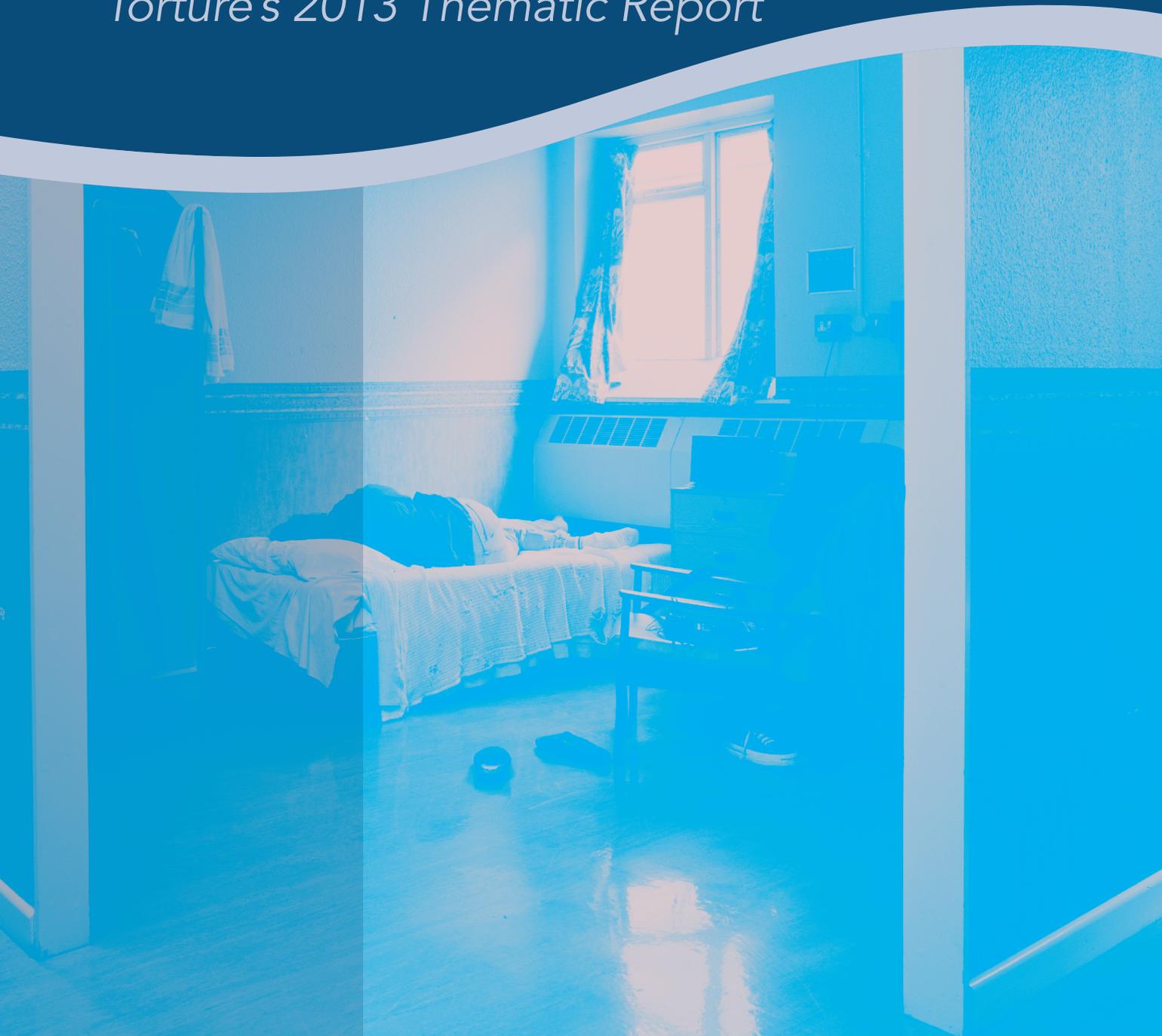


Torture in Healthcare Settings: *Reflections on the Special Rapporteur on Torture's 2013 Thematic Report*



AMERICAN UNIVERSITY
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COLLEGE OF LAW

CENTER FOR HUMAN RIGHTS
& HUMANITARIAN LAW

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Anti-Torture Initiative

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Disclaimer

The ideas, opinions and conclusions expressed in this volume are those of the authors only, and do not necessarily represent the views of the American University Washington College of Law Center for Human Rights & Humanitarian Law, the United Nations, the UN Special Rapporteurship on Torture or the Open Society Foundations.

This publication is intended to generate a broad discussion on the matter of abusive practices in health care settings. For that reason, it may be freely reviewed, abstracted, reproduced and translated, in part or in whole, but it is not for sale or for use in conjunction with commercial purposes. Any changes to the text of this publication must be approved by the Anti-Torture Initiative (ATI) of the Center for Human Rights & Humanitarian Law of American University Washington College of Law. If any section is reproduced, due credit must be given to the Center for Human Rights & Humanitarian Law Anti-Torture Initiative and to this publication.

About the Center for Human Rights & Humanitarian Law and the Anti-Torture Initiative

Established in 1990, the Center for Human Rights & Humanitarian Law explores emerging intersections in the law and seeks to create new tools and strategies for the creative advancement of international human rights norms through work with students, academics and practitioners. The Center runs a variety of projects, conferences and workshops on issues ranging from combating torture, enhancing the human rights of persons with disability, promoting human rights in the US, building capacity and strategies for human rights education, seeking solutions to promote human rights in business and more. The Center seeks to enhance the understanding and implementation of human rights and humanitarian law globally.

The Center's Anti-Torture Initiative (ATI) was created in 2012 to expand the strategies used by the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (SRT) in furtherance of its mandate; to support, monitor, and assess implementation of the SRT's recommendations; and to provide a multi-dynamic model for effective thematic and country-specific follow-up. The ATI employs diverse methodology and best-practices to develop comprehensive thematic and country-specific follow up initiatives, with the aim of facilitating the domestic implementation of the SRT's recommendations, and helping to promote the complete elimination of torture. The ATI is an independent project but works closely with the SRT and the UN Office of the High Commissioner for Human Rights, as well as with civil society organizations and government representatives in selected countries to engage with the SRT in follow-up activities, and to promote public dialogue on the issue of torture. The Anti-Torture Initiative is generously supported by the Oak Foundation and the Open Society Foundations.

For more information about the work of the Center and the Anti-Torture Initiative, please visit www.WCLCenterforHR.org or www.antitorture.org.

About the Mandate of the UN Special Rapporteur on Torture

The mandate of the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (SRT) was established in 1985 as a thematic Special Procedure under the now extinct UN Commission for Human Rights. The SRT today operates under the umbrella of the Human Rights Council, together with the other UN Special Procedures Mechanisms. The Special Procedures consist of independent experts who work individually as Special Rapporteurs, or as members of Working Groups, and have specific mandates to monitor, advise, and publicly report on human rights issues from a thematic or country specific perspective. Juan E. Méndez was appointed SRT by the United Nations Human Rights Council in October 2010 for a period of three years, to investigate and report on issues involving torture worldwide. His mandate was renewed in October 2013.

Foreword

As part of its mission to create new tools and strategies for the creative advancement of international human rights norms, in 2012, the Center for Human Rights & Humanitarian Law at American University Washington College of Law and WCL Visiting Professor Juan E. Méndez, created *The Anti-Torture Initiative* (ATI). The ATI supports the mandate of the United Nations Special Rapporteur on torture and other cruel, inhuman and degrading treatment or punishment (SRT), a position which Professor Méndez holds. The ATI monitors and assesses the implementation of the SRT's country-specific and thematic recommendations, develops effective follow-up models for expanded implementation for SRT recommendations, and supports the creative advancement of the SRT mandate to end torture worldwide.

The publication of this volume, *Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture's 2013 Thematic Report*, is one such creative model. It is a first-of-its-kind compilation, which seeks to follow-up and expand upon a thematic report by the SRT. The volume asks a wide variety of stakeholders and thought-leaders to reflect on the SRT's 2013 report on Torture and Ill-Treatment in Health Care Settings (A/HRC/22/53), and to provide a critique and analysis to help promote discussion of the myriad of important issues raised in the report.

The SRT report is important as it tries to clarify that abusive practices occurring under medical supervision may not be defended by governments on the grounds of medical necessity, treatment, or administrative efficiency. It analyses practices such as compulsory detention for medical treatment, violations of reproductive rights, denial of pain treatment, treatment of persons with psycho-social disabilities and some marginalized groups, including LGBTI, persons who use drugs, and sex workers, and how these "treatments" may constitute a violation of the prohibition of torture and cruel, inhuman, and degrading treatment. The SRT report seeks to address existing gaps in law and policy to prevent torture and ill-treatment in the name of medical treatment in health care settings worldwide, emphasizing States' obligations to prevent, prosecute, and punish those responsible for ill-treatment, and to provide redress and rehabilitation for victims. Constrained as it is by an UN-imposed word limit, the SRT's report is meant to be a starting-point for discussion, not the final word on the topic.

Immediately following its presentation to the UN Human Rights Council in March 2013, the SRT report sparked a great deal of discussion and debate about a range of issues, including the nature of certain methods of treatment, the responsibilities and actions of health care professionals, the role of patients or clients in determining their treatment, and gaps in law and policy which can help prevent abusive practices. The debate has been robust and the discussion about different dimensions of the SRT's report very welcome.

This volume seeks to contribute to that debate, by creating space to elaborate on the SRT report. The publication chronicles part of the robust response by lawyers, academics, medical professionals, policy-makers and advocates to the cross-cutting issues explored by the SRT report.

Section I of this volume provides a broad overview of the problem of torture and ill-treatment in health care settings worldwide. The unique context of detention in health care settings is explored, and the interplay between the right to health framework in international human rights law and the prohibition against torture and ill-treatment are addressed. The types of violations broadly identified as occurring in health care settings are those involving forced or coerced medical interventions, the denial of care, the provision of care in a humiliating manner, or the provision of inferior care on a discriminatory basis.

Section II addresses the unique challenges posed by the abusive treatment of persons with psychosocial and mental disabilities, with a particular view to questions of legal capacity and informed consent for psychiatric treatment and interventions. This section also examines the impact of the UN Convention on the Rights of Persons with Disabilities (CRPD), its emerging role in international human rights and disability law, and its interaction with the UN Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT). This section also includes several articles addressing abuses committed against marginalized groups and vulnerable persons. The issue of prevalent discrimination on the basis of gender identity and sexual orientation is addressed. The abusive treatment of people institutionalized for drug dependence in some parts of the world, and the implications of the denial of pain treatment for palliative care, are discussed in the final two articles.

While some authors take issue with some of the SRT's findings, arguing either that the SRT has gone too far or has not gone far enough, the authors featured in this compilation all seek to help further elucidate standards for appropriate treatment in health care settings and we are grateful for their contributions. Most significantly, they do so whilst placing a foremost emphasis on the need to recognize the rights of victims and the obligations of governments to prevent and redress the abusive practices and policies that continue to affect millions of people worldwide—an undertaking on which everyone can agree.

Hadar Harris

Executive Director

Center for Human Rights & Humanitarian Law

American University Washington College of Law

Introduction

Despite the wealth of information and abundance of accounts and testimonies about abuses committed in health-care settings, until recently these issues have not been publicly denounced as amounting to torture or ill-treatment. Along with other previously published groundbreaking reports by the Mental Disability Advocacy Center, Human Rights Watch and Open Society Foundations, my 2013 report (A/HRC/22/53) (see in appendix) was aimed at illustrating some of the undetected and unrecognized abusive practices in health-care settings and most importantly to call for recognition and for an absolute ban of such abuses, as well as monitoring and accountability. While doing so, the 2013 report attempted to reflect evolving standards, some of which are not strictly within the mandate or the expertise of the Special Rapporteur on Torture.

The process of research and consultations that preceded the drafting of the report revealed the great breadth and complexity of the problems. The legality or illegality of these practices depends on interpretative principles (regarding, for example, consent, medical necessity and existence of therapeutic alternatives) that are not fully settled; indeed, both the progress of science and recent developments in domestic and international law are rapidly changing the landscape of what is permissible and appropriate as health care “treatment.” More detailed criteria for certain concepts need to be worked out. Following the publication of my report, we have received some helpful feedback of certain aspects related, for example, to the interpretation on the provisions of the Convention on the Rights of Persons with Disabilities. We felt it was important to continue to generate and promote the discussion of some contentious aspects of this topic with a view to contribute to the understanding of the critical aspects in the nexus between torture and other ill-treatment. The report was made public deliberately to solicit comments and to expand on the recommendations or elaborate and analyse contentious issues, pitfalls, gaps and potential problems as well as implications and consequences of implementing the recommendations contained in my report.

This publication consists of a compilation of articles submitted by experts and practitioners who have been invited to reflect and expand upon key aspects of my report as well as on implementation of recommendations contained therein. Given each author’s valuable and specific expertise, we deferred to them to identify the topic of their article. We tried to have a cross section of opinions in some of the contested matters, as well as to obtain the participation of the best-known experts and practitioners in each of the subtopics covered. The following topics have been covered in the compilation: *Interpretative and guiding principles and the evolution and application of lack of legal capacity as a doorway for torture and other ill-treatment; Emerging recognition of different forms of abuses in health-care settings as torture and other ill-treatment, including compulsory detention for medical conditions; Denial of pain relief; Persons with psycho-social disabilities or intellectual disabilities; Special protection of minority and marginalized groups and individuals as a critical component of the obligation to prevent torture and other ill-treatment; Reproductive rights violations.* The concluding part of this compilation looks at recognition, enforcement and accountability of various abusive practices occurring in health-care settings as well as the need to obtain redress and fair and adequate compensation, including the means for as full rehabilitation as possible.

While we are aware that the aims and objectives of this publication may be ambitious, we have tried to be as comprehensive as possible, to shed light on different facets of the issue of torture and other ill-treatment occurring in the context of health-care settings. The detailed evidence presented by various authors is a valuable contribution to our understanding of torture and other ill-treatment as a reality in health-care settings. This publication seeks to further clarify the main areas of concern raised in the report and most importantly, to generate and contribute to a discussion about the application and implementation of human rights standards in relation to situations arising in the context of health-care settings. In conjunction with the 2013 report, it is aimed at practitioners and law-makers, States and concerned parties around the globe faced with the responsibility of creating a policy and legislative framework with due regard to the international human rights norms and standards. Given the contentious nature of some positions I adopted in my report, this publication also seeks to serve as a forum for debate and clarification on the state of international law on the subject. It is my hope that in conjunction with my report to the United Nations, it will encourage legislators and practitioners around the world to stimulate reforms based on recent developments of international human rights norms and standards applicable outside the context of prison settings. I hope it will also contribute to advocates' efforts by bringing to light often undetected or unrecognized forms of abusive practices that are condoned as "treatment."

Torture in the Context of Healthcare

"Specific Purpose"

In order to demonstrate how abusive practices in health-care settings meet the definition of torture, I have examined the key elements of the definition of torture and ill-treatment and its applicability to the abuses in health-care settings. I have noted that the application of the criteria of severe pain or suffering, intent, and involvement of a public official or other person acting in an official capacity, by consent or acquiescence to abuses in health-care settings, is relatively straightforward and that the criterion of the specific purpose warrants some analysis (for example, when the main purpose is unlawful discrimination). There is a general acceptance that the stated purposes explicitly named in Article 1 of CAT, for which pain and suffering amounting to torture is inflicted, are only of an indicative nature and not exhaustive. At the same time, only purposes which have "something in common with the purposes expressly listed" are sufficient.

As for the State's core obligations under the prohibition of torture and ill-treatment, I have noted that under CAT "each State party should prohibit, prevent and redress torture and ill-treatment in all contexts of custody or control, for example, in prisons, hospitals, schools, institutions that engage in the care of children, the aged, the mentally ill or disabled, in military service, and other institutions as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm." As underlined by the CAT, the prohibition of torture must be enforced in all types of institutions and States must exercise due diligence to prevent, investigate, prosecute and punish violations by non-State officials or private actors.

Interpretative and Guiding Principles (Legal Capacity, Informed Consent, Medical Necessity)

I have examined several interpretative and guiding principles, such as legal capacity and informed consent in line with the Convention on the Rights of Persons with Disabilities (CRPD), as well as the notion of powerlessness and the doctrine of “medical necessity.”

I have noted that medical treatments of an intrusive and irreversible nature, if they lack a therapeutic purpose, constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned. This is particularly the case when intrusive and irreversible, non-consensual treatments are performed on patients from marginalized groups, such as persons with disabilities, notwithstanding claims of good intentions or medical necessity.

The report further questioned the “medical necessity” established by the European Court of Human Rights (ECtHR) where the Court held that continuously sedating and administering forcible feeding to a patient who was physically restrained was nevertheless consistent with article 3 of the European Convention on Human Rights (ECHR). The doctrine of medical necessity continues to be invoked as an obstacle to protection from arbitrary abuses in health-care settings and it is important to clarify that treatment provided in violation of the terms of the CRPD cannot be legitimate or justified under the medical necessity doctrine.

Persons with Psychosocial Disabilities

The Disability Discourse and the Repeal of Legal Provisions Authorizing Confinement and Compulsory Treatment

Despite the significant strides made in the development of norms for the abolition of forced psychiatric interventions on the basis of disability alone as a form of torture and ill-treatment and the authoritative guidance provided by the CRPD, severe abuses continue to be committed in health-care settings where choices by people with disabilities are often overridden based on their supposed “best interests,” and where serious violations and discrimination against persons with disabilities may be masked as “good intentions” of health professionals.

The mandate has previously declared that there can be no therapeutic justification for the use of solitary confinement and prolonged restraint of persons with disabilities in psychiatric institutions; both prolonged seclusion and restraint may constitute torture and ill-treatment. As mentioned above, the imposition of solitary confinement of any duration on persons with mental disabilities is cruel, inhuman or degrading treatment. Non-consensual detention, seclusion and restraints can only be legitimate to prevent serious harm to the patient or to others, and with measures and for the time strictly necessary to avoid such harm. The State has the burden to legislate and enforce this narrow scope of non-consensual treatment.

Fully respecting each person’s legal capacity is a first step in the prevention of torture and ill-treatment. As already established by the mandate, medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose or when aimed at correcting or alleviating a disability, may constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned.

With respect to domestic legislation allowing forced interventions, I noted that forced interventions, often wrongfully justified by theories of incapacity and therapeutic necessity inconsistent with the CRPD, are legitimized under national laws, and may enjoy wide public support as being in the alleged “best interest” of the person concerned. Nevertheless, to the extent that they inflict severe pain and suffering, they violate the absolute prohibition of torture and cruel, inhuman and degrading treatment. Concern for the autonomy and dignity of persons with disabilities leads me to urge revision of domestic legislation allowing for forced interventions.

