropriate considerations. For example, they sometimes occur in the context of ignorance or stigma surrounding mental disabilities, and expediency or indifference on the part of staff. This is inherently incompatible with the right to health, the prohibition of discrimination on the ground of disability, and other provisions in the [UN's MI Principles]. In these circumstances, it is ***especially important that the procedural safeguards protecting the right to informed consent are both watertight and strictly applied.***[56]

Given the potentially painful and dangerous nature of psychotropic medications, the unjustified, coercive use of medication in violation of internationally accepted standards should be considered a form of inhuman and degrading treatment in violation of article 5(2) of the American Convention. People detained for psychiatric treatment are both emotionally vulnerable and placed in a position of powerlessness as a result of such treatment in the institution. The European Court of Human Rights has stated that "all the circumstances of the case" including the "state of health of the victim" should be taken into consideration in determining whether the ill-treatment attains the "minimum level of severity" to fall within the scope of the convention's protections.[57] In determining whether inhuman or degrading treatment exists, the European Court has held that a government holds a heightened level of responsibility for "increased vigilance" for a person detained for psychiatric treatment.[58]

Despite the stated purpose of "treatment" to help a person, the administration of psychotropic medications may cause intense pain and serious danger. The European Court of Human Rights has found that practices not intended to hurt a person with a disability may constitute degrading treatment where they cause intense pain or

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[56] Hunt Report, *supra* note 5, at paras. 90-91 (emphasis added). Paul Hunt has called for stricter protections of the right to informed consent for people with mental disabilities under international law.

[57] *Price v. United Kingdom*, Application No. 3394/96, 10 July 2001

[58] *Herczegfalvy v. Austria, Judgment of 24 September 1993, 244 Eur. Ct. H.R. (ser. A), para. 82, 15 E.H.R.R. 437 (1993)* The European 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." *See discussion in* Rosenthal & Sundram, *supra* note 2, at 516 (discussing the case and the European Court's doctrine of increased vigilance relating to treatment in psychiatric hospitals).

humiliation.[59] Under the Inter-American Convention to Prevent and Punish Torture,[60] an improper purpose by the perpetrator need not be shown, as "physical or mental pain or suffering" that is inflicted "for any . . . purpose"[61] constitutes torture. Where psychiatric treatment is used for an unlawful purpose – such as punishment – the violation of article 5 is clear. When the effects of psychotropic medications are painful and dangerous, and where they are used as a form of punishment, the forced used of such treatment may rise to the level of torture.

#7 In relation to the specific case of Mr. Damiao Ximenes Lopes, could you indicate if obligatory physical restraint for a psychotic patient who is aggressive conforms to the applicable international standards? In such a case, how should the restraint be carried out?

The record indicates that Mr. Ximenes Lópes was subject to severe beatings in response to his "reaction to the use of force" and his refusal to take medications. When his mother came to visit him, she stated that his hands were tied behind his back, he was falling down he could no longer stand, his nose was bleeding, his eyes were swollen shut, he was dirty and smelled of feces and urine, he had bruises all over his body, and his head was so swollen that it appeared as though it was not him.

The purpose of a restraint, when used appropriately, is to ***prevent*** injury to the patient or others. Usually, this involves immobilizing the patient's limbs until the immediate episode that warranted the use of the restraint is over –usually a brief period of time. Inflicting injury under the guise of restraint is never appropriate, and is usually a clear indicator that the facility has not appropriately trained its staff in safe methods of utilizing restraints.

Beating a patient can never be a legitimate form of physical restraint. Nor is it ever legally or medically justifiable to beat a person being held in physical restraints – whether the underlying use of physical restraints is justified or not. There are strict standards for when any forms of restraints may be legitimately used. In order to protect

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[59] *Price v. United Kingdom*, *supra* note 55. In Price, the European Court found a violation of article 3 when a woman in a wheelchair was held in a jail for seven days without an accessible bed or toilet facilities. In order for her to relieve herself, she was forced to sit in her wheelchair undressed for hours in front of male guards. The court found degrading treatment in violation of the ECHR even though it found "no evidence in this case of any positive intention to humiliate or debase the applicant." *See discussion in* Rosenthal & Sundram, *supra* note 2 at 514.

[60] Inter-American Convention to Prevent and Punish Torture, Dec. 9, 1985, O.A.S.T.S. No. 67, *entered into force* Feb. 28, 1987, *at* http://www.cidh.org/Basicos/basic9.htm. Brasil ratified the Inter-American Convention to Prevent and Punish Torture on July 20, 1989.

[61] *Id.* art. 2.

against immediate harm, physical restraints may be applied with appropriate safeguards. Given the inherent dangers of physical restraints, however, the State is under a strict obligation to ensure humane conditions.