With respect to involuntary commitment in psychiatric institutions, I noted that the CRPD has been very explicit in calling for the prohibition of disability-based detention, i.e. civil commitment and compulsory institutionalization or confinement based on disability. It establishes that community living, with support, is no longer a favorable policy development but an internationally recognized right. The CRPD radically departs from the previously existing approach by forbidding deprivation of liberty based on the existence of any disability, including mental or intellectual, as discriminatory. Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished. This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, except in the narrow circumstances mentioned above. Likewise, it is necessary to review and overhaul provisions authorizing the preventive detention of persons with disabilities on grounds such as the *potential or likelihood* of them posing a danger to themselves or others (rather than the actual clear and present danger of such an outcome), in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.

Deprivation of liberty on grounds of mental illness is unjustified if its basis is discrimination or prejudice against persons with disabilities. Under the European Convention on Human Rights, mental disorder must be of a certain severity in order to justify detention. The severity of the mental illness is not by itself sufficient to justify detention; the State must also show that detention is necessary to protect the safety of the person or of others. In the ECtHR jurisprudence, except in emergency cases, the individual concerned should not be deprived of his liberty unless he has been reliably shown to be of “unsound mind.” (ECHR, *Winterwerp v. The Netherlands*; ECHR, *E v. Norway*). However, as detention in a psychiatric context may lead to non-consensual psychiatric treatment, the mandate has stated that deprivation of liberty that is based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture. In making such an assessment, factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.

In my report, the reference to the European Court of Human Rights’ decision in *Winterwerp v. The Netherlands* (at para. 69 and footnote 88) was meant to be critical. I disagree with that judgment because justifying non-consensual treatment on the fact that the patient is “of unsound mind” raises a discriminatory basis for the treatment, which is impermissible (see para. 68 of my report, citing CRPD). Similarly, at para. 34, I cited another decision of the ECtHR, in *Herczegfalvy v. Austria*, also in disapproval (and there more clearly stated), in the context of medical necessity.

I want to put the burden on States to show that involuntary commitment is necessary under very strict and narrow circumstances: a) when the patient is a danger to him or herself or others; b) in emergency circumstances; c) in both cases for a limited time and with limited means, strictly sufficient only to prevent the risk of major harm.

I intend for all countries to overhaul their domestic legislation with regards to legal capacity and other applicable interpretative standards. The exact way in which new laws and regulations should be drafted is beyond my expertise and exceeds the purpose of my report as well as of this collection of essays. I do hope that the report will generate an earnest and urgent discussion of the matter.

The CRPD offers the most comprehensive set of standards on the rights of persons with disabilities, and it is important that States review the anti-torture framework in relation to persons with disabilities in line with the CRPD. States should impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs for both long- and short- term application. The obligation to end forced psychiatric interventions based on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation.

Forced treatment and commitment should be replaced by services in the community that meet needs expressed by persons with disabilities and respect the autonomy, choices, dignity and privacy of the person concerned. States must revise the legal provisions that allow detention on mental health grounds or in mental health facilities, and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned.

Analysis of Reproductive Rights Violations as Forms of Torture or Ill-Treatment

My report seeks to identify the reproductive rights practices in health-care settings that I believe amount to torture or ill-treatment. It further seeks to clarify the gender-specific forms of torture with a view to ensure that the torture protection framework is applied in a gender-inclusive manner. This intention is best illustrated in one of my recent joint press releases issued together with the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; the Special Rapporteur on violence against women, its causes and consequences; and the Chairperson of the Working Group on the issue of discrimination against women in law and in practice. On 26 April 2013, we called on the Government of El Salvador to provide life-saving treatment to a 22 year old woman who has been diagnosed with high risk of pregnancy-related death. This individual case where the increased suffering related to the situation of uncertainty faced amounted to a cruel, inhumane and degrading situation, exemplifies the urgent need to launch a national dialogue on abortion legislation. It is paramount to consider the introduction of exceptions to its general prohibition, especially in cases of therapeutic abortion and pregnancy resulting from rape or incest.

Juan E. Méndez

Special Rapporteur on torture and other cruel,
inhuman or degrading treatment or punishment

I.

The Prohibition of Torture and the Right to Health: An Overview

- 3** A Contribution by the Special Rapporteur on the Right to Health:
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Claudio Grossman

A Contribution by the Special Rapporteur on The Right to Health: Right to Health and Freedom From Torture and Ill-Treatment in Healthcare Settings

ANAND GROVER & JAMSHID GAZIYEV*

Abstract

The article reflects and expands on key aspects of the report of the Special Rapporteur on Torture, Mr. Juan E. Méndez, concerning torture and ill-treatment in healthcare settings (A/HRC/22/53), by providing an assessment of those elements from the right to health framework and by emphasizing the indivisibility and interdependence of the right to health and the freedom from torture and ill-treatment. It outlines the right to health framework and elaborates on policies and practices that lead to abuse and violations in healthcare settings due to discrimination and stigma towards vulnerable and marginalized persons, or due to criminalization of certain healthcare services and information. The authors further observe that despite the proscription of non-consensual medical treatment, many vulnerable and marginalized persons continue to be subjected to involuntary medical procedures. In order to address such gaps in the protection of human rights in healthcare settings and to prevent, prosecute and redress violations and abuses therein, the article emphasizes the urgency of comprehensive accountability mechanisms. Such mechanisms should be accessible, transparent and effective, at a minimum, and could benefit from protection afforded under the framework of prevention and prohibition of torture and ill-treatment. The article concludes by emphasizing that, in the reform process towards such holistic accountability mechanisms, there should be full participation of survivors, advocates, and representatives of patients groups, communities and civil society organizations and that healthcare providers and their professional associations should be empowered to identify and challenge abuses and violations in healthcare settings.

*Anand Grover is the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (right to health). Jamshid Gaziyevev is a Human Rights Officer at the United Nations Office of the High Commissioner for Human Rights. The views expressed in the article are those of the authors and do not necessarily represent the official policy of the United Nations.

Introduction

Abuse and ill-treatment in healthcare settings, be it in hospitals, hospices or prison clinics, is not a new phenomenon. In the aftermath of the Second World War, the scale of the involvement of medical professionals in the horrors committed by Nazi Germany was horrifying. It served as a catalyst for changes. Modern international human rights law was spearheaded, cementing universal human rights for everyone, everywhere. The absolute prohibition of torture was internationally proclaimed through the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, as well as the International Covenant of Civil and Political Rights, the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. The international community has also recognized the right of everyone to enjoy the highest attainable standard of physical and mental health through the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and other international treaties.

The medical profession adopted numerous ethical guidelines that uniformly prohibit torture and cruel, inhuman or degrading treatment or punishment (ill-treatment).¹ Medical participation in torture or ill-treatment, as well as in any act to diminish the ability of the victim to resist such treatment, is explicitly condemned. In 1982, the United Nations General Assembly adopted Principles of medical ethics relevant to the role of health personnel, particularly physicians, in the protection of prisoners and detainees against torture and other cruel, inhuman or degrading treatment or punishment, in which it declared that it is a gross contravention of medical ethics, as well as an offence under applicable international instruments, for health personnel to engage, actively or passively, in acts which constitute participation in, complicity in, incitement to or attempts to commit torture or ill-treatment.² In its resolution 16/23, the Human Rights Council also condemned “all forms of torture and other cruel, inhuman, or degrading treatment or punishment, including through intimidation, which are and shall remain prohibited at any time and in any place whatsoever and can thus be never justified.”

Torture and ill-treatment in healthcare settings has received little focused attention by the mandate of the Special Rapporteur on the right to health, as prevention and prohibition of torture and ill-treatment has conventionally fallen within the scope of the mandate of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (“Special Rapporteur on Torture”). However, due to the alarming increase of complaints about ill-treatment in various healthcare settings, the Special Rapporteur on the right to health has addressed such violations and related abuses from the right to health framework.³

¹ See World Medical Association’s Declaration of Tokyo (1975); Declaration of Hamburg, (1997); Declaration of Malta (2006); Resolution on the Responsibility of Physicians in the Documentation and Denunciation of Acts of Torture or Cruel or Inhuman or Degrading Treatment (2007).

² G.A. Res. 37/194, Principle 2, U.N. Doc. A/RES/37/194 (Dec. 18, 1982).

³ See, e.g., U.N. Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health [U.N. Special Rapporteur on the Right to Health], *Report of the Special Rapporteur: Paul Hunt* [hereinafter *Special Rapporteur Paul Hunt’s 2004 Report*], U.N. Doc. E/CN.4/2004/49 (2004) (by Paul Hunt); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt* [hereinafter *Special Rapporteur Paul Hunt’s 2005 Report*], U.N. Doc. E/CN.4/2005/51 (2005) (by Paul Hunt); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* [hereinafter *Special Rapporteur on the Right to Health’s 2009 Report*], U.N. Doc. A/64/272 (2009); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* [hereinafter *Special Rapporteur on the Right to Health’s 2010 Report*], U.N. Doc.

Similarly, the mandate of the Special Rapporteur on Torture had initially paid little specific attention to mistreatment in healthcare settings because “the denial of health-care has often been understood as essentially interfering with the ‘right to health,’” until he presented a report to the twenty-second session of the Human Right Council, in which he aimed to “analyse all forms of mistreatment premised on or attempted to be justified on the basis of health-care policies, under the common rubric of their purported justification as ‘health-care treatment’, and to find cross-cutting issues that apply to all or most of these practices.”⁴

The discussion below will therefore reflect and expand on key aspects of the report of the Special Rapporteur on Torture concerning torture and ill-treatment in healthcare settings (A/HRC/22/53) from the perspective of the right to health.

Discussion

1. Indivisibility and Interdependency of Human Rights

We start our discussion by emphasizing the underlying principle that has guided the mandate of the Special Rapporteur on the right to health—the principle of universality, indivisibility and interdependency of all human rights. The Vienna Declaration and Program of Action unequivocally stated that: “All human rights are universal, indivisible and interdependent and interrelated.”⁵ As a general rule, international human rights law recognizes the indivisibility and interdependence of the rights enunciated in the two covenants of the International Bill of Rights.⁶ This is predicated on the recognition that on the one hand, the enjoyment of civil and political rights requires respect for and promotion of economic and social rights and, on the other hand, that economic and social rights are not second best to civil and political rights.⁷

United Nations human rights mechanisms have consistently reiterated this approach in their pronouncements.⁸ More specifically and in relation to the right to health, the Committee on Economic, Social and Cultural Rights noted that:

*The right to health is closely related to and dependent upon the realization of other human rights, as contained in the International Bill of Rights, including the right to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health.*⁹

A/65/255 (2010); U.N. Special Rapporteur on the Right to Health, *Interim Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* [hereinafter *Special Rapporteur on the Right to Health’s General Assembly Report*], U.N. Doc. A/66/254 (2011); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, Anand Grover [hereinafter *Special Rapporteur Anand Grover’s 2012 Report*], U.N. Doc. A/HRC/20/15/Add.2 (2012) (by Anand Grover).

⁴ U.N. Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment [U.N. Special Rapporteur on Torture], *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* [hereinafter *Special Rapporteur on Torture 2013 Report*], paras. 11, 13 A/HRC/22/53 (2013).

⁵ Vienna Declaration and Program of Action, World Conference on Human Rights in Vienna, (June 25, 1993).

⁶ See Office of the High Commissioner on Human Rights [OHCHR], *Fact Sheet No.2: The International Bill of Human Rights* (1996).

⁷ See CLARE OVEY & ROBIN WHITE, *THE EUROPEAN CONVENTION ON HUMAN RIGHTS* 40 (2006).

⁸ See, e.g., Hum. Rts. C. Res. 12/2, U.N. Doc. A/HRC/RES/12/2 (Oct. 12, 2009); Hum. Rts. C. Res. 14/7, U.N. Doc. A/HRC/RES/14/7 (June 23, 2010).

⁹ U.N. Comm. On Economic, Social and Cultural Rights [CESCR], *General Comment No.14*, para. 3, U.N. Doc. E/C.12/2000/4 (2000).

Such an integrated approach brings the implementation of human rights closer to “the lived experience of rights” because “real people do not experience the needs or deprivations in their lives according to categories of lives.”¹⁰

The promotion and protection of the right to health therefore strengthens the prevention of torture and ill-treatment, while the prohibition of torture in healthcare settings reinforces the realization of the right to health. While recognizing that violations could fall within diverse legal frameworks, the principle of indivisibility and interdependency of human rights dictates that crosscutting human rights violations should not fall through the cracks of classifications. Increasingly, abuses and violations defy the seemingly neat contours of the mandates of the international human rights mechanisms. Take an example of corruption. It enables degrading treatment and has a detrimental impact on the human rights of persons who are detained or imprisoned.¹¹ The Subcommittee on Prevention of Torture previously noted the concurrent impact of corruption on the incidence of torture and ill-treatment in prisons and on the right to health of persons deprived of liberty, who constitute “a vulnerable group for which the impact of corruption is even greater, since they are less able to defend themselves or to report it.”¹² On another occasion, the Subcommittee stated that corruption “discriminates against anyone who fails to comply and places them in a position of extreme vulnerability,” affecting “the right to health and to food, the right to adequate standard of living, and the right to communicate with the outside, especially with the family” and ensuring silence, blocking complaints and guaranteeing impunity.¹³

Conditions of detention also illustrate the indivisibility and interdependency of the right to health and freedom from torture and ill-treatment. According to the international law, detainees and prisoners are entitled to a standard of healthcare equivalent to that available in the general community, without discrimination based on their legal status.¹⁴ The Committee against Torture and the Special Rapporteur on Torture consistently found that inadequate conditions of detention and failure to provide adequate health services to detainees and prisoners could amount to ill-treatment.¹⁵ The United Nations Human Rights Committee observed that the failure to protect the health of detained persons could amount to inhuman treatment, and that inadequate medical care

¹⁰ Alicia Ely Yamin, *The Future in the Mirror: Incorporating Strategies for the Defense and Promotion of Economic, Social and Cultural Rights into the Mainstream Human Rights Agenda*, 27 HUM. RTS. Q. 1200, 1219 (2005).

¹¹ See U.N. Special Rapporteur on Torture or Other Cruel, Inhuman or Degrading Treatment or Punishment, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak: Mission to Togo*, para. 91, U.N. Doc A/HRC/7/3/Add.5 (2008)(by Manfred Nowak); U.N. Human Rights Council, *Report of the Working Group on Arbitrary Detention*, paras. 56, 60, 74, U.N. Doc. A/HRC/10/21 (2009); U.N. Hum. Rts Comm., *Concluding Observations of the Human Rights Committee: The Former Yugoslav Republic of Macedonia*, para.8, U.N. Doc. CCPR/C/MKD/CO/2 (2008); U.N. Comm. On Economic, Social, and Cultural Rights, *Concluding observations of the Committee on Economic, Social and Cultural Rights: Republic of Moldova*, para.12, U.N. Doc. E/C.12/1/Add.91 (2003); U.N. Comm. On Economic, Social, and Cultural Rights, *Consideration of Reports Submitted By States Parties Under Articles 16 and 17 of the Covenant: Kenya*, para. 10, U.N. Doc. E/C.12/KEN/CO/1 (2008).

¹² U.N. Subcommittee on Torture, *Report on the Visit of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment to the Republic of Paraguay*, para. 62, U.N. Doc. CAT/OP/PRY/2 (2010).

¹³ U.N. Subcommittee on Torture, *Report on the visit of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment to Honduras*, para. 208, U.N. Doc. CAT/OP/HND/1 (2010).

¹⁴ See U.N. Basic Principles for the Treatment of Prisoners, G.A. Res. 45/111, U.N. Doc. A/RES/45/111 (Dec. 14, 1990); Standard Minimum Rules for the Treatment of Prisoners, E.S.C. Res. 663C, 2076 (1955); Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment, G.A. Res. 43/173, U.N. Doc. A/RES/43/173 (Dec. 9, 1998).

¹⁵ See U.N. Comm. against Torture [UNCAT], *Report of the Committee against Torture*, A/53/44 (1998); U.N. Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, para. 9, U.N. Doc. A/62/221 (2007) (by Manfred Nowak).

in prisons can amount in some cases to torture in violation of article 7 of ICCPR.¹⁶ The Committee further pronounced that States must ensure adequate medical care for all detainees based on their combined duties to ensure the right to life, freedom from torture and ill-treatment, and humane treatment of prisoners in accordance with articles 6, 7 and 10 of ICCPR respectively. Moreover, the principle of “retaining all rights” by persons who are deprived of their liberty includes the enjoyment of both the right to health and the protection against torture and ill-treatment.¹⁷

Similarly, at the regional level, the European Court of Human Rights has interpreted that article 3 of the European Convention of Human Rights (prohibition of torture or ill-treatment) imposes an obligation to secure the right to health of persons deprived of their liberty.¹⁸ Several judgments of the Court reflect its position that circumstances violating the right to health of persons deprived of their liberty, including unsanitary pre-trial detention and prison facilities, lack of medical care, and death of prisoners and detainees as a result of defective medical assistance, may amount to article 3 violations.¹⁹ The Court has indirectly redressed violations of the right to health of prisoners and detainees by affording damages for violations of the prohibition of inhuman and degrading treatment, which can be considered *de facto* reparations for violations of the right to health that is not expressly provided in the European Convention of Human Rights.²⁰

Some national courts have also adjudicated in the similar fashion. In the United States, which has not yet ratified the ICESCR, an inmate’s right to healthcare draws from the Eighth Amendment’s prohibition of cruel and unusual punishment to prisoners. Even though the initial intention was the prevention of torture and ill-treatment, the United States Supreme Court has interpreted the clause to include “a right to medical treatment for convicted inmates that does not allow wanton and willful infliction of pain.”²¹ Furthermore, in *Estelle v. Gamble*, the Supreme Court held that “deliberate indifference to serious medical needs is prohibited whether the indifference is manifested by prison doctors in their response to the prisoner’s needs or by prison guards intentionally denying or delaying access to medical care or intentionally interfering with the treatment once prescribed.”²²

2. Right to Health Framework

The right of everyone to the enjoyment of the highest attainable standard of physical and mental health (“right to health”) is codified in numerous international human rights treaties, including in article 25 (1) of the Universal Declaration of Human Rights (UDHR); article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR); article 24 of the Convention on the Rights of the Child (CRC); article 12 of the Convention on the Elimination of All

¹⁶ See *Cabal and Pasini v. Australia*, para. 7.7, U.N. Doc. CCPR/C/78/D/1020/2002 (Aug. 7, 2003); *Womah Mukong v. Cameroon*, U.N. Doc. CCPR/C/51/D/458/1991 (1994).

¹⁷ U.N. General Assembly, Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment, G.A. Res. 43/173, Principles 1 and 6 (Dec. 9, 1988).

¹⁸ See *Poltoratskiy v. Ukraine*, App. No. 38812/97, Eur. Ct. H.R. 39 (2003); *Kalashnikov v. Russia*, App. No. 47095/99, Eur. Ct. H.R. 36 (2002); *Kudla v. Poland*, App. No. 30210/96, Eur. Ct. H.R. 35 (2000).

¹⁹ See *Nevmerzhitsky v. Ukraine*, App. No. 54825/00, Eur. Ct. H.R. 43 (2005); *Sarban v. Moldova*, App. No. 3456/05 Eur. Ct. H.R. (2006); *McGlinchey v. United Kingdom*, App. No. 50390/99, Eur. Ct. H.R. 37 (2003); *Yakovenko v. Ukraine*, App. No. 15825/06 Eur. Ct. H.R. (2008); *Mouisel v. France*, App. No. 67263/01, Eur. Ct. H.R. 38 (2002); *Bragadireanu v. Romania*, App. No. 22088/04, Eur. Ct. H.R. (2008).

²⁰ Ingrid Nifosi-Sutton, *The Power of the European Court of Human Rights to Order Specific Non-Monetary Relief: A Critical Appraisal from a Right to Health Perspective*, 23 HARV. H. R. J. 67 (2010).

²¹ See, Mary Sylla & David Thomas, *The Rules Law and AIDS in Corrections*, HIV EDUCATION PRISON PROJECT NEWS (Nov. 2000) (construing *Spicer v. Williamson*, 132 S.E. 291 (N.C. 1926)).

²² See *Estelle v. Gamble*, 429 U.S. 97, 104-105 (1976).

Forms of Discrimination against Women (CEDAW); article 5 of the International Covenant on the Elimination of Racial Discrimination (CERD); article 25 of the Convention on the Rights of Persons with Disabilities (CRPD); and article 28 of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.

In addition to the international standards, the right to health is recognized in various regional human rights treaties, including the African Charter on Human and Peoples' Rights (art. 16); the African Charter on the Rights and Welfare of the Child (art. 14); the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, known as the "Protocol of San Salvador" (art. 10); and the European Social Charter (art. 11). Other regional instruments, which do not explicitly recognize the right to health but offer indirect protections through other health-related rights, include the American Declaration on the Rights and Duties of Man, the American Convention on Human Rights, the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, and the European Convention for the Protection of Human Rights and Fundamental Freedoms and its protocols. The right to health is also enshrined in over 110 national constitutions.²³

With regard to the jurisprudential content, the right to health is not to be understood as a right to be healthy, but rather as a right to facilities, goods, services and conditions that are conducive to the realization of the highest attainable standard of physical and mental health. Such health facilities, goods and services should be available, accessible, acceptable and of good quality.²⁴ The right to health is an inclusive right that extends not only to timely and appropriate health care, but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.²⁵

The right to health contains both freedoms and entitlements.²⁶ Entitlements include the right to a system of health protection, including health care and the underlying determinants of health, which provides equality of opportunity for people to enjoy the highest attainable standard of health. Freedoms include such rights as the right to control one's health and body and to be free from discrimination and non-consensual medical treatment and experimentation. Violations in this regard, including administration of non-consensual medication, forcible testing, involuntary sterilization and denial of certain healthcare services and goods, would often undermine the freedom from torture or ill-treatment and be incompatible with the right to the highest attainable to health. While the Special Rapporteur on the right to health has referred to the above acts as violations of the right to health,²⁷ the Special Rapporteur on Torture has emphasized that, if done on a discrim-

²³ U.N. Special Rapporteur on the Right to Health, *2004 Report*, para. 15, U.N. Doc. A/59/422 (2004) (by Paul Hunt); OHCHR & WORLD HEALTH ORGANIZATION [WHO], FACT SHEET NO. 31: THE RIGHT TO HEALTH 10 (2008).

²⁴ See CESCR, *General Comment No.14*, *supra* note 9, at para. 12; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Paul Hunt [hereinafter *Special Rapporteur Paul Hunt's 2007 Report*], paras. 68-76, U.N. Doc. A/HRC/4/28 (2007) (by Paul Hunt).

²⁵ CESCR, *General Comment No.14*, *supra* note 9, para. 8.

²⁶ *Id.*, para. 11.

²⁷ See Special Rapporteur on the Right to Health's 2009 Report, *supra* note 3, at paras. 62, 76; Special Rapporteur on the Right to Health's 2010 Report, *supra* note 3, at para. 30; Special Rapporteur on the Right to Health's General Assembly Report, *supra* note 3, at paras. 12, 16, 34, 48; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, Anand Grover, para. 56, U.N. Doc. A/HRC/20/15/Add.2 (2012) (by Anand Grover).

inatory basis and without respecting consent and necessity requirements, they may constitute a violation of the right to be free from torture and ill-treatment.²⁸

The international right to physical and mental health is subject to progressive realization and resource constraints. In terms of progressive realization, all States have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of the right to health. In other words, States are expected to be doing better in five years time than what they are doing today.²⁹ Resource constraints on States would imply that what is legally required of a developed State is of a higher standard than what is legally required of a least-developed country.³⁰ However, all rights enunciated in the ICESCR including the right to health are to be guaranteed to the maximum of resources available to the State.³¹

It should be emphasized, however, that the right to health also imposes obligations of immediate effect, including the guarantees of non-discrimination and equal treatment, as well as the obligation to take deliberate, concrete and targeted steps towards the full realization of the right to health, such as the preparation of a national public health strategy and plan of action. The right to health also encompasses the active and informed participation of individuals and communities in health decision-making that affects them. Because the right to health gives rise to entitlements and obligations, it demands effective mechanisms of accountability.

It has been well determined that human rights impose three types of obligations on States: the obligations to respect, protect and fulfill.³² These are equivalent State duties concerning the right to the highest attainable standard of health. The duty to respect requires the State to refrain from denying or limiting equal access for all persons, including prisoners, minorities, asylum-seekers and illegal immigrants, to preventive, curative and palliative health services. The duty to protect requires States to take measures that prevent third parties (e.g. private companies) from interfering with the right to health; to ensure that third parties do not limit people's access to health-related information and services; and that health professionals provide care to patients with their free and informed consent. The duty to fulfill requires States to adopt appropriate legislative, administrative, budgetary, judicial and other measures towards the full realization of the right to health.

3. Discrimination, Stigma and Criminalization

The mandate of the Special Rapporteur on the right to health has observed that many policies and practices leading to abuse and violations in healthcare settings are due to discrimination and stigma targeted at vulnerable and marginalized persons or due to criminalization of certain healthcare services, goods and information. This is despite the fact that non-discrimination and equal

²⁸ See U.N. Special Rapporteur on Torture, *Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* [hereinafter *Special Rapporteur Manfred Nowak's 2008 Report*], paras. 40, 48, U.N. Doc. A/63/175 (2008) (by Manfred Nowak); U.N. Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* [hereinafter *Special Rapporteur Manfred Nowak's 2009 Report*], para. 65, U.N. Doc. A/HRC/10/44 (2009) (by Manfred Nowak); Special Rapporteur on Torture 2013 Report, *supra* note 4, at paras. 48, 71, 79.

²⁹ Special Rapporteur Paul Hunt's 2007 Report, *supra* note 24, at para.59.

³⁰ Special Rapporteur Paul Hunt's 2005 Report, *supra* note 3, at para. 33.

³¹ CESCR, *General Comment No. 14*, *supra* note 9, at para. 47; CESCR, *General Comment No. 3*, at para. 9; CESCR, *General Comment No. 13*, at para. 45; U.N. Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, *Interim report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, paras. 6-8, U.N. Doc. A/67/302 (2012).

³² See CESCR, *General Comment No. 14*, *supra* note 9, para. 33 and *passim*.

treatment are among the most critical components of international human rights, including the right to health. Discrimination on grounds of gender, race, ethnicity, health status, sexual orientation, gender identity and other factors is a social determinant of health, which reinforces existing social divisions and inequalities. Social inequalities, fuelled by discrimination and marginalization of particular groups, shape both the distribution of diseases and the course of health outcomes amongst those affected.³³

Furthermore, discrimination and stigma constitute a failure to respect human dignity and equality by devaluing those affected, often exacerbating the inequalities already experienced by those vulnerable and marginalized groups.³⁴ The impact of stigma and discrimination on the right to health of particular populations is often compounded by abuses in healthcare settings. It has been observed that torture and ill-treatment in healthcare settings commonly occur among socially marginalized populations, or “people who are perceived as ‘deviant’ by authorities, who pose a ‘nuisance’ to health providers, who lack the power to complain or assert their rights or who are associated with stigmatised or criminalised behaviours.”³⁵ The Special Rapporteur on Torture recognized that ensuring special protection of marginalized groups and individuals is a vital component of the obligation to prevent torture and ill-treatment.³⁶ Similar to the CESCR’s emphasis on paying special attention to ensuring the enjoyment of the right to health by vulnerable and marginalized persons,³⁷ the Committee against Torture reiterated that States have a heightened obligation to protect such persons from torture due to the higher risk of them experiencing torture and ill-treatment.³⁸

The mandate of the Special Rapporteur on the right to health has explored and documented numerous examples of violations frequently suffered by vulnerable and marginalized groups. For example, people who use drugs or are dependent on drugs have frequently been victims of stigmatization and criminalization because of punitive approaches to drug control, which have resulted in countless human rights violations by perpetrating risky behaviors, detaining in “rehabilitation centers” for mandatory treatment, reducing access to care and medicines, particularly to opioid substitution therapies and analgesics, and restricting access to information about medical treatment.³⁹

In his submission to the Committee against Torture regarding drug control laws, the Special Rapporteur on the right to health observed the detrimental impact of drug control laws on drug users’ freedom from stigma and discrimination, namely due to the fear of sanction and incarceration, abysmal privacy and confidentiality of medical information, and harassment by police offi-

³³ See U.N. Special Rapporteur on Physical and Mental Health, *Report of the Special Rapporteur, Paul Hunt*, paras. 59-64, U.N. Doc. E/CN.4/2003/58 (2003).

³⁴ *Id.*, para. 62.

³⁵ *Campaign to Stop Torture in Health Care, Torture and Ill-Treatment in Health Settings: A Failure of Accountability*, 16 INTERRIGHTS BULLETIN 160 (2011).

³⁶ Special Rapporteur on Torture 2013 Report, *supra* note 4, at para. 26.

³⁷ See CESCR, *General Comment No. 14*, *supra* note 9, at paras. 12(b), 18, 35, 37, 40, 43(a), 52, 62.

³⁸ U.N. Comm. against Torture [CAT], *General Comment No.2*, at para. 21.

³⁹ See Special Rapporteur on the Right to Health’s 2010 Report, *supra* note 3; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt, Mission to Sweden* [hereinafter *Special Rapporteur on the Right to Health, Mission to Sweden*], A/HRC/4/28/Add.2 (2007)(by Paul Hunt); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, U.N. Doc. A/HRC/14/20/Add.3 (2010) (by Anand Grover); Special Rapporteur Anand Grover’s 2012 Report, *supra* note 3; Special Rapporteur Manfred Nowak’s 2009 Report, *supra* note 27, at para. 65.

cial.⁴⁰ The mandate of the Special Rapporteur on Torture has also considered areas where torture and ill-treatment occur as a direct and indirect result of drug policies, focusing on drugs users in the context of the criminal justice system and restricted access to drugs for palliative care.⁴¹ Both Rapporteurs have opined that the “‘war on drugs’ has distracted countries from their obligation to ensure that narcotic drugs are available for medical purposes”, and that “such failure by the governments to ensure access to controlled medicines for pain relief or treat drug dependence may violate international conventions proscribing cruel, inhuman or degrading treatment or punishment.”⁴² In fact, both mandates have sought to bridge the gap between the two parallel “universes” (drug policies and human rights) by recommending to adopt less restrictive approaches to drug control in favor of more supportive “harm-reduction” programs to prevent HIV among injection drug users, protect people’s health and lower future health costs.⁴³

Discrimination and stigma also continue to pose a serious threat to sexual and reproductive health for many groups, including women, sexual minorities, refugees, people with disabilities, rural communities, indigenous persons, people living with HIV/AIDS, sex workers, and people held in detention.⁴⁴ In addition to copious communications issued to States on allegations of violations of sexual and reproductive health, the mandate of the Special Rapporteur on the right to health has considered the issue in detail on numerous occasions: first, to stress that the sexual and reproductive health is an integral element of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; second, to explore criminalization of consensual same-sex conduct, sexual orientation and gender identity; and third, to consider the impact of criminal and other legal restrictions on the right to sexual and reproductive health.⁴⁵ The causal relationship between the gender stereotyping, discrimination and marginalization of women and girls and their enjoyment of their right to sexual and reproductive health has also been well documented.⁴⁶

In the context of sexual and reproductive health, freedoms associated with the right to health include a right to control one’s health and body. The freedom components of sexual and reproductive health are subject to neither progressive realization nor resource availability. Thus, for example, there is an immediate obligation on a State not to engage in forced sterilization and in discriminatory practices. Rape and other forms of sexual violence, including forced pregnancy, non-consensual abortion and female genital mutilation all represent serious breaches of sexual and reproductive freedoms, and are fundamentally and inherently inconsistent with the right to

⁴⁰ Anand Grover, *Submission From the Special Rapporteur on the Right to Health to the Committee against Torture Regarding Drug Control Laws* (Oct. 12, 2012) available at, www.ohchr.org/Documents/Issues/Health/drugPolicyLaw.pdf.

⁴¹ See Special Rapporteur Manfred Nowak’s 2009 Report, *supra* note 27.

⁴² Manfred Nowak & Anand Grover, *A Misguided ‘War on Drugs’*, THE NEW YORK TIMES, June 26, 2009.

⁴³ See Special Rapporteur on the Right to Health, Mission to Sweden, *supra* note 39; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, U.N. Doc. A/HRC/14/20/Add.3 (2010) (by Anand Grover); Special Rapporteur Anand Grover’s 2012 Report, *supra* note 3; Manfred Nowak & Anand Grover, *supra* note 40; Anand Grover, *supra* note 39; U.N. Special Rapporteur on Torture & U.N. Special Rapporteur on the Right to Health, *Letter to Chairperson of the Commission on Narcotic Drugs*, G/SO 214 (52-21) (Dec. 10, 2008).

⁴⁴ Special Rapporteur Paul Hunt’s 2004 Report, *supra* note 3, at para. 33.

⁴⁵ See Special Rapporteur Paul Hunt’s 2004 Report, *supra* note 3, at paras. 7-56; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, U.N. Doc. A/HRC/14/20 (2010) (by Anand Grover); Special Rapporteur on the Right to Health’s General Assembly Report, *supra* note 3.

⁴⁶ See U.N. Special Rapporteur on Violence Against Women, Its Causes and Consequences, *Report of the Special Rapporteur on Violence Against Women, Its Causes and Consequences*, U.N. Doc. E/CN.4/2002/83 (2002) (by Radhika Coomaraswamy); Special Rapporteur Paul Hunt’s 2004 Report, *supra* note 3.

health.⁴⁷ Furthermore, the Special Rapporteur on Torture examined gender-specific forms of torture in order to ensure that absolute prohibition of torture is applied in a gender-inclusive manner.⁴⁸ He also observed that discrimination plays a prominent role in considering reproductive rights violations as forms of torture or ill-treatment because sex and gender bias commonly underlie such violations.⁴⁹

Entitlements associated with the right to sexual and reproductive health cast a duty on States to ensure reproductive health and maternal and child health services, including appropriate services for women in connection with pregnancy. States should improve a wide range of sexual and reproductive health services, including access to family planning, pre- and post-natal care, emergency obstetric services and access to information. Furthermore, women should have equal access to information on sexual and reproductive health issues. In the context of State duties under the right to sexual and reproductive health, the obligation to respect requires States to refrain from denying or limiting equal access for all persons to sexual and reproductive health services, as well as to their underlying determinants; the obligation to protect means that they should take steps to prevent third parties from jeopardizing the sexual and reproductive health of others, including through sexual violence and harmful cultural practices; whereas the obligation to fulfill requires States to give recognition to the right to sexual and reproductive health, in national political and legal systems.⁵⁰

Nevertheless, healthcare settings abound with examples of violations of women's sexual and reproductive rights, from abusive treatment and humiliation in institutional settings, to denial of available medical care to forced abortion and sterilization.⁵¹ Moreover, criminal laws and other legal restrictions on sexual and reproductive health may be in violation of women's right to health in many ways, including by interfering with human dignity.⁵² Criminalization generates and perpetuates stigma; restricts women's ability to make full use of available sexual and reproductive healthcare goods, services and information; denies their full participation in society; and distorts perceptions among healthcare professionals which, as a result, can hinder their access to healthcare services.⁵³

With regard to criminal laws concerning consensual same-sex conduct, sexual orientation and gender identity, the Special Rapporteur on the right to health observed that such laws often infringe on various human rights, including the right to health.⁵⁴ The Special Rapporteur on Torture further noted that "members of sexual minorities are disproportionately subjected to torture and other forms of ill-treatment" and that "discrimination on grounds of sexual orientation or gender identity may often contribute to the process of the dehumanization of the victim, which is often a nec-

⁴⁷ Special Rapporteur Paul Hunt's 2004 Report, *supra* note 3, at para. 27.

⁴⁸ See U.N. Special Rapporteur on Torture, *Report on the Question of Torture and Other Cruel, Inhuman or Degrading Punishment*, U.N. Doc. A/54/426 (1999) (by Sir Nigel Rodley); U.N. Special Rapporteur on Torture, *Interim Report on the Question of Torture and Other Cruel, Inhuman or Degrading Punishment*, U.N. Doc. A/55/290 (2000) (by Sir Nigel Rodley).

⁴⁹ Special Rapporteur on Torture 2013 Report, *supra* note 4, at para. 37.

⁵⁰ Special Rapporteur Paul Hunt's 2004 Report, *supra* note 3, at paras. 43-44.

⁵¹ See Special Rapporteur on Torture 2013 Report, *supra* note 4, at paras. 46-50; U.N. Special Rapporteur On The Right To Health, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, para. 80, U.N. Doc. A/HRC/4/28 (2007) (by Paul Hunt).

⁵² See Special Rapporteur on the Right to Health's General Assembly Report, *supra* note 3.

⁵³ Special Rapporteur on the Right to Health's General Assembly Report, *supra* note 3, at para. 17.