In the case of Mr. Ximenes Lópes, there is no showing that he presented an immediate danger to himself or others. Nor is there any showing that any less restrictive approaches to responding to his aggression were made. Thus, the use of any form of physical restraints was illegal. Once Mr. Ximenes Lópes was restrained by having his hands tied behind his back, the State had a heightened duty to protect him in his extremely vulnerable state. The use of additional physical force and beatings constitutes an additional violation of his right to humane care.

International human rights standards are clear that physical intimidation or abuse may *never* constitute the appropriate use of physical restraints. International human rights law limits any use of restraints to "officially approved procedures" by "qualified members of staff"[62] rather than the rogue acts such as beatings. In any circumstances, a patient has a right to treatment that is "the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others."[63] As described below, many less intrusive – and certainly less dangerous approaches exist – to respond to aggressive behavior.

International standards recognize restraints only as a last resort after all such alternatives have been exhausted. Under the MI Principles, seclusion or restraints may be used "only when it is the *only means available* to prevent immediate or imminent harm to the patient or others."[64] There is nothing in the record to indicate that staff attempted less intrusive or dangerous alternatives to respond to Mr. Ximenes Lópes' behavior. Nor is there any showing in the record that Mr. Ximenes Lópes actually presented any immediate or imminent harm. Merely "aggressive" behavior is not sufficient to justify the use of restraints. As described above, what appears to be aggressive in a person going through an acute psychotic episode may simply be unusual and bizarre behavior, and may not actually be dangerous.

International human rights law places strict restrictions on the use of physical restraints or seclusion because of the inherent dangers of this practice. Mental health professionals recognize that seclusion or restraints are "safety interventions of last resort and are not treatment interventions."[65] Good mental health practice requires every effort to avoid the use of seclusion or restraints whenever possible because:

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[62] MI Principles 11(11).

[63] MI Principle 9(1).

[64] MI Principles, principle 11(11) (emphasis added).

[65] National Association of State Mental Health Program Directors (NASMHPD), "Position Statement on Seclusion and Restraint," July 13, 1999, [herinafter NASMHPD

> The use of seclusion and restraint creates significant risks for people with psychiatric disabilities. These risks include serious injury or death, retraumatization of people who have a history of trauma, and loss of dignity and other psychological harm. In light of these potential serious consequences, seclusion and restraint should be used only when there exists an imminent risk of danger to the individual or others and no other safe and effective intervention is possible.[66]

When a person experiences a psychotic episode and is aggressive, as Mr Ximenes Lópes is described in the record, there are many alternatives that should be tried before restraints or seclusion are used. Mental health programs should strive to "maintain an environment and culture of caring that will minimize the need for the use of seclusion and restraint."[67] The following are a number of such approaches mental health programs may take to avoid the use of seclusion and restraints:

> (1) early identification and assessment of individuals who may be at risk of receiving these interventions;
>
> (2) high quality, active treatment programs (including, for example, peer-delivered services) operated by trained and competent staff who effectively employ individualized alternative strategies to prevent and defuse escalating situations;
>
> (3) policies and procedures that clearly state that seclusion and restraint will be used only as emergency safety measures; and
>
> (4) effective quality assurance programs to ensure this goal is met and to provide a methodology for continuous quality improvement.[68]

If the above approaches have been taken and restraints or seclusion must be used, mental health standards suggest that the "least restrictive seclusion and restraint method that is safe and effective should be administered."[69] When seclusion and restraints are going to be administered, MI Principle 11 creates six types of procedural protections to protect against abuse:

Standards], published on the web at http://www.nasmhpd.org/general_files/position_statement/posses1.htm .

[66] *Id*

[67] *Id*

[68] *Id*

[69] *Id*

1. Any practice of seclusion or restraints must follow "officially approved procedures."
2. Restraints "shall not be prolonged beyond the period which is strictly necessary" for safety purposes.
3. "All 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."
4. "A patient who is restrained shall be kept under humane conditions. . . ."
5. The person being restrained must be "under the care and close and regular supervision of qualified members of the staff."
6. "A personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient."

There is extensive mental health literature describing what might constitute "humane conditions" for the use of seclusion and physical restraints. At minimum, humane conditions includes that the "dignity, privacy, and safety" of the individual be maintained.[70] There is no indication that any of the above procedural protections where used in the practices intended to control Mr. Ximenes Lópes' behavior. His treatment was certainly neither safe nor dignified.