⁵⁴ U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, para. 6, U.N. Doc. A/HRC/14/20 (2010) (by Anand Grover).

essary condition for torture and ill-treatment to take place.”⁵⁵ The U.N. High Commissioner for Human Rights, United Nations entities and its human rights mechanisms have also emphasized the negative health impact of criminalization.⁵⁶

4. Legal Capacity and Informed Consent

Even though the right to health and freedom from torture and ill-treatment both underlie respect for legal capacity and proscribe non-consensual medical treatment or experimentation,⁵⁷ many vulnerable and marginalized persons continue to be subjected to involuntary medical procedures. According to the Special Rapporteur on the right to health, informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, the guarantee of which is “a fundamental feature of respecting an individual’s autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services.”⁵⁸ While the Special Rapporteur on Torture defines capacity as a rebuttable presumption, implying that “‘incapacity’ must be proven before a person can be designated as incapable of making decisions.”⁵⁹ Thus, the right to be free from non-consensual medical treatment is subject to neither progressive realization nor resource availability, and has immediate application as the requirement of non-discrimination.

Vulnerable and marginalized groups and individuals warrant special consideration regarding the protection of informed consent due to vulnerabilities stemming from their economic, political social and cultural circumstances. Despite legal provisions guaranteeing informed consent at the

⁵⁵ See U.N. Special Rapporteur on Torture, *Report on the Question of Torture and Other Cruel, Inhuman or Degrading Punishment Sir Nigel Rodley*, para. 19, U.N. Doc. A/56/156 (1999) (by Sir Nigel Rodley); U.N. Special Rapporteur on Torture, *Report on the Question of Torture and Other Cruel, Inhuman or Degrading Punishment, Mission to Brazil*, para. 199, E/CN.4/2001/66/Add.2 (Mar. 2001) (by Sir Nigel Rodley); U.N. Special Rapporteur on Torture, *Report of the Special Rapporteur, Sir Nigel Rodley, Annex III p.11*, U.N. Doc. E/CN.4/2002/76 (2001) (by Sir, Nigel Rodley); U.N. Special Rapporteur on Torture, *Summary of Information, Including Individual Cases, Transmitted to Governments and Replies Received*, paras.1019, 1161, U.N. Doc. E/CN.4/2005/62/Add.1 (2005)(by Theo van Boven).

⁵⁶ See *Toonen v. Australia*, Communication No. 488/1992, para. 8.5, U.N. Doc. CCPR/C/50/D/488/1992 (1994); U.N. Comm. against Torture, *Consideration of Reports Submitted by States Parties Under Article 19 of the Convention: Conclusions and Recommendations of the Committee against Torture: Peru*, para. 23, U.N. Doc. CAT/C/PER/CO/4 (2006); U.N. Hum. Rts Comm., *Concluding observations of the Human Rights Committee: Togo (Addendum: Information Received from Togo on the Implementation of the Concluding Observations of the Committee)*, para. 14, CCPR/C/TGO/CO/4 (2013); U.N. Hum. Rts Comm., *Concluding Observations of the Human Rights Committee: Grenada*, para. 21, U.N. Doc. CCPR/C/GRD/CO/1 (2009); Comm. on the Elimination of Discrimination against Women, *Concluding Observation of the Committee on the Elimination of Discrimination against Women: Uganda*, paras. 43-44, U.N. Doc. CEDAW/C/UGA/CO/7 (2010); Comm. on the Rts. Of the Child, *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Third periodic Reports of States Parties due in 1997, Chile*, para. 29, U.N. Doc. CRC/C/CHL/CO/3; OHCHR, *Discriminatory Laws and Practices and Acts of Violence Against Individuals Based on Their Sexual Orientation and Gender Identity: Report of the United Nations High Commissioner for Human Rights*, paras.54-57, A/HRC/19/41 (2011); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover*, paras.14, 347, U.N. Doc. A/HRC/14/20/Add.1 (2010) (by Anand Grover); *Report of the Special Rapporteur on the Promotion and Protection of the Right to Freedom of Opinion and Expression, Frank La Rue*, para. 675, U.N. Doc. A/HRC/17/27/Add.1 (2011); UNAIDS, *GETTING TO ZERO: 2011-2015 STRATEGY* (2010); U.N. Special Rapporteur on the Situation of Human Rights Defenders, *Report Submitted By the Special Rapporteur on the Situation of Human Rights Defenders, Margaret Sekaggya: Addendum, Summary of cases transmitted to Governments and replies received*, paras. 346-355, U.N. Doc. A/HRC/10/12/Add.1 (2009) (by Margaret Sekaggya).

⁵⁷ See Special Rapporteur Paul Hunt’s 2005 Report, *supra* note 3; Special Rapporteur on the Right to Health’s 2009 Report, *supra* note 3; Special Rapporteur Manfred Nowak’s 2009 Report, *supra* note 27; Special Rapporteur on Torture 2013 Report, *supra* note 4; CESCR, *General Comment No. 14*, *supra* note 9, para. 8; CCPR, *General Comment No.20*, para. 7.

⁵⁸ Special Rapporteur on the Right to Health’s 2009 Report, *supra* note 3, at paras. 9, 18.

⁵⁹ Special Rapporteur on Torture 2013 Report, *supra* note 4, at para. 27.

national level, it continues to be undermined in the healthcare settings as a result of the power imbalance in doctor-patient and researcher-subject relationships.⁶⁰ While structural inequalities and powerlessness, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to the deprivation of legal capacity.⁶¹

Persons with disabilities are particularly vulnerable. Prejudices against them being incompetent or dangerous to themselves or others, coupled with existing laws and practices limiting legal capacity, often compromise their informed consent.⁶² Because of their varying ability to protect their own interests without assistance, persons with mental disabilities are even more vulnerable to discrimination, stigma and social exclusion.⁶³

Both Special Rapporteurs on the right to health and on torture have received numerous concerns about prolonged and involuntary detention of persons with mental disabilities in institutions, restrictions on legal capacity affecting the right to refuse treatment, forced sterilization of girls and women with disabilities, and stigmatization against people with disabilities in healthcare. Furthermore, gruesome accounts of abuses of persons with mental disabilities have also been documented in healthcare settings, including rape and sexual abuse, being chained to soiled beds or held inside cages, violence and torture, non-consensual medical treatment, unmodified use of electro-convulsive therapy, and grossly inadequate sanitation and nutrition.⁶⁴

Far from providing a supporting environment, healthcare settings are often where human rights abuses occur, which is particularly true in segregated services, including residential psychiatric institutions and psychiatric sections of prisons.⁶⁵ Regrettably, it is in the medical context that persons with mental disabilities often “experience serious abuse and violations of their right to physical and mental integrity, notably in relation to experimentation or treatments directed to correct and alleviate particular impairments.”⁶⁶ Pertinently, the Special Rapporteur on Torture observed that intrusive and irreversible, forced treatment or involuntary sterilization is often argued to be a medically necessary treatment for “the so-called best interest of the person concerned,” which is an issue that “continues to be an obstacle to protection from arbitrary abuses in healthcare settings.”⁶⁷

In articles 14 and 25, the Convention on the Rights of Persons with Disabilities clearly prohibits deprivation of liberty based on the existence of any disability and reaffirms that the existence of a disability is not a lawful justification for denial of informed consent. The Committee on the Rights of Persons with Disabilities and Special Rapporteurs on the right to health and on torture have all called for the prohibition of disability-based detention and expressed their support for ensuring the right of persons with disabilities to community living and integration through community-based

⁶⁰ Special Rapporteur on the Right to Health's 2009 Report, *supra* note 3, at paras. 46, 92.

⁶¹ Special Rapporteur Manfred Nowak's 2008 Report, *supra* note 27, at paras. 47, 74; Special Rapporteur on the Right to Health's 2009 Report, *supra* note 3, at para. 92; U.N. Comm. on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of China*, paras. 38, U.N. Doc. CRPD/C/CHN/CO/1 and Corr.1, (Oct. 15, 2012).

⁶² See *Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities - Report of the Secretary-General*, U.N. ENABLE, U.N. Doc. A/58/181; Special Rapporteur on the Right to Health's 2009 Report, *supra* note 3, at para. 92.

⁶³ Special Rapporteur Paul Hunt's 2005 Report, *supra* note 3, at para. 79.

⁶⁴ See Special Rapporteur Paul Hunt's 2005 Report, *supra* note 3, at paras. 7-12; Special Rapporteur on Torture 2013 Report, *supra* note 4, at para. 59.

⁶⁵ Paul Hunt & Judith Mesquita, *Mental Disabilities and the Human Right to the Highest Attainable Standard of Health*, 28 HUM. RTS. Q. 333 (2006).

⁶⁶ Special Rapporteur Manfred Nowak's 2008 Report, *supra* note 27, at paras. 57-65.

⁶⁷ Special Rapporteur on Torture 2013 Report, *supra* note 4, at paras. 32-35.

treatment.⁶⁸ As was repeatedly noted by the Special Rapporteur on the right to health, community integration can prevent institutionalization and is an important strategy in breaking down stigma and addressing discrimination against persons with mental disabilities and better supports their dignity, autonomy, equality and participation in society.

5. Accountability and Participation

Accountability is one of the central features of human rights. Without it, human rights can become no more than window-dressing. Accountability provides individuals and communities with an opportunity to understand how those with human rights responsibilities have discharged their duties. Equally, it provides those with human rights responsibilities the opportunity to explain what they have done and why.⁶⁹ Where violations have occurred, accountability requires redress, which include the investigation, prosecution and punishment of perpetrators.

According to the right to health framework, in a health system there must be accountability mechanisms that are accessible, transparent and effective, at a minimum.⁷⁰ Human rights accountability is also concerned with ensuring that health systems are improving, and the right to health is progressively realized for all, including vulnerable and marginalized individuals, communities and populations.

There are many different types of accountability mechanisms, including national human rights institutions, health commissioners, democratically elected local health councils, public hearings, patients' committees, impact assessments, judicial proceedings, and others.⁷¹ However, accountability in respect of health systems is often extremely weak, and sometimes the same body that provides health services also deals with regulating and holding it to account.⁷²

There is also judicial accountability, which has been considered in many of the reports of the Special Rapporteur on the right to health,⁷³ as well as administrative forms of accountability such

⁶⁸ See U.N. Comm. on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of China*, paras. 92-93, U.N. Doc. CRPD/C/CHN/CO/1 and Corr.1, (Oct. 15, 2012); U.N. Comm. on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Periodic Report of Hungary*, paras. 27-28, U.N. Doc. CRPD/C/HUN/CO/1 (Oct. 22, 2012); Special Rapporteur Manfred Nowak's 2008 Report, *supra* note 27, paras. 64-65; Special Rapporteur on Torture 2013 Report, *supra* note 4, at paras. 67-70; Special Rapporteur Paul Hunt's 2005 Report, *supra* note 3; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health: Addendum, Mission to Tajikistan*, para. 36, 38, 43, 51(b,c,m), A/HRC/23//Add.2 (2013)(by Anand Grover).

⁶⁹ U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health* [hereinafter *Special Rapporteur Paul Hunt's 2008 Report*], paras. 8-9, U.N. Doc. A/63/263 (2008) (by Paul Hunt).

⁷⁰ See Special Rapporteur Paul Hunt's 2007 Report, *supra* note 24, at para. 46; U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, paras. 65, 99-106, U.N. Doc. A/HRC/7/11 and Corr.1 (2008) (by Paul Hunt).

⁷¹ Special Rapporteur Paul Hunt's 2008 Report, *supra* note 68, at para. 11.

⁷² Special Rapporteur Paul Hunt's 2008 Report, *supra* note 68, at para.12; see also U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Mission to Uganda*, paras. 86-93, U.N. Doc. E/CN.4/2006/48/Add.2 (2006) (by Paul Hunt); U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Mission to Romania*, paras. 26-27, U.N. Doc. E/CN.4/2005/51/Add.4 (2005) (by Paul Hunt); Special Rapporteur on the Right to Health, *Mission to Sweden*, *supra* note 38, at paras. 31-33, 122-123.

⁷³ For more detailed discussion of judicial accountability, see Special Rapporteur Paul Hunt's 2007 Report, *supra* note 24, at section III.

as health impact assessments.⁷⁴ In addition, there are various mechanisms that are available at the regional and international levels.⁷⁵

International human rights law does not prescribe a single framework for domestic mechanisms of accountability and redress.⁷⁶ So human rights abuses in healthcare settings would have to be monitored through different mechanisms. Such mechanisms can be invoked for the protection afforded under the framework of prevention and prohibition of torture and ill-treatment. In fact, according to the General Comment No. 2 of the Committee against Torture, the prohibition against torture relates not only to public officials in the broader sense, including law enforcement agents, public healthcare and social workers, but also to those working in private hospitals and institutions.⁷⁷ Furthermore, the Committee held that the prohibition of torture must be applied in all types of institutions and it is the duty of the State to exercise due diligence to prevent, investigate, prosecute and punish non-State officials or private actors.⁷⁸ The Special Rapporteur on Torture observed that: "Examining abuses in health-care settings from a torture protection framework provides the opportunity to solidify an understanding of these violations and to highlight the positive obligations that States have to prevent, prosecute and redress such violations."⁷⁹

In order to strengthen accountability for ensuring the right to health and preventing ill-treatment in healthcare settings, States should go beyond singling out individual instances of abuses in healthcare settings, and identify and review laws, policies and practices that cause abuses and violations. In this reform process, States should ensure full participation of survivors, advocates, and representatives of patients groups, communities and civil society organizations. The right to health requires that health policies, programs and projects are participatory. The media, civil society organizations, community and patients groups have a crucial role to play. The active and informed participation of all stakeholders can broaden consensus and a sense of "ownership," promote collaboration and increase the chances of success.⁸⁰

It is also important to empower healthcare providers and their professional associations to challenge such laws and policies and protect them from dual loyalty conflicts, when they are "naturally caught in a difficult bind when there is conflict between their obligations to their patients and abusive laws and policies that restrict their actions."⁸¹ We should urge States to recognize institutions that should intervene to prevent or remediate the dual loyalty conflict in "the systemic factors that drive both health inequalities and discrimination, as well as more egregious forms of human rights violations, such as participation in torture."⁸²

⁷⁴ See U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, Section III, U.N. Doc A/62/214 (2007).

⁷⁵ See OHCHR & WORLD HEALTH ORGANIZATION [WHO], FACT SHEET NO. 31: THE RIGHT TO HEALTH SECTION IV (2008); HELEN POTTS, *Accountability and the Right to the Highest Attainable Standard of Health*, U. OF ESSEX (2008).

⁷⁶ OHCHR & WORLD HEALTH ORGANIZATION [WHO], FACT SHEET NO. 31: THE RIGHT TO HEALTH 31 (2008).

⁷⁷ CAT, *General Comment No.2*, para. 17, CAT/C/GC/2.

⁷⁸ *Id.*, at paras. 15-18.

⁷⁹ Special Rapporteur on Torture 2013 Report, *supra* note 4, at para. 82.

⁸⁰ Special Rapporteur Paul Hunt's 2004 Report, *supra* note 3, at para. 48.

⁸¹ See Joseph Amon, *Abusing Patients: Health Providers' Complicity in Torture and Cruel, Inhuman or Degrading Treatment*, HUMAN RIGHTS WATCH (2010); Open Society Foundations & Stop Torture in Health Care, *Government Accountability for Torture and Ill-Treatment in Health Settings*, An Open Society Foundations Briefing Paper (2011).

⁸² See Leslie London, *What Is a Human Rights-Based Approach to Health and Does It Matter?*, 10 HEALTH AND HUM. RTS. 69 (2008).

Conclusion

The preceding discussion has focused on abuses in healthcare setting from the perspective of the right to health and drawn on issues such as discrimination, stigma and informed consent, which are common to violations of the right to health and the freedom from torture and ill-treatment. It has also emphasized the indivisibility and interdependence of the right to health and prohibition of torture and ill-treatment, especially in detention and healthcare settings and called for a comprehensive protection and accountability mechanisms to prevent, prosecute and redress violations and abuses in healthcare. It is encouraging to observe that the analogous, holistic approach has been adopted by the Special Rapporteur on Torture in his report (A/HRC/22/53) and the recent General Comment of the Committee against Torture, which extends the duty to provide remedy and reparation to all acts of ill-treatment, whether they occur in healthcare settings or not.⁸³ It is therefore compelling to join the Special Rapporteur on Torture in his conclusion that “the framework opens new possibilities for holistic social processes that foster appreciation of the lived experiences or persons, including measures of satisfaction and guarantees of non-repetition, and the repeal of inconsistent legal provisions.”⁸⁴

⁸³ See CAT, *General Comment No.3*, para.1. CAT/C/GC/3

⁸⁴ Special Rapporteur on Torture’s 2013 Report, *supra* note 4, at para. 84.

The Problem of Torture in Health Care

TAMAR EZER*, JONATHAN COHEN**, RYAN QUINN***

Abstract

Torture and acts of cruel, inhuman, and degrading treatment are among the most widely proscribed violations of international and regional human rights law. Although the UN Human Rights Committee has clarified that this prohibition applies beyond abuses that occur in detention settings, it has rarely been recognized in the context of health care settings. However, a shift is taking place. In early 2011, a coalition of organizations launched the Campaign to Stop Torture in Health Care with the aim of increasing accountability for these abuses. Then, in February 2013, the Special Rapporteur on Torture issued a landmark report, which embraces the paradigm applying the prohibition against torture to health care settings and identifies examples of such abuse and the policies that promote it.

Currently, severe abuse is rampant in health care settings, particularly against socially marginalized groups—people living with HIV or tuberculosis, people with disabilities, people who use drugs, sex workers, ethnic minorities, gender and sexual minorities, and people in need of palliative care. Many such abuses appear to rise to the level of torture or ill-treatment. In particular, three broad (and sometimes overlapping) categories of abuse can be identified: (1) forced or coerced medical interventions; (2) denial of care or provision of inferior care on a discriminatory basis; and (3) provision of medical treatment in a humiliating manner. In many cases, torture and ill-treatment in health care are also attended by violations of the right to liberty, particularly in hospitals, tuberculosis centers, drug treatment centers, and mental health facilities. A human rights approach to health care would call for community-based treatment in a number of these instances.

Viewing violations in health care settings through an anti-torture lens highlights the particular vulnerability of marginalized groups to abuse, the misuse of medical procedures as a form of social control, and the intersection between torture in health care and the deprivation of liberty. Applying an anti-torture framework also lifts the shroud of darkness that has allowed these abuses to continue with impunity under the guise of medical “expertise” or “necessity.” Additionally, the anti-torture lens is a powerful tool that sets up an immediate and non-derogable obligation for states to remedy these abuses. It thereby can help foster health care settings that genuinely serve as places of care for all people.

* Senior Program Officer, Law and Health Initiative, Public Health Program, Open Society Foundations, 224 West 57th St., New York, New York 10019, USA, tamar.ezer@opensocietyfoundations.org. The authors are grateful to Matthew Goodro, who interned with OSF’s Law and Health Initiative in the spring of 2009, for his work and research on which this paper draws.

**Deputy Director, Public Health Program, Open Society Foundations, 224 West 57th St., New York, New York 10019, USA, jonathan.cohen@opensocietyfoundations.org.

***B.C.L./LL.B. Candidate in the Faculty of Law at McGill University, Montréal, Quebec, Canada, ryan.andrew.quinn@gmail.com.

Introduction

Torture and other acts of cruel, inhuman, or degrading treatment (CIDT) are among the most widely proscribed violations of international and regional human rights law.¹ The legal prohibition against torture and CIDT is both universal and expansive: “torture” constitutes “any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person” for a wrongful purpose,² whether in contexts with which torture is commonly associated, such as prisons and pretrial detention facilities, or in contexts such as schools, hospitals, orphanages, and social care institutions.³ The lack of application of anti-torture norms to the latter has contributed to a perception that torture is principally a matter for the criminal justice system and that abuses in educational and medical institutions are the purview of social rights norms pertaining to education and health. This article questions this dichotomy and argues that much can be achieved for victims of torture and the advancement of international law by systematically applying the prohibition against torture to health care settings.

The UN Human Rights Committee (HRC) has explicitly recognized that the prohibition against torture and CIDT goes beyond abuses that occur in detention settings. Indeed, it has noted in particular that Article 7 of the International Covenant on Civil and Political Rights (ICCPR) protects “children, pupils, and patients in teaching and medical institutions.”⁴ Despite this recognition, Article 7 and its analogues have rarely been applied to health care settings, except to the extent that health care is provided (or denied) in the contexts of prisons, detention centers, and the point of arrest, where human rights abuses in patient care that amount to torture or CIDT are extensive and well documented. Standards have evolved, for example, on the failure to provide adequate care to detained persons.⁵ With respect to non-penal health care settings, the jurisprudence applying the prohibition against torture and CIDT has focused on both the role of medical professionals in traditional state-sponsored torture and the treatment of people with mental disabilities in institutions.⁶

Building on this momentum, a shift is taking place, and the prohibition against torture has begun to be applied to general health care settings. In early 2011, a coalition of organizations working to combat severe human rights violations in health care settings launched the Campaign to Stop Torture in Health Care, aiming to increasing state accountability for these abuses.⁷ The Campaign recognized that it is precisely because health care settings are not considered places

¹ International Covenant on Civil and Political Rights art. 7, Mar. 23, 1976, S. Exec. Doc. No. E, 95-2, 999 U.N.T.S. 171 [hereinafter ICCPR]; Convention Against Torture and Other Forms of Cruel, Inhuman or Degrading Treatment or Punishment art. 2, 16, June 26, 1987, 1465 U.N.T.S. 85 [hereinafter CAT]; African Charter on Human and Peoples’ Rights art. 5, Oct. 21, 1986, 21 I.L.M. 58; American Convention on Human Rights art. 5(2), July 18, 1978, 1144 U.N.T.S. 123; European Convention for the Protection of Human Rights and Fundamental Freedoms art. 3, Sept. 3, 1953, ETS 5 [hereinafter European Convention on Human Rights].

² CAT, *supra* note 1, at art. 1.

³ Human Rights Committee, General Comment No. 20, *Torture or cruel, inhuman, or degrading treatment or punishment*, U.N. Doc. HRI/GEN/1/Rev.1 (Mar. 10, 1992).

⁴ *Id.*

⁵ See, e.g., *Yakovenko v. Ukraine*, App. No. 15825/06 Eur. Ct. H.R. (2008); *Musial v. Poland*, App. No. 28300/06 Eur. Ct. H.R. (2009).

⁶ See, e.g., Committee Against Torture, Conclusions and recommendations of the Committee against Torture: Russian Federation, ¶ 18, U.N. Doc. CAT/C/RUS/CO/4 (Feb. 6, 2007), available at <http://www.refworld.org/docid/465edff52.html>; Human Rights Committee, *Consideration of reports submitted by States parties under article 40 of the Covenant: Concluding Observations of the Human Rights Committee*, U.N. Doc. CCPR/C/NOR/CO/6 (Nov. 18, 2011), available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G11/471/23/PDF/G1147123.pdf?OpenElement>; *Stanev v. Bulgaria*, App. No. 36760/06 Eur. Ct. H.R. (2012).

⁷ See, e.g., Francois Girard, *Stop Torture in Health Care*, OPEN SOCIETY FOUNDATIONS (Mar. 29, 2011), available at www.opensocietyfoundations.org/voices/stop-torture-health-care-0.

of abuse that they are poorly monitored and violations continue. Then, in February 2013, the UN Special Rapporteur on Torture issued a landmark report embracing the paradigm “which increasingly encompasses various forms of abuse in health-care settings within the discourse on torture,” and identifying examples of such abuse and the policies that promote them.⁸

This article explores in detail how the prohibition against torture and CIDT can be applied to the context of general health care. Currently, human rights violations are rampant in health care settings, particularly against socially excluded or marginalized groups—for example, people living with HIV or tuberculosis, people with disabilities, people who use drugs, sex workers, ethnic minorities, gender and sexual minorities, and people in need of palliative care. Many such abuses appear to rise to the level of torture or CIDT. In particular, three broad (and sometimes overlapping) categories of abuse can be identified: (1) forced or coerced medical interventions; (2) denial of care or provision of inferior care on a discriminatory basis; and (3) provision of medical treatment in a humiliating manner. While all acts of torture and CIDT are deplorable, their occurrence in health care settings is cause for especial alarm because these are settings where one would expect to find human rights realized. Furthermore, such egregious abuses undermine the health care system as a whole and patients’ confidence in it.

There are compelling legal reasons to address abuses in health care settings under the banner of torture and CIDT, including triggering state obligations for their immediate redress and prevention. With respect to torture, the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) requires every state to:

- “take effective legislative, administrative, judicial or other measures to prevent acts of torture.”⁹
- “ensure that all acts of torture are offences under its criminal law[.]”¹⁰
- “ensure that education and information regarding the prohibition against torture are fully included in the training of law enforcement personnel, civil or military, medical personnel, public officials and other persons who may be involved in the custody, interrogation or treatment of any individual subjected to any form of arrest, detention or imprisonment.”¹¹
- “proceed to a prompt and impartial investigation, whenever there is reasonable ground to believe that an act of torture has been committed.”¹²
- provide victims with a civil remedy and “an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible[.]”¹³

CAT imposes similar obligations with respect to CIDT, likewise requiring states to take preventive measures, educate officials (including medical personnel), proceed to a prompt and impartial investigation of allegations, and establish an appropriate complaint mechanism.¹⁴ Unlike the right to the highest attainable standard of health, a social and economic right, the prohibition against torture and CIDT calls for immediate action and is not subject to progressive realization.¹⁵ It is also more amenable to litigation in most jurisdictions.

⁸ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 15, Human Rights Council, U.N. Doc. A/HRC/22/53 (Feb. 1, 2013) (by Juan E. Méndez); see also Special Rapporteur on Torture, *supra*, ¶ 39.

⁹ CAT, *supra* note 1, at art. 2.

¹⁰ CAT, *supra* note 1, at art. 4.

¹¹ CAT, *supra* note 1, at art. 10.

¹² CAT, *supra* note 1, at art. 12.

¹³ CAT, *supra* note 1, at art. 14.

¹⁴ CAT, *supra* note 1, at art. 16(1).

¹⁵ ICCPR, *supra* note 1, at art. 2.

Another important feature of the prohibition against torture and CIDT is that it is non-derogable. In the context of torture, CAT states, “No exceptional circumstance whatsoever, whether a state of war or a threat of war, internal political instability or any other public emergency, may be invoked as a justification for torture.”¹⁶ The ICCPR clarifies that the prohibition against CIDT is non-derogable as well.¹⁷

This article is laid out as follows: Section 1 provides background on relevant international law; Section 2 applies the law to the three categories of abuse in health care settings noted above, using illustrative examples; Section 3 explores in greater depth the significant connection between torture in health care and deprivation of liberty; and the Conclusion reflects on key themes and the significance of an anti-torture framework for violations in health care settings. It should be noted that Section 2 does not purport to compile exhaustively all health care abuses that rise to the level of torture or CIDT. We have sought to develop a representative sampling of abuses reported rather than to be comprehensive.

Discussion

1. Legal Background

Before applying the norms against torture and CIDT systematically to the field of health care, it is necessary to review them and consider the similarities and differences between (1) torture; (2) cruel and inhuman treatment; and (3) degrading treatment. This is particularly important because the stigma that results from applying the label of “torture” to acts involving medical professionals can be counterproductive if applied carelessly. Moreover, it is important to recognize that applying a human rights approach focuses attention on state responsibility and systemic violations and not on penalizing individual health care providers.

A useful concept when considering the application of anti-torture norms to the health care context is that of dual loyalty, defined as “simultaneous obligations, express or implied, to a patient and a third party, often the state.”¹⁸ Where the interests of the patient and the state are aligned, dual loyalty imposes little risk. Where they conflict, however, this creates potential for abuse, including torture. The International Dual Loyalty Working Group, convened by Physicians for Human Rights in 1993, has identified common situations where dual loyalty conflicts arise and has provided recommendations for preventing them—and the abuses they can lead to—within the context of medical ethics and professionalism. These recommendations, which can help to prevent abuse from occurring in the first place, potentially complement the legal remedies for violations of anti-torture norms implied in this article.¹⁹

The UN Special Rapporteur on Torture has observed that state duties to prevent torture apply “not only to public officials...but also to doctors, health-care professionals and social workers, including those working in private hospitals.”²⁰ Two recent cases from Brazil, adjudicated by the Committee on the Elimination of Discrimination against Women and the Inter-American Court

¹⁶ CAT, *supra* note 1, at art. 2(2).

¹⁷ ICCPR, *supra* note 1, at art. 4(2), 7.

¹⁸ INTERNATIONAL DUAL LOYALTY WORKING GROUP, DUAL LOYALTY & HUMAN RIGHTS IN HEALTH PROFESSIONAL PRACTICE: PROPOSED GUIDELINES & INSTITUTIONAL MECHANISMS 11 (2002), available at https://s3.amazonaws.com/PHR_Reports/dualloyalties-2002-report.pdf.

¹⁹ *Id.*

²⁰ Special Rapporteur on Torture, *supra* note 8, ¶ 24.

of Human Rights, have confirmed that privately run medical clinics fall well within the purview of government anti-torture obligations.²¹ This signals to states that they cannot circumvent their responsibility to protect human rights in health care policies and practices by outsourcing their medical services to private actors. On the contrary, they remain accountable to the victims of torture and CIDT perpetrated in any health care setting within their jurisdiction.

The legal definitions of torture and CIDT are broad enough to encompass a range of abuses prevalent in health care settings. Under international law, any infliction of severe pain and suffering by a state actor or with state instigation, consent, or acquiescence can constitute torture or ill-treatment, depending on the circumstances.²² Most prohibitions against torture cover abuses ranging from torture to cruel and inhuman treatment to degrading treatment. These three categories of abuse are distinguished through a number of factors: (1) the severity of pain or suffering inflicted; (2) the type of pain or suffering inflicted; (3) whether or not the pain or suffering was inflicted intentionally and for an improper purpose; and (4) whether the pain or suffering is incidental to lawful sanctions.

A finding of either torture or cruel and inhuman treatment requires a demonstration of “severe” pain or suffering, which is not the case for degrading treatment.²³ The European Court of Human Rights (ECtHR) has explained that a finding of severity depends on the totality of the circumstances, including “the duration of the treatment; its physical and mental effects; and, in some cases, the sex, age, and state of health of the victim.”²⁴ These considerations are highly relevant to abuses committed in the health care context, where victims are almost always in a vulnerable position because of their need for medical attention and relative powerlessness compared to health care professionals.

Article 1 of CAT makes clear that torture and CIDT may be predicated on strictly mental pain or suffering, strictly physical pain or suffering, or a combination of the two. The pain and suffering associated with degrading treatment is also closely linked to humiliation. As noted by the previous Special Rapporteur on Torture, “degrading treatment or punishment is specifically the infliction of pain or suffering, whether physical or mental, which aims at humiliating the victim.”²⁵

Outside the ECtHR, most authorities distinguish between torture and CIDT in terms of two additional elements: (1) the intent to cause pain and suffering; and (2) doing so for an improper purpose. This distinction stems from the definition of torture found in Article 1 of CAT, which includes both elements, whereas CAT’s definition of CIDT does not have similar requirements. As the previous Special Rapporteur explained, unlike torture, CIDT can be intentional or negligent and may or may not have a specific purpose.²⁶

As to the improper purpose requirement, Article 1(1) of CAT lists a number of examples that would support a finding of torture: “obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having

²¹ Committee on the Elimination of Discrimination against Women, *Alyne da Silva Pimental Teixeira v. Brazil* Comm. No. 17/2008, ¶ 7.5, U.N. Doc. CEDAW/C/49/D/17/2008 (Aug. 10, 2011); *Ximenes Lopes v. Brazil*, Merits, Reparations, and Costs, Inter-Am. Ct. H.R. (ser. C) No. 149, ¶ 141 (July 4, 2006).

²² CAT, *supra* note 1, at art. 1, 16.

²³ Special Rapporteur on Torture, *supra* note 8, ¶ 75.

²⁴ *Keenan v. United Kingdom*, App. No. 27229/95 Eur. Ct. H.R., ¶ 109 (2001).

²⁵ MANFRED NOWAK & ELIZABETH McARTHUR, *THE UNITED NATIONS CONVENTION AGAINST TORTURE: A COMMENTARY* 558 (2008).

²⁶ *Id.*

committed, or intimidating or coercing him or a third person, or...*any reason based on discrimination of any kind*" [emphasis added].

The discrimination clause may be particularly relevant to the health care context as the examples in the next section demonstrate. Article 1 further exempts pain and suffering "arising only from, inherent in or incidental to lawful sanctions" from supporting a finding of torture. There is no similar exemption for CIDT. "Lawful sanctions" are commonly interpreted as those accepted under international standards.²⁷

Each category of abuse in this paper encompasses a range, covering degrading treatment to cruel and inhuman treatment to torture. With this framework in mind, the following section explores three categories of abuse in health care settings: (a) forced or coerced medical interventions; (b) denial of care or provision of inferior care on a discriminatory basis; and (c) provision of medical treatment in a humiliating manner.

2. Types of Torture and Ill-Treatment in Health Care

a. Forced and Coerced Medical Interventions

Forced and coerced medical interventions, the performance of medical interventions without the informed consent of the patient, often rise to the level of torture or CIDT. When forced or coerced treatment takes place in the context of reproductive health, for example, the potential for severe pain and suffering increases as a result of the intimately personal nature of such procedures. Likewise, non-consensual medical interventions can have a particularly harsh impact on socially excluded and marginalized populations, such as people living with HIV, people who use drugs, sex workers, ethnic minorities, and gender and sexual minorities, whose experience of health care systems may already be shaped by social stigma and discrimination.

i. Forced or Coerced Sterilization

The recent report of the UN Special Rapporteur on Torture outlines the "increasingly global problem" of forced or coerced sterilization of members of marginalized groups "based on discriminatory notions that they are 'unfit' to bear children."²⁸ Women targeted with this practice include minorities, such as Roma in the Czech Republic,²⁹ Hungary,³⁰ and Slovakia³¹ and indigenous women in Peru,³² as well as women living with HIV.³³ Nearly 20 percent of women living with

²⁷ SARAH JOSEPH ET AL., SEEKING REMEDIES FOR TORTURE VICTIMS: A HANDBOOK ON THE INDIVIDUAL COMPLAINTS PROCEDURES OF THE UN TREATY BODIES 213 (2006).

²⁸ Special Rapporteur on Torture, *supra* note 8, ¶ 48.

²⁹ Committee on the Elimination of All Forms of Discrimination against Women, *Concluding Comments of the Committee on the Elimination of Discrimination against Women: Czech Republic*, ¶ 23, U.N. Doc. CEDAW/C/CZE/CO/3 (Aug. 25, 2006), available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N06/480/60/PDF/N0648060.pdf?OpenElement>; see also Ed Holt, *Roma Women Reveal that Forced Sterilization Remains*, 365 *The Lancet* 927 (2005).

³⁰ Committee on the Elimination of All Forms of Discrimination against Women, *A.S. v. Hungary* Comm. No. 4/2004, U.N. Doc. CEDAW/C/36/D/4/2004 (2006), available at http://www.escr-net.org/caselaw/caselaw_show.htm?doc_id=1053033.

³¹ CENTER FOR REPRODUCTIVE RIGHTS & PORADNA PRE OBCIANSKE A LUDSKÉ PRÁVA (CENTER FOR CIVIL AND HUMAN RIGHTS), *BODY AND SOUL: FORCED STERILIZATION AND OTHER ASSAULTS ON ROMA REPRODUCTIVE FREEDOM IN SLOVAKIA* (2003), available at http://reproductiverights.org/sites/default/files/documents/bo_slov_part1.pdf.

³² Ángel Páez, *Peru: IACHR Calls for Justice for Victims of Forced Sterilization*, INTER-PRESS SERVICE, Nov. 26, 2009.

³³ See, e.g., HUMAN RIGHTS WATCH, *A TEST OF INEQUALITY: DISCRIMINATION AGAINST WOMEN LIVING WITH HIV IN THE DOMINICAN REPUBLIC* 41-43 (2004), available at <http://www.hrw.org/reports/2004/07/12/test-inequality>;

HIV interviewed in Namibia in 2009 reported sterilization against their will,³⁴ and 56 percent of women living with HIV surveyed in Chile in 2004 reported pressure not to have children.³⁵ In many cases, women are not asked for their consent at all, and sterilization takes place while they undergo a caesarean section or abdominal surgery. Other accounts report that women are coerced into consenting as a condition of other medical treatment, or asked to consent while in labor without being informed of the permanence of the procedure or alternative forms of birth control.

Women and girls with disabilities are another group especially vulnerable to non-consensual sterilization, particularly where state laws deny them protections accorded to other women. For instance, in many countries sterilization is condoned for eugenics-based population control, pregnancy prevention (including pregnancy resulting from sexual abuse), and menstrual management. Legal guardians making life-altering decisions, including sterilization, on behalf of women with disabilities is a widespread practice, further leading to this abuse.³⁶

Many transgender and intersex persons endure forced medical interventions that attempt to fit them into traditional gender norms. As recognized by the Special Rapporteur, several jurisdictions require transgender persons to undergo unwanted sterilization in order to have their gender legally recognized.³⁷ While many transgender individuals may desire sterilization procedures as part of their transition, it is problematic for the state to make this a mandatory pre-condition for gender recognition. Similarly, children born with intersex conditions or atypical sex organs are often subjected to unnecessary and irreversible medical procedures such as sterilization.³⁸

The impacts of these abuses can be severe. Women suffer personally from ongoing pain, the physical effects of botched sterilizations, grief, and loss of self-esteem. As one woman in South Africa described it, "I feel like half a woman all the time."³⁹ Forced or coerced sterilization can also result in distressing social consequences, including abandonment by partners and loss of economic support. One woman in Namibia explained, "In African culture, if you are not able to have children, you are ostracized."⁴⁰ She further explained that the stigma is worse than that of living with HIV.⁴¹ Women who have been subjected to non-consensual sterilization can also develop a fear of the health care system and a reluctance to seek further care.

AFRICAN GENDER AND MEDIA INITIATIVE, *ROBBED OF CHOICE: FORCED AND COERCED STERILIZATION EXPERIENCES OF WOMEN LIVING WITH HIV IN KENYA* (2012), available at <http://kelinkkenya.org/wp-content/uploads/2010/10/Report-on-Robbed-Of-Choice-Forced-and-Coerced-Sterilization-Experiences-of-Women-Living-with-HIV-in-Kenya.pdf>.

³⁴ INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS, *THE FORCED AND COERCED STERILIZATION OF HIV POSITIVE WOMEN IN NAMIBIA* (2009), available at <http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf>.

³⁵ FRANCISCO VIDAL & MARINA CARRASCO, *MUJERES CHILENAS VIVIENDO CON VIH/SIDA: DERECHOS SEXUALES Y REPRODUCTIVOS?* [available in Spanish] (VIVO Positivo, Universidad Arcis, and FLASCO-Chile, 2004), available at http://www.feim.org.ar/pdf/blog_violencia/chile/MujeresChilenas_con_VIH_y_DSyR.pdf at 93.

³⁶ OPEN SOCIETY FOUNDATIONS, *STERILIZATION OF WOMEN AND GIRLS WITH DISABILITIES: A BRIEFING PAPER* (2011), available at <http://opensocietyfoundations.org/sites/default/files/sterilization-women-disabilities-20111101.pdf>.

³⁷ Special Rapporteur on Torture, *supra* note 8, ¶ 78.

³⁸ *Id.* ¶ 77.

³⁹ SETHEMBISO MTHEMBU, ZAYNAB ESSACK & ANN STRODE, "I FEEL LIKE HALF A WOMAN ALL THE TIME": A QUALITATIVE REPORT OF HIV AND WOMEN'S EXPERIENCES OF COERCED AND FORCED STERILIZATION IN SOUTH AFRICA (2011), available at <http://www.africawin.org/download/5/>.

⁴⁰ OPEN SOCIETY FOUNDATIONS, *AGAINST HER WILL: FORCED AND COERCED STERILIZATION OF WOMEN WORLDWIDE* (2011), available at <http://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf>.

⁴¹ *Id.*

The Special Rapporteur's recent report is instructive in framing these unwanted medical interventions as serious human rights violations. He unequivocally declares non-consensual sterilization "an act of violence, a form of social control, and a violation of the right to be free from torture and other [CIDT]." He calls upon states "to outlaw forced or coerced sterilization in all circumstances" and clarifies that sterilization for purposes of pregnancy prevention can never be justified on grounds of medical emergency.⁴² Moreover, the Special Rapporteur recognizes the particular vulnerability of socially excluded and marginalized groups in the context of forced sterilization. In so doing, he goes further than existing standards, such as the International Federation of Gynecology and Obstetrics (FIGO) Guidelines, to condemn the forced sterilization of transgender and intersex persons.⁴³

ii. Forced or Coerced Abortions

Closely related to the widespread practice of non-consensual sterilization is that of forced or coerced abortions, particularly as performed on women with disabilities and women living with HIV. As with unduly restrictive access to safe abortions, the Special Rapporteur on Torture makes clear that the subjection of women to unwanted abortions without their informed consent constitutes a breach of Article 7 of the ICCPR.⁴⁴ In particular, and in keeping with the non-discrimination component of torture and CIDT, the previous Special Rapporteur singled out forced abortions and sterilization of women with disabilities as amounting to torture or CIDT when "conducted with the legal consent of the person's guardian but against the disabled woman's will."⁴⁵

The sentiment that "pregnancy ought to be prevented at all cost[s] in HIV-infected women" has led many health care providers surveyed in Kenya to misinform patients living with HIV about the risk of transmission and the steps that can be taken to limit this risk.⁴⁶ Similarly, a report from Ukraine documents cases in which "doctors failed to inform pregnant women living with HIV about prevention of mother-to-child HIV transmission" and, instead, exaggerated the reality of the risk and persuaded them to undergo abortions.⁴⁷ One woman in Namibia, interviewed by the International Community of Women with HIV/AIDS (ICW), described being given an abortifacient without her knowledge simply because her nurse did not think she should be pregnant.⁴⁸ As with forced and coerced sterilization, the mental, emotional, and physical suffering occasioned by forced or coerced abortion is often severe. The Special Rapporteur has thus taken on an important initiative by including forced abortions among "the reproductive rights practices in health-care settings that he believes amount to torture or ill-treatment."⁴⁹

⁴² Special Rapporteur on Torture, *supra* note 8, ¶ 33, 48, 88.

⁴³ *Id.* ¶ 76-78, 88.

⁴⁴ *Id.* ¶ 50.

⁴⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Rights, Including the Right to Development*, ¶ 38, 69, Human Rights Council, U.N. Doc. A/HRC/7/3 (Jan. 15, 2008) (by Manfred Nowak).

⁴⁶ CENTER FOR REPRODUCTIVE RIGHTS AND FEDERATION OF WOMEN LAWYERS—KENYA, *AT RISK: RIGHTS VIOLATIONS OF HIV-POSITIVE WOMEN IN KENYAN HEALTH FACILITIES 44* (2008), available at <http://reproductiverights.org/sites/crr.civicactions.net/files/documents/At%20Risk.pdf>.

⁴⁷ HUMAN RIGHTS WATCH, *RHETORIC AND RISK: HUMAN RIGHTS ABUSES IMPEDING UKRAINE'S FIGHT AGAINST HIV/AIDS 44* (2006), available at <http://www.hrw.org/reports/2006/03/01/rhetoric-and-risk>.

⁴⁸ INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS, *supra* note 34.

⁴⁹ Special Rapporteur on Torture, *supra* note 8, ¶ 45.

iii. 'Treatment' of Sexual and Gender Minorities

Another rampant form of forced medical treatment documented by the UN Special Rapporteur on Torture consists of attempts to "treat" or "cure" sexual and gender minorities "because they fail to conform to socially constructed gender expectations."⁵⁰ Too many health care providers continue to treat homosexuality as a mental disorder, a form of discrimination that may amount to CIDT, and subject them to "conversion therapy" with severe psychological consequences.⁵¹ Transgender persons also routinely face ill-treatment in health care settings beyond the coerced sterilization procedures noted above, such as when they are subjected to arbitrary requirements to undergo psychiatric evaluation or genital surgery.

As the Special Rapporteur has observed, intersex children in many countries are routinely forced to undergo unwanted medical procedures "leaving them with permanent, irreversible infertility and causing severe mental suffering."⁵² These interventions may also go beyond the sterilization practices noted above and extend to hormone therapy and genital-normalizing surgeries such as clitoral "reduction."⁵³ Such procedures are typically performed in an attempt to impose a biological gender of either male or female and can cause scarring, loss of sexual sensation, pain, incontinence, and lifelong depression.⁵⁴ Parents of intersex children are frequently pressured to consent to this "treatment" on their behalf without adequate information about its long-term risk to sexual function and mental health.⁵⁵ Intersex children are also often exposed to humiliating and unnecessary exams or used as teaching tools or for medical experiments.⁵⁶

It is important to recognize, however, that even less drastic treatment of gender and sexual minorities can amount to CIDT. A focus group conducted in Kyrgyzstan, for instance, found that many transgender men are counseled by their psychologists to "try to be girly" and "put on makeup, wear a dress, and look like a woman."⁵⁷ This willful ignorance of gender and sexual minorities' lived realities not only denies them appropriate health care but also generally alienates them from society. The Special Rapporteur aptly observes that such "treatment" of gender and sexual minorities as having mental disorders results in the dehumanization of these patients, supporting a finding of torture or CIDT.⁵⁸

⁵⁰ *Id.* ¶ 79.

⁵¹ See, e.g., D.C. Haldeman, *Therapeutic Antidotes: Helping Gay and Bisexual Men Recover from Conversion Therapies*, 5 J. GAY & LESBIAN MENTAL HEALTH 117 (2001).

⁵² Special Rapporteur on Torture, *supra* note 8, ¶ 77.

⁵³ P.A. Lee et al., *Consensus Statement on Management of Intersex Disorders*, 118 PEDIATRICS e488 (2006).

⁵⁴ Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?*, 7 MICH. J. OF GENDER & L. 1 (2000); MARCUS DE MARÍA ARANA, SAN FRANCISCO HUMAN RIGHTS COMMISSION, A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL "NORMALIZATION" OF INTERSEX PEOPLE (2005).

⁵⁵ Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 BERKELEY J. GENDER L. & JUST. 59 (2006).

⁵⁶ ADVOCATES FOR INFORMED CHOICE, KNOW YOUR RIGHTS (2010), available at <http://aiclegal.org/publications/>; Alice Dreger & Ellen K. Feder, *Bad Vibrations*, HASTINGS CENTER BIOETHICS FORUM (June 16, 2010), available at <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4370&blogid=140>; Catherine Elton, *A Prenatal Treatment Raises Questions of Medical Ethics*, TIME (June 18, 2010); Sharon Begley, *The Anti-Lesbian Drug*, NEWSWEEK (July 2, 2010).

⁵⁷ OPEN SOCIETY FOUNDATIONS, ACCESS TO HEALTH CARE FOR LGBT PEOPLE IN KYRGYZSTAN 33 (2007), available at <http://www.opensocietyfoundations.org/reports/access-health-care-lgbt-people-kyrgyzstan>.

⁵⁸ Special Rapporteur on Torture, *supra* note 8, ¶ 79.

iv. Forced Medical Examinations

The practice of forced medical examinations carried out on socially excluded and marginalized populations can also amount to CIDT under certain circumstances. The UN Special Rapporteur on Torture's report describes a number of non-consensual examinations, including "the 'medically worthless' practices of subjecting men suspected of homosexual conduct to non-consensual anal examinations to 'prove' their homosexuality."⁵⁹ These examinations have been well documented in Egypt, Turkey, Romania, and Zimbabwe.⁶⁰ One man shared the following story of his anal examination by the director of Egypt's Forensic Medical Authority and six other doctors: "They all felt me up, each in turn, pulling my buttocks apart. They brought this feather against my anus and tickled it. [...] After the feather came the fingers. Then they stuck something else inside. I would cry and he would stick stuff inside[.]"⁶¹

Forced medical examinations can also rise to the level of CIDT in the context of HIV testing. In his discussion on sex workers, the Special Rapporteur notes, "Public health rationales have in some instances led to mandatory HIV testing and exposure of their HIV status, accompanied by punitive measures."⁶² In his view, compulsory HIV testing can amount to degrading treatment if imposed on a discriminatory basis and without meeting requirements of consent and necessity.⁶³ In 2008, police in Macedonia rounded up more than 30 people in an area known for sex work and subjected them to forced testing for HIV, hepatitis B, and hepatitis C. Following the arrests, the Ministry of the Interior released a press announcement disclosing personal information about the detainees, and media outlets published photos and videos of them.⁶⁴ Likewise, in Austria, where registered sex workers are required to undergo weekly medical check-ups and take regular blood tests for sexually transmitted diseases, CAT has noted "reports of alleged lack of privacy and humiliating circumstances amounting to degrading treatment during medical examinations."⁶⁵

The impact of forced medical examinations on other criminalized populations cannot be ignored. While the Special Rapporteur comments at length on the detention of people who use drugs and their subjection to "unknown or experimental medications,"⁶⁶ they are also often forced to undergo invasive medical examinations. Although such examinations may be permissible for the purpose of gathering evidence for court proceedings, they must be judicially supervised and conducted with respect for health and human dignity. In *Jalloh v. Germany*, the ECtHR ruled that a doctor's forced administration of an emetic in order to induce vomiting in a man suspected of having swallowed cocaine constituted a violation of the prohibition against inhuman treatment, especially in view of the procedure's "particularly intrusive nature" and the fact that the emetic had been administered with "force verging on brutality."⁶⁷



⁵⁹ *Id.* ¶ 79.

⁶⁰ Scott Long, *When Doctors Torture: The Anus and the State in Egypt and Beyond*, 7 HEALTH & HUM. RTS: AN INT'L J. 114 (2004).

⁶¹ *Id.* at 123-124.

⁶² Special Rapporteur on Torture, *supra* note 8, ¶ 75.

⁶³ *Id.* ¶ 71.

⁶⁴ Sex Workers' Rights Advocacy Network (SWAN), *In Focus: Macedonia Alert: Police Raids, Detention, Involuntary STI-Tests* (Nov. 25, 2008), available at <http://swannet.org/en/node/1219>.

⁶⁵ CENTER FOR REPRODUCTIVE RIGHTS, REPRODUCTIVE RIGHTS VIOLATIONS AS TORTURE AND CRUEL, INHUMAN, OR DEGRADING TREATMENT OR PUNISHMENT: A CRITICAL HUMAN RIGHTS ANALYSIS 19 (2011).

⁶⁶ Special Rapporteur on Torture, *supra* note 8, ¶ 40-41.

⁶⁷ *Jalloh v. Germany*, App. No. 54810/00 Eur. Ct. H.R. ¶ 71, 77, 79 (2006).

The foregoing categories of forced and coerced medical interventions demonstrate consistent patterns of discrimination against socially excluded and marginalized groups in health care settings. As noted above, the Special Rapporteur has taken a powerful stance against non-consensual treatment, whether it stems from medical professionals' disregard for their patients' wishes or from their willful blindness to the gravity of the intervention concerned. Framing forced and coerced treatment as torture and CIDT enjoins states to ensure that health care providers not only obtain their patients' informed consent to medical interventions but also refrain from any act that would inflict severe pain and suffering.

b. Denial of Care or Provision of Inferior Care on a Discriminatory Basis

Necessary medical care is routinely denied to members of the same populations as described above, including people living with HIV, people who use drugs, sex workers, ethnic minorities, and sexual and gender minorities. Likewise, pain relief in the form of controlled essential medicines is often denied to patients in need of palliative care. Even when health care is provided to these populations, it is often of inferior quality. In many cases, this denial of care or provision of inferior care may rise to the level of torture or CIDT, particularly when these patients' physical suffering is exacerbated by overt acts of discrimination on the part of medical professionals. This discriminatory treatment further reveals that these violations are systemic and not merely arbitrary acts of neglect.

i. People Living with HIV

The continued stigma associated with HIV and the misconceptions concerning its means of transmission, even among medical professionals, often contribute to denial of treatment and inferior care for people living with HIV. As noted by the UN Special Rapporteur on Torture, in many countries people living with HIV "are reportedly turned away from hospitals, summarily discharged, denied access to medical services unless they consent to sterilization, and provided poor quality care that is both dehumanizing and damaging to their already fragile health status."⁶⁸ This mistreatment frequently rises to the level of CIDT.

In Vietnam, people living with HIV reported in 2007 being ignored by health care professionals, marked as HIV positive on their clothes, segregated from other patients, and denied services such as lymph node incisions, in-patient admission, and cleaning.⁶⁹ A 2006 report from Ukraine found that people living with HIV "were often denied emergency medical treatment, including by ambulances [that] refused to pick them up; were kicked out of hospitals; and were provided inadequate treatment by doctors who refused even to touch them."⁷⁰ In another 2011 account, a woman in India was refused treatment for her fifth pregnancy once medical staff learned she was HIV positive, leading her to give birth in the street. She later died from delivery complications that could have been avoided had she been given quality maternal healthcare.⁷¹ In some cases, this ill-treatment extends to the family members of people living with HIV; in one case, the medical

⁶⁸ Special Rapporteur on Torture, *supra* note 8, ¶ 71.

⁶⁹ KHUAT THI HAI OANH, ACCESS TO TUBERCULOSIS SERVICES AMONG PEOPLE LIVING WITH HIV IN VIETNAM (2007) (on file with Open Society Foundations).

⁷⁰ HUMAN RIGHTS WATCH, *supra* note 47, at 44.

⁷¹ CENTER FOR REPRODUCTIVE RIGHTS, *supra* note 65, at 24.

treatment of a Ukrainian woman's son was halted altogether once his health care providers learned his mother was HIV positive.⁷²

This denial of care or provision of inferior care is exacerbated when people living with HIV are also members of other socially excluded or marginalized groups. In Namibia, despite a policy of providing HIV prevention and treatment services free of charge to those who cannot afford them, sex workers who meet eligibility requirements are often discriminated against and denied these services.⁷³ In Jamaica, where HIV is stereotyped as a "gay disease," a 2004 report documented that medical professionals had avoided touching the skin of people living with HIV with medical equipment; one nurse said she was "concerned about contracting the virus from patients who ... 'really hopelessly wanted you to get HIV too.'"⁷⁴ There have also been reports in the last decade in Ukraine and Vietnam of tuberculosis centers refusing to treat people living with HIV.⁷⁵ Refusals to provide people living with HIV with quality medical care amount to CIDT and further fuel these patients' social stigmatization.

ii. People Who Use Drugs

Denial of care and provision of substandard care are widespread among criminalized populations, including people who use drugs. In his recent report, the UN Special Rapporteur on Torture singles out the "severe physical pain, suffering and humiliation" resulting from state drug policies that restrict effective drug treatment.⁷⁶ He further notes that in countries where people who use drugs are detained in so-called rehabilitation centers, "medical professionals trained to manage drug dependence disorders as mental illnesses are often unavailable."⁷⁷ In particular, the Special Rapporteur points out that people who use drugs and are also living with HIV are denied emergency medical treatment and anti-retroviral treatment, and that people who use drugs are denied opiate substitution treatment in both custodial and non-custodial settings.⁷⁸

In Ukraine, Human Rights Watch has documented cases of people who use drugs being refused by ambulances, kicked out of hospitals, provided treatment in an inadequate or abusive manner, and denied emergency care. One man reported being denied a hospital room and told by a doctor, "Why do you come here and make more problems for us? You are guilty yourself for this."⁷⁹ Another person was denied treatment for TB once the clinic workers found out she was a drug user: "I was staying at a tuberculosis clinic. My tuberculosis should have been operated [on]. As soon as they found out that I was an addict, I was refused."⁸⁰ A 2008 report by the NGO Aman Plus in Kyrgyzstan documented similar cases of ill-treatment; according to an outreach worker who brought a woman to a clinic for a leg abscess related to drug injection, the doctor asked her, "Why

⁷² HUMAN RIGHTS WATCH, *supra* note 47, at 57.

⁷³ OPEN SOCIETY INSTITUTE, RIGHTS NOT RESCUE: A REPORT ON FEMALE, MALE, AND TRANS SEX WORKERS' HUMAN RIGHTS IN BOTSWANA, NAMIBIA, AND SOUTH AFRICA 44, 46 (2009).

⁷⁴ HUMAN RIGHTS WATCH, HATED TO DEATH: HOMOPHOBIA, VIOLENCE, AND JAMAICA'S HIV/AIDS EPIDEMIC 39 (2004), available at <http://www.hrw.org/reports/2004/11/15/hated-death>.

⁷⁵ KHUAT THI HAI OANH, *supra* note 69; HUMAN RIGHTS WATCH, *supra* note 47, at 52.

⁷⁶ Special Rapporteur on Torture, *supra* note 8, ¶ 74.

⁷⁷ *Id.* ¶ 41.

⁷⁸ *Id.* ¶ 73.

⁷⁹ HUMAN RIGHTS WATCH, *supra* note 47, at 47.

⁸⁰ CENTRAL AND EASTERN EUROPEAN HARM REDUCTION NETWORK, SEX WORK, HIV/AIDS, AND HUMAN RIGHTS IN CENTRAL AND EASTERN EUROPE AND CENTRAL ASIA (2005), available at http://www.opensocietyfoundations.org/sites/default/files/sex%2520work%2520in%2520ceeca_report_2005.pdf.

do you mess with her, she's a drug addict!"⁸¹ Contributing to the abuse is that limited coordination and integration of services in Ukraine and throughout Eastern Europe and Central Asia often force patients to choose between TB, HIV, and drug treatment.⁸²

As noted by the Special Rapporteur, the denial of appropriate care to people who use drugs persists "in complete disregard of the chronic nature of dependency and of the scientific evidence pointing to the ineffectiveness of punitive measures."⁸³ On a personal level, denial of care or provision of inferior care often leads people who use drugs to feel less than human, as conveyed by one woman in Kyrgyzstan who reported being told by her doctor, "All addicts, all, are sick with AIDS, even if nothing is found in the blood samples. Nobody will look after you." This same woman explained, "[The doctors'] attitude is full of disgust and alienation. They do not want to communicate with you, nothing at all."⁸⁴ Clearly, the harassment faced by people who use drugs not only confirms that medical professionals' refusal to treat them amounts to CIDT but also leads them to feel further ostracized by their communities.

iii. Sex Workers

The criminalized status of sex workers also results in their ill-treatment in health care settings. As observed by the UN Special Rapporteur on Torture, a report on sex workers in Botswana, Namibia, and South Africa documented negative and obstructive attitudes on the part of medical professionals, including denial of necessary health care services.⁸⁵ One sex worker reported being "afraid to go to the clinic" because of harassment from nurses and doctors. Another was chased out of a hospital after a doctor screamed, "You are a prostitute!" to her in front of other staff and patients. A sex worker in Kyrgyzstan said that when she went to the hospital with appendicitis, the nurse was rude to her after learning she worked in a sauna, "saying that girls like me should be killed or put in jail."⁸⁶ She was discharged from the hospital before her stitches were removed.

This ill-treatment is often compounded in the case of sex workers who use drugs and those living with HIV. In fact, in 2009, the Eurasian Harm Reduction Network reported that these sex workers are the most discriminated against in health care settings overall.⁸⁷ Similarly, one male sex worker seeking HIV treatment in Namibia said, "The nurse called a few other nurses and they were laughing at me."⁸⁸ These examples showcase the indignity with which medical professionals often treat sex workers. In this light, the Special Rapporteur is right to recognize that "acts aimed at humiliating the victim, regardless of whether severe pain has been inflicted, may constitute

⁸¹ OPEN SOCIETY INSTITUTE & SOROS FOUNDATION KYRGYZSTAN, OBSERVANCE OF THE RIGHTS OF INJECTING DRUG USERS IN THE PUBLIC HEALTH CARE SYSTEM (2008), available at http://soros.kg/wp-content/uploads/2012/03/aman-eng2_2.pdf.

⁸² See MATT CURTIS, WORLD HEALTH ORGANIZATION, BUILDING INTEGRATED CARE SERVICES FOR INJECTION DRUG USERS IN UKRAINE (2010), available at http://www.euro.who.int/__data/assets/pdf_file/0016/130651/e94651.pdf; WORLD HEALTH ORGANIZATION, UNITED NATIONS OFFICE ON DRUGS AND CRIME & JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS, POLICY GUIDELINES FOR COLLABORATIVE TB AND HIV SERVICES FOR INJECTING AND OTHER DRUG USERS (2008).

⁸³ Special Rapporteur on Torture, *supra* note 8, ¶ 74.

⁸⁴ CENTRAL AND EASTERN EUROPEAN HARM REDUCTION NETWORK, *supra* note 80.

⁸⁵ Special Rapporteur on Torture, *supra* note 8, ¶ 75.

⁸⁶ Public Association Musaada, *Observance of the Rights of Sex Workers to Obtain Health Care: Monitoring of Human Rights in Medical Institutions in Osh City in the Kyrgyz Republic*, Open Society Institute and Soros Foundation Kyrgyzstan (2008), available at <http://cop.health-rights.org/files/f/f/ffd78724efdf6140baa1ff3f7d7754d2.pdf>.

⁸⁷ CENTRAL AND EASTERN EUROPEAN HARM REDUCTION NETWORK, *supra* note 80.

⁸⁸ OPEN SOCIETY INSTITUTE, *supra* note 73.

degrading treatment or punishment because of the incumbent mental suffering.”⁸⁹ Indeed, the pain, suffering, and humiliation faced by many sex workers show that the denial of quality care described above frequently rises to the level of torture or CIDT.

iv. Roma

Roma in Central and Eastern Europe face what the European Roma Rights Center (ERRC) has called “a consistent pattern of discriminatory treatment” by medical professionals.⁹⁰ Although the Special Rapporteur does not specifically address their mistreatment in his recent report, Roma routinely experience denial of medical treatment or provision of substandard care amounting to CIDT, especially when accompanied by insults made by healthcare providers. In one case documented by the ERRC, a woman whose son had died after being released from the hospital said that when she asked to see her son’s medical file, a doctor told her, “It’s not a big thing—one Gypsy less.”⁹¹ A recent report on Roma health rights in Macedonia, Romania, and Serbia confirms the persistence of these abuses and points out that life expectancy among Roma is 10 years below the regional average.⁹²

Denial of medical care to Roma has taken the form of ambulances failing to respond to requests for assistance coming from Roma neighborhoods, outright refusals by medical professionals to provide services to Roma, and demands for payment for services that ought to be provided at no cost. In one case documented in Croatia in 2006, a 20-year-old Roma woman gave birth to a stillborn after an ambulance took 90 minutes to arrive at her home in a Roma settlement; one dispatcher mockingly told the woman’s husband to “put his wife in a wheel-barrow and wheel her to the medical center.”⁹³ In another case, a woman was inappropriately charged for medical treatment for a spontaneous miscarriage because the doctor assumed that Roma women induce their own miscarriages to avoid paying the cost of surgical abortions.⁹⁴ A particularly humiliating practice is the segregation of Roma patients into rooms called “gypsy rooms” or the “Chinese quarter.” According to the ERRC, these Roma wards are of inferior quality “in material and sanitary conditions and services.”⁹⁵ It has also been reported that Roma women accompanying their children are made to clean the ward.⁹⁶

Even a preliminary consideration of the discrimination in access to health care faced by Roma shows the critical importance of including ethnic minorities in assessments of the impact of denial of care and provision of substandard care. The drastic marginalization of Roma from many aspects of public life is only worsened by health care professionals’ refusals to provide them with quality medical care. Likewise, the humiliating treatment attending such refusals only strengthens the case for a finding of CIDT perpetrated against Roma in health care settings.

⁸⁹ Special Rapporteur on Torture, *supra* note 8, ¶ 75.

⁹⁰ EUROPEAN ROMA RIGHTS CENTER, *AMBULANCE NOT ON THE WAY: THE DISGRACE OF HEALTH CARE FOR ROMA IN EUROPE* (2006), available at <http://www.errc.org/cms/upload/media/01/E6/m000001E6.pdf>, at 39.

⁹¹ *Id.* at 41.

⁹² OPEN SOCIETY FOUNDATIONS, *ROMA HEALTH RIGHTS IN MACEDONIA, ROMANIA, AND SERBIA: A BASELINE FOR LEGAL ADVOCACY* (2013), available at <http://www.opensocietyfoundations.org/sites/default/files/roma-health-rights-macedonia-romania-serbia-20130628.pdf>.

⁹³ EUROPEAN ROMA RIGHTS CENTER, *supra* note 90 at 49-50.

⁹⁴ *Id.* at 51-52.

⁹⁵ *Id.* at 51-54.

⁹⁶ *Id.* at 54.

v. LGBTI Persons

Lesbian, gay, bisexual, transgender, and intersex (LGBTI) persons also report being denied care or provided with substandard care. The UN Special Rapporteur on Torture confirms this widespread discrimination in his recent report, citing the Pan American Health Organization's denunciation of ill-treatment by health care professionals toward gender and sexual minorities.⁹⁷ In Kyrgyzstan, doctors have refused to treat LGBTI persons and accompanied this refusal with cruel and degrading comments such as: homosexuality is "absurd," "condemned by Islam," or "abnormal" and LGBTI people are "not our patients."⁹⁸ Health care providers in Jamaica have likewise "refused to treat men whom they knew or perceived to be gay and made abusive comments to them, at times instigating abusive comments by others."⁹⁹

Transgender people also routinely face degrading treatment in health care settings, often stemming from discrimination and prejudice on the basis of gender identity or presentation. In the United States, a 2010 report of the National Gay and Lesbian Task Force and the National Center for Transgender Equality documented cases in which medical professionals refused to provide care to transgender people, leading them to postpone their own care due to fear of disrespect and harassment in medical settings.¹⁰⁰ One survey respondent reported problems finding a doctor who would treat or "even look at you like a human being." A 2008 survey from Europe similarly found that transgender people avoided seeking routine medical care because they anticipated prejudicial treatment; nearly one-third of respondents said they had been refused treatment because their health care practitioners did not approve of gender reassignment.¹⁰¹ The denial of quality care experienced by many LGBTI persons can easily be found to be CIDT, particularly when health care workers are explicit in both their disapproval of gender and sexual minorities and their unwillingness to treat them.

vi. Denial of Controlled Essential Medicines

The denial of controlled essential medicines is an important sub-category of denial of care that warrants close attention, particularly in the contexts of pain management and opioid substitution treatment, both of which rely on opiate-based medications. This denial of treatment is often linked to discriminatory notions that people with life-limiting illnesses, the dying, or people who use drugs are unworthy of care; it is also linked to concerns and ideologies about drug control prevailing over the relief of suffering. In his recent report, the UN Special Rapporteur on Torture devotes special attention to the global scale of this problem, noting that "83 per cent of the world population has either no or inadequate access to treatment for moderate or severe pain. Tens of millions of people, including around 5.5 million terminal cancer patients and 1 million end-stage HIV/AIDS patients, suffer from moderate to severe pain each year without treatment."¹⁰² He notes

⁹⁷ Special Rapporteur on Torture, *supra* note 8, ¶ 76.

⁹⁸ OPEN SOCIETY FOUNDATIONS, *supra* note 57, at 20.

⁹⁹ HUMAN RIGHTS WATCH, *supra* note 74, at 38.

¹⁰⁰ JAIME M. GRANT ET AL., NATIONAL CENTER FOR TRANSGENDER EQUALITY & THE NATIONAL GAY AND LESBIAN TASK FORCE, NATIONAL TRANSGENDER DISCRIMINATION SURVEY REPORT ON HEALTH AND HEALTH CARE (2010), *available at* http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.

¹⁰¹ STEPHEN WHITTLE ET AL., THE EUROPEAN REGION OF THE INTERNATIONAL LESBIAN AND GAY ASSOCIATION & TRANSGENDER EUROPE TRANSGENDER EUROSTUDY: LEGAL SURVEY AND FOCUS ON THE TRANSGENDER EXPERIENCE OF HEALTH CARE 10 (2008), *available at* <http://www.pfc.org.uk/pdf/eurostudy.pdf>.

¹⁰² Special Rapporteur on Torture, *supra* note 8, ¶ 51.

with particular concern the dire lack of access to morphine in low- and middle-income countries despite their “having about half of all cancer patients and 95 per cent of all new HIV infections.”¹⁰³

As noted by the Special Rapporteur, denial of controlled essential medicines such as morphine most often stems from poorly conceived government policies and unduly restrictive drug control regulations, although other factors, such as “inadequate infrastructure,” “ingrained prejudices about using opioids for medical purposes,” and “the absence of pain management policies or guidelines for practitioners,” play a significant role as well.¹⁰⁴ Where states fail to take reasonable measures to avoid condemning patients to unnecessary and severe suffering, they “not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”¹⁰⁵

The pain and suffering occasioned by denial of pain medication are severe. Human Rights Watch has noted in particular:

*It can lead to reduced mobility and consequent loss of strength; compromise the immune system; interfere with the person's ability to eat, concentrate, sleep, or interact with others...A WHO study found that people who live with chronic pain are four times more likely to suffer from depression and anxiety. The physical effect of chronic pain and the psychological strain it causes can even influence the course of the disease.*¹⁰⁶

One cancer patient in Ukraine described his pain as being “so bad that my whole body seemed to break. We would call the ambulance every 2 to 3 hours because I could not stand the pain.”¹⁰⁷ The severity of this suffering, perpetuated by government policies that fail to attend to the essential needs and human dignity of those in need of palliative care, warrants close consideration in terms of denial of care amounting to ill-treatment. The Special Rapporteur echoes his predecessor on this point, reiterating his assertion that “the failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against [CIDT].”¹⁰⁸

Access to pain relief is a widespread problem not only in the context of a life-limiting illness but also in the provision of treatment to people who use or formerly used illicit drugs. One 28-year-old man in Kyrgyzstan who formerly used drugs reported in 2007 that he had been tied down and denied anesthesia while undergoing a shoulder operation: “I was screaming, awake, feeling all the pain, screaming and screaming as they hammered the nails into my bones.” When he later asked why he had not been given anesthesia, his doctor replied, “Because you are a drug user. If I give you anesthesia, you will remember your drugs and tomorrow go buy more.”¹⁰⁹ Another form of ill-treatment and possibly torture of people who use drugs is the denial of opiate substitution treatment, particularly as a way of eliciting criminal confessions from persons in police custody or pre-trial detention by inducing painful withdrawal symptoms.¹¹⁰ Both the former Special Rapporteur

¹⁰³ *Id.* ¶ 52.

¹⁰⁴ *Id.* ¶ 53.

¹⁰⁵ *Id.* ¶ 55.

¹⁰⁶ HUMAN RIGHTS WATCH, “PLEASE, DO NOT MAKE US SUFFER ANY MORE...”: ACCESS TO PAIN TREATMENT AS A HUMAN RIGHT 6-7 (2009), available at <http://www.hrw.org/reports/2009/03/02/please-do-not-make-us-suffer-any-more>.

¹⁰⁷ OPEN SOCIETY FOUNDATIONS, PALLIATIVE CARE AS A HUMAN RIGHT: A FACT SHEET 2 (2011), available at <http://opensocietyfoundations.org/sites/default/files/palliative-care-human-right-20110524.pdf>.

¹⁰⁸ Special Rapporteur on Torture, *supra* note 8, ¶ 56.

¹⁰⁹ DAVID TRILLING, KYRGYZSTAN: DOCTORS DENY TREATMENT TO UNDESIRABLES (2009), available at <http://www.eurasianet.org/departments/insightb/articles/eav022009.shtml>.

¹¹⁰ According to the previous Special Rapporteur on Torture, “[I]f withdrawal symptoms are used for any of the purposes cited in [the] definition of torture enshrined in Article 1 of the Convention against Torture, this might amount to torture.” Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and*

on Torture¹¹¹ and the ECtHR¹¹² have deemed the denial of methadone treatment in custodial settings to be a violation of the right to be free from torture and CIDT in certain circumstances. Similar reasoning ought to apply to non-custodial contexts, particularly in instances where governments, such as the Russian Federation, impose a complete ban on substitution treatment.¹¹³



This section has explored denial of care and provision of inferior care as applied to a selection of populations marginalized because of their criminalized behavior, their sexual, gender, or ethnic minority status, or the stigma surrounding their health conditions. As noted above, the reasons these groups are routinely denied quality health care range from overt discrimination on the part of medical professionals to unbalanced and inappropriate government policies. Regardless of what gives rise to this systemic denial of care, the extreme pain and suffering it causes must be recognized as triggering state obligations to “take measures to protect people under their jurisdiction from inhuman and degrading treatment.”¹¹⁴

c. Provision of Medical Treatment in a Humiliating Manner

Even where health care is apparently provided in compliance with international human rights standards, it may nevertheless be attended by humiliating treatment that causes severe pain and suffering. The UN Special Rapporteur on Torture clarifies that this humiliation can violate legal norms against degrading treatment regardless of the reasons behind it.¹¹⁵ One way in which health care professionals degrade patients is by disclosing private and sensitive information about their medical conditions or personal characteristics (e.g., history of drug use or sex work) to their colleagues, public officials, or the wider public. Public disclosure by a medical professional of a person’s status as a member of a stigmatized group often causes intense humiliation and may lead to actual or threatened violence.

Such public disclosure of a person’s status is most egregious when it is made to the public at large. The Special Rapporteur notes the particular vulnerability of sex workers to breaches of privacy and confidentiality and recognizes the further indignity these breaches add to sex workers’ experience of health care settings.¹¹⁶ In 2007, a sex worker in Kyrgyzstan described her experience being rounded up with her colleagues following a raid by the ‘Berkut’ [special police unit] and taken to a narcological center where they were forced to undress in a cold room. Only later did she and her colleagues discover that their detention had been filmed; it aired the following day on local television.¹¹⁷

The personal and social consequences of such public disclosure cannot be overstated. The Special Rapporteur makes clear that unauthorized disclosure of HIV status to sexual partners, family members, employers, and other medical professionals may even lead to violence.¹¹⁸ In one

Other Cruel, Inhuman or Degrading Treatment or Punishment, ¶ 57 U.N. Doc. A/HRC/10/44 (Feb. 17, 2009) (by Manfred Nowak).

¹¹¹ *Id.* ¶ 71.

¹¹² *McGlinchey and Others v. United Kingdom*, App. No. 50390/99 Eur. Ct. H.R. (2003).

¹¹³ HUMAN RIGHTS WATCH, LESSONS NOT LEARNED: HUMAN RIGHTS ABUSES AND HIV/AIDS IN THE RUSSIAN FEDERATION (2004), available at <http://www.hrw.org/reports/2004/04/27/lessons-not-learned>.

¹¹⁴ Special Rapporteur on Torture, *supra* note 8, ¶ 56.

¹¹⁵ *Id.* ¶ 18.

¹¹⁶ *Id.* ¶ 75.

¹¹⁷ Public Association Musaada, *supra* note 86.

¹¹⁸ Special Rapporteur on Torture, *supra* note 8, ¶ 71.

account from 2007, the chief physician at a regional HIV/AIDS prevention center in Kyrgyzstan allowed television reporters to film one of his patients without his consent: “[He] was clearly identified in the footage as a person living with HIV/AIDS. ... He could not show up in the street without being jeered at and insulted. People pointed fingers at him, refused to serve him at stores...and drove him out of public places.”¹¹⁹

More common than disclosure of a person's status through the media are cases where medical professionals make such disclosures in public places, such as hospital waiting rooms. One young man in Jamaica described how he and a friend left the hospital without receiving treatment because of homophobic remarks made by the nurse on duty: “We had to leave because the crowd was looking us and then on the road they were hurling words at us, ‘batty man fi dead.’ I felt threatened.”¹²⁰

Members of other stigmatized groups experience similar abuses. The Special Rapporteur notes that the use of drug registries by police and medical professionals not only violates patient confidentiality but also infringes on the civil rights of people who use drugs, contributing to their further ill-treatment in health care settings.¹²¹ One man in Kyrgyzstan described in 2007 how he was treated once his doctor noticed he was accompanied by a social worker known to work with people who use drugs: “When the doctor noticed me and the person who brought me there, he started saying loudly that I was HIV infected, although that was not true. The employees from the registration desk joined in with him and didn't want to serve me.”¹²² Transgender persons report similar violations in Kyrgyzstan, including the use of derogatory terms by medical staff in crowded waiting rooms.¹²³ These public breaches of patient confidentiality, when accompanied by insulting and humiliating statements, often further ostracize already-stigmatized patients both in intention and in effect.

As suggested above, disclosure of a person's status as a member of a marginalized group may also lead to violence. A 2000 survey of studies conducted on the correlation of violence and HIV found evidence of a risk of physical violence upon disclosure of HIV status, particularly for women.¹²⁴ Although many reports describe generally positive reactions upon such disclosure, “for those women already in abusive relationships, disclosure of HIV-positive test results may provide another trigger for additional violence.”¹²⁵ To the extent that non-consensual disclosure of a person's medical condition or personal characteristics leads to physical violence, such violations of patient confidentiality may trigger state obligations under the prohibition against CIDT.

3. Torture and Deprivation of Liberty in Health Care

In many cases, torture and CIDT in health care are attended by violations of the right to liberty. This section of the article explores the interplay between torture and CIDT and deprivations of liberty by examining practices and conditions that inflict pain, suffering, and humiliation within the context of institutionalized health care. Although the UN Special Rapporteur on Torture's report focuses on deprivations of liberty in drug treatment centers and mental health facilities, these

¹¹⁹ Erik Iriskulbekov & Ayslgul Balybaeva, *First HIV Legal Precedent in Kyrgyzstan: Breach of Medical Privacy* 12 HIV/AIDS POLICY AND LAW REVIEW 2/3 (2007) at 71.

¹²⁰ HUMAN RIGHTS WATCH, *supra* note 74, at 38.

¹²¹ Special Rapporteur on Torture, *supra* note 8, ¶ 72.

¹²² DAVID TRILLING, *supra* note 109.

¹²³ OPEN SOCIETY FOUNDATIONS, *supra* note 57.

¹²⁴ Suzanne Maman et al., *The Intersections of HIV and Violence: Directions for Future Research and Interventions*, 50 SOC. SCI. & MED. 459, 474 (2000).

¹²⁵ *Id.* at 475.

abuses are also rampant in settings such as hospitals and tuberculosis centers. They range from inhumane physical conditions to inappropriate punishment and inadequate treatment. The powerlessness of individuals whose liberty has been restricted renders them more vulnerable to abuse in any environment, and health care settings are no exception.

a. Hospitals

One alarming practice that can amount to torture or CIDT is the involuntary detention in hospitals, often in inhumane conditions, of patients who are unable to pay their medical bills.¹²⁶ The deprivation of a person's liberty without due process and accompanied by severe pain and suffering may itself amount to CIDT. The practice of holding patients in hospitals against their will, however, also specifically triggers the well-established duty of the state to provide adequate medical care and acceptable conditions for persons deprived of their liberty.¹²⁷

In 2006, Human Rights Watch documented that, in many hospitals in Burundi, patients who cannot pay their medical bills "are prevented from leaving the premises by security guards from private companies contracted by hospitals. ... Several detainees said guards followed them around even within the hospital premises."¹²⁸ Testimony from victims of this practice reveals the personal impact of this experience. As one patient described it, "I am really imprisoned here. ... The guards threaten me. Whenever I come near the exit, they tell me that I cannot leave because I have not settled the bill."¹²⁹ In some cases, detention practices in hospitals closely resemble those of more traditional custodial settings such as prisons.

In many of these cases, detention of non-paying patients appears to meet the severity requirement for a finding of torture. In one case, two caesarean-delivered newborns were left untreated for their respiratory problems and vomiting. Their mothers described how doctors and nurses would not enter the lock-up where they were being held. In another, a poor farmer recounted how nurses refused to remove the stitches from her caesarean delivery until she had paid her bill, putting her at grave risk of infection.¹³⁰ Hospital detainees were also often forced to vacate their beds for paying patients. One man described his experience following five weeks' detention in a Burundi hospital as follows: "I feel like I am in a prison here. I lost my bed last night to a sick person who could pay. So I slept on the floor."¹³¹

A lack of adequate food for hospital detainees has also been widely reported. In its 2006 report, Human Rights Watch explained that hospitals in Burundi do not generally provide their patients with food, a serious human rights violation particularly for persons kept in hospitals against their will.¹³² There is little doubt that if a prison had a policy of denying food to inmates, this practice would violate the prohibition against torture and CIDT. This same principle should apply where persons are involuntarily held in hospitals because of their inability to pay medical bills.

¹²⁶ HUMAN RIGHTS WATCH, *A HIGH PRICE TO PAY: DETENTION OF POOR PATIENTS IN HOSPITALS* (2006), available at http://www.hrw.org/sites/default/files/reports/burundi0906webwcover_1.pdf.

¹²⁷ *Yakovenko v. Ukraine*, App. No. 15825/06 Eur. Ct. H.R. (2008).

¹²⁸ HUMAN RIGHTS WATCH, *supra* note 126, at 31.

¹²⁹ *Id.* at 31.

¹³⁰ *Id.* at 35.

¹³¹ *Id.* at 37.

¹³² *Id.* at 36.

b. Tuberculosis Centers

The emergence of multi-drug-resistant and extensively drug-resistant tuberculosis (MDR- and XDR-TB) has sparked considerable debate about the use of detention to quell the spread of the highly contagious disease. No consensus has emerged as to whether and under what circumstances detention in the context of TB control accords with international human rights law, but even those who support the measure agree that certain minimum conditions must be satisfied in order to justify it. As one expert puts it, “whenever restrictions on the freedom of movement or privacy are imposed, their enforcement must always respect human dignity, be culturally sensitive, and be periodically reviewed by the courts.”¹³³ In practice, this is often not the case, and persons with TB are often unnecessarily and inhumanely detained despite an absence of proof of their inability to adhere to treatment and other infection control regimens in the community.

In March 2008, *The New York Times* described the Jose Pearson Tuberculosis hospital, a detention center in South Africa for people with drug-resistant TB, as “a prison for the sick,” with overcrowding, razor wire to prevent patients from escaping, poor ventilation fueling the further spread of TB, and a single social worker for more than 300 detainees.¹³⁴ One detained patient told the newspaper, “The only discharge you get from this place is to the mortuary.” Poor conditions in TB treatment facilities can lead to transmission to health care workers and to the development of additional drug resistance, resulting in patients that are more difficult and costly to treat.¹³⁵ Treatment in the community is a more effective and less rights-violating alternative to detention of people with tuberculosis, who have an absolute right to freedom from CIDT and to due process to challenge their confinement.¹³⁶

Any use of detention for persons infected with drug-resistant TB requires close monitoring to ensure compliance with relevant international human rights standards. Arguably, the disparity between the goals of detaining persons with drug-resistant TB and detaining persons in a criminal justice context suggests that those who are detained for purposes of preventive health care should be assured an even higher standard of treatment. In any case, failure to provide adequate conditions of detention in tuberculosis centers should be understood as a violation of the prohibition against torture and CIDT no less than it is in penal settings.

c. Drug Treatment Centers

A number of drug “treatment” settings raise serious concerns about violations of the prohibition against torture and CIDT. The UN Special Rapporteur on Torture describes the compulsory detention of people who use drugs in many so-called rehabilitation centers run by military or paramilitary, police or security forces, or private companies: “Persons who use, or are suspected of using, drugs and who do not voluntarily opt for drug treatment and rehabilitation are confined

¹³³ Andrea Boggio et al., *Limitations on Human Rights: Are They Justifiable to Reduce the Burden of TB in the Era of MDR- and XDR-TB?*, 10 HEALTH & HUM. RTS.: AN INT’L J. 121 (2008); see also Commission on Human Rights, *Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights*, Annex, U.N. Doc. E/CN.4/1984/4 (1984).

¹³⁴ Celia W. Dugger, *TB Patients Chafe Under Lockdown in South Africa*, THE NEW YORK TIMES, Mar. 25, 2008.

¹³⁵ See, e.g., Julie Jarand et al., *Extensively Drug-resistant Tuberculosis (XDR-TB) among Health Care Workers in South Africa*, 15 TROPICAL MED. INT’L HEALTH 1179 (2010); Saloshini Naidoo, *TB in Health Care Workers in KwaZulu-Natal, South Africa*, 10 INT’L J. TUBERCULOSIS & LUNG DISEASE 676 (2006).

¹³⁶ Joseph J. Amon et al., *Limitations on Human Rights in the Context of Drug-Resistant Tuberculosis: A reply to Boggio et al.*, HUMAN RIGHTS WATCH (Oct. 7, 2009), available at <http://www.hrw.org/news/2009/10/07/limitations-human-rights-context-drug-resistant-tuberculosis>.

in such centres and compelled to undergo diverse interventions” as well as “physical disciplinary exercises, often including military-style drills.”¹³⁷ The Special Rapporteur notes that these practices continue unabated despite “numerous calls by various international and regional organizations to close compulsory drug detention centres” and the many injunctions and recommendations issued by WHO, UNODC, and the Commission on Narcotic Drugs.¹³⁸

The impact of detention in these settings on people who use drugs is often severe. In many Asian countries, including Cambodia, China, Laos, Malaysia, Thailand, and Vietnam, thousands of children and adults who use drugs are administratively detained without due process in compulsory centers that purport to provide addiction treatment but in fact inflict abuse amounting to torture and CIDT. Practices documented in these centers include long hours of forced labor under extremely harsh conditions; partial lobotomy of people who use drugs by inserting heated needles into their brain for up to a week; imprisonment in thorn-tree cages; handcuffing of people who use drugs to beds while they undergo withdrawal; suspension by the arms and legs for hours and beatings on the feet; and sexual abuse of inmates by guards. Medical care is routinely denied. In a 2010 Human Rights Watch report, a doctor in one drug detention center in China explained, “The purpose of the detox center is really just disciplinary; it’s not to give people medical care.”¹³⁹

The so-called treatment policies just described can easily be made out as violations of the prohibition against torture and CIDT. Additionally, they amount to deprivations of the right to liberty for persons whose drug use warrants the careful and compassionate provision of health care that fosters their ability to participate in and contribute to their communities. As the Special Rapporteur cautions, “those remanded to compulsory treatment in the punitive drug-free centres continue to exceed, exponentially, the number receiving evidence-based treatment for drug dependence.”¹⁴⁰ Not surprisingly, the widespread practice of detaining people who use drugs not only subjects them to abuses rising to the level of torture or CIDT but also exacerbates their social exclusion and further compromises their health.

d. Mental Health Facilities

People with disabilities are especially vulnerable to torture and CIDT in (real and supposed) health care settings. The situation is especially dire for the thousands who are forced to live for decades and often for life in long-stay closed institutions. Restrictions on legal capacity that affect the right to refuse treatment, mental health laws that override refusal to consent to treatment, laws that suspend the right to liberty, and stigmatization against people with disabilities in health care systems are of particular concern. The UN Special Rapporteur on Torture makes clear that “[i]nappropriate or unnecessary non-consensual institutionalization of individuals may amount to torture or ill-treatment as use of force beyond that which is strictly necessary.”¹⁴¹ He further insists that states bear the onus of showing that detention on grounds of mental illness is “necessary to protect the safety of the person or of others,” and that such deprivations of liberty should be the exception given the prevalence of non-consensual treatment in this context.¹⁴²

¹³⁷ Special Rapporteur on Torture, *supra* note 8, ¶ 40, 42.

¹³⁸ *Id.* ¶ 43.

¹³⁹ OPEN SOCIETY FOUNDATIONS, HUMAN RIGHTS ABUSES IN THE NAME OF DRUG TREATMENT: REPORTS FROM THE FIELD (2010), available at http://www.opensocietyfoundations.org/sites/default/files/treatmentabuse_20090309.pdf.

¹⁴⁰ Special Rapporteur on Torture, *supra* note 8, ¶ 44.

¹⁴¹ *Id.* ¶ 70.

¹⁴² *Id.* ¶ 69.

In a 2007 report on Serbia, Mental Disability Rights International (MDRI) alleged torture and CIDT against children and adults in institutions marked by “unhygienic conditions and filth.”¹⁴³ Bedridden patients were forced “to urinate and defecate in metal buckets which are kept under their beds,” locked away in small isolation rooms as punishment, subjected to lack of heat during the winter, and forced to sleep in bedrooms contaminated by mice and rats.¹⁴⁴ Medical neglect led to emaciated and dehydrated children lying in cribs, children with untreated hydrocephalus (an abnormal buildup of cerebral spinal fluid that causes swelling in the brain and skull and often death), and people with open cuts and sores, eye infections, and missing or rotten teeth. Also documented were dehumanizing practices such as shaving residents’ heads, denying them access to their personal clothes and effects, and imposing “work therapy” whereby residents are forced to do chores in exchange for rewards such as coffee.¹⁴⁵ Similarly, in a psychiatric hospital in Kyrgyzstan, the NGO Mental Health and Society found in 2009 that patients were forced to bake bread in the name of “labor therapy.” Though the patients were unpaid for this work, the hospital charged the government market prices for the product.¹⁴⁶ Another major problem is the widespread and extensive use of physical restraints—sometimes throughout a patient’s lifetime—without any standards controlling their usage or any justification for using them.¹⁴⁷

The use of cage beds in mental health facilities is still practiced and violates the right to be free from torture and ill-treatment. In a 2003 report, the Mental Disability Advocacy Center (MDAC) documented the routine use of cage beds in Hungary, the Czech Republic, Slovakia, and Slovenia; they are used as a substitute for adequate staffing or as punishment against people with severe intellectual disabilities, elderly people with dementia, and psychiatric patients.¹⁴⁸ A former user of psychiatric services said of the use of cage beds, “You feel like you would rather kill yourself than be in there for several days.”¹⁴⁹ Another reported having been rendered unconscious by an involuntary injection administered just after giving birth and then being placed in a cage bed. When she woke up, she was not permitted to use the bathroom and “had to do it in the cage bed like an animal.”¹⁵⁰ When determining where conditions of institutionalization in mental health facilities fall on the spectrum from CIDT to torture, the Special Rapporteur indicates that “factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.”¹⁵¹ The foregoing examples make clear that the deplorable physical conditions, dehumanizing practices, and extraordinary physical restrictions imposed on people with disabilities in many mental health facilities inflict the requisite degree of pain, suffering, and humiliation so as to violate the prohibition against torture and CIDT.



¹⁴³ MENTAL DISABILITY RIGHTS INTERNATIONAL, *TORMENT NOT TREATMENT: SERBIA’S SEGREGATION AND ABUSE OF CHILDREN AND ADULTS WITH DISABILITIES 6* (2007), available at <http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/Serbia-rep-english.pdf>.

¹⁴⁴ *Id.* at 7, 13.

¹⁴⁵ *Id.* at 12-13.

¹⁴⁶ BURUL MAKENBAEVA, MENTAL HEALTH AND SOCIETY & OPEN SOCIETY INSTITUTE, *BUDGET OF MENTAL HEALTHCARE: DO THE PUBLIC MONEY FLOWS MEET THE NEEDS OF PEOPLE WITH MENTAL HEALTH PROBLEMS?* (2009).

¹⁴⁷ MENTAL DISABILITY RIGHTS INTERNATIONAL, *supra* note 143, at 25-26.

¹⁴⁸ MENTAL DISABILITY ADVOCACY CENTER, *CAGE BEDS: INHUMAN AND DEGRADING TREATMENT OR PUNISHMENT IN FOUR EU ACCESSION COUNTRIES* (2003), available at http://www.mdac.info/sites/mdac.info/files/English_Cage_Beds.pdf.

¹⁴⁹ *Id.* at 34.

¹⁵⁰ *Id.* at 35.

¹⁵¹ Special Rapporteur on Torture, *supra* note 8, ¶ 69.

The prohibition against torture and CIDT in health care has been most extensively developed in the context of prison and pretrial detention settings, where the most common health care–related abuse consists of failing to provide detainees with adequate medical care. This issue has been litigated frequently, particularly in the ECtHR, which has held that detained persons must be provided with the same level of health care that is available in the general community.¹⁵² This section of the article has emphasized the critical importance of extending this same standard to more conventional health care settings outside the immediate criminal justice context—hospitals, tuberculosis centers, drug treatment centers, and mental health facilities—where patients’ liberty is often similarly curtailed with severe consequences. If