The unjustified use of physical restraints in this case violates article 5(2) of the American Convention. When physical restraints are used with intent to protect a psychiatric patient – but they are not applied in a humane manner – this practice constitutes inhuman and degrading treatment under article 5(2). The UN Human Rights Committee has similarly found that "prolonged solitary confinement" may constitute inhuman and degrading treatment under the International Covenant on Civil and Political Rights.[71]

When seclusion or restraint is used as punishment, coercion, or for other improper purposes, the human rights violation is even more serious. Mental health standards are clear that "[s]eclusion and restraint should never be used for the purposes of discipline, coercion, or staff convenience, or as a replacement for adequate levels of staff or active treatment."[72] Where such the use of restraints causes extreme physical or mental pain or suffering, their improper use for an unlawful purpose such as punishment may constitute torture.

Whether or not the beating of Mr. Ximenes Lópes was intended as punishment, there was no legitimate purpose in administering such beatings to a restrained individual. In this case, the combined effect of beating and restraints was clearly painful and

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[70] NASMHPD Standard, *supra* note 61.

[71] United Nations Office of the High Commissioner on Human Rights, MANUAL ON HUMAN RIGHTS REPORTING, HR/PUB 91/1 (Rev.1), General Comment 20(44), para 6, at 197.

[72] *Id.*

dangerous. Thus, the beating of Mr. Ximenes Lópes held defenselessly with his hands tied behind his back – when the State has a heightened responsibility of increased vigilance[73] to protect him as a psychiatric patient and because of the restraints – constitutes torture.

#8 In relation to the specific case could you indicate if the physical restraint by specialized personnel of a psychotic patient who is aggressive, disarmed, could imply the necessity of beating the patient to the extreme that blows cause his death?

It is never necessary to beat or harm a psychiatric patient in any manner -- certainly not in any way that creates a risk to health or even death. The fact that Mr. Ximenes Lópes was disarmed and already in the custody of the government demonstrates that any such action was grossly disproportionate to any threat he may have presented. Mental health facilities are established to respond to the needs of individuals who may be dangerous to themselves or others. Indeed, the presence of dangerousness is one of the main criteria for admission to a psychiatric facility under international standards.[74] No one may be detained in a facility that is not properly equipped with staff trained to respond to just this situation.[75] Psychiatric facilities are required to provide "such health and social care as is appropriate to his or her health needs."[76] and it is affirmatively the obligation of such facilities to ensure that "[e]very patient shall be protected from harm."[77]

Given the inherent vulnerability of a person going through a psychiatric crisis, there is a level of responsibility of state authorities to protect such individuals that is higher than it would be for any other detainee.[78] In the case of Mr. Ximenes Lópes, the right to protection from harm only starts with the right to protections against beating. Having been detained by the government for the purpose of mental health treatment, the government assumes responsibilities for his proper care. This includes the affirmative right to appropriate mental health care to assist Mr. Ximenes Lópes in coping with his agitated state so that he could avoid this mistreatment to which he was subjected.

The right to protection from harm in a psychiatric facility is protected by the right to life under article 4 of the American Convention, the article 5 right to protection against inhuman and degrading treatment, and the right to health, under article 10 of the Protocol

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[73] *See* notes 56 - 60 and accompanying text.

[74] MI Principle 16(1)

[75] MI Principle 16(3).

[76] MI Principle 8(1).

[77] MI Principle 8(2).

[78] *See* note 56 and accompanying text

of San Salvador. The right to health is closely linked with the protection of the "right to 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.[79]

The MI Principles provide guidance as to the responsibilities of governments to protect the right to life and health. Under the 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."[80] Principle 8 is important because it makes the link between inappropriate mental health care and other more commonly understood types of harm, such as abuse by staff or patients.

> 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 and predatory individuals from the more vulnerable, to provide adequate supervision to prevent physical and sexual assaults between patients, and to train staff adequately to equip them with the skills needed for the work required.[81]

Mr. Ximenes Lópes' beating – and ultimately his death – could have been avoided if the state had met its affirmative obligations to provide trained staff equipped with the skills necessary to assist him with a mental disability, even if he was aggressive as a result of a psychotic episode.

The failure to provide Mr. Ximenes Lópes with conditions in the psychiatric facility that would ensure the protection of the basic rights accorded to all other citizens constitutes discrimination in violation of the American Convention on Disability.

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[79] The UN Human Rights Committee, established by the International Covenant on Civil and Political Rights (ICCPR) to interpret that 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.

[80] MI Principle 8.

[81] Rosenthal & Sundram, *supra* note 2, at 522, *citing* 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).

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The failure to provide Mr. Ximenes Lópes with this assistance violated his right to health, his right to protection against inhuman and degrading treatment, and his right to life.

Subscribed and sworn to before me by

_____ this 21st day of October 2005

District of Columbia _____
ss:
Subscribed and sworn to before me this
11th day of October, 2005

Donald W. Hemshaw, Notary Public
My Commission Expires August 14, 2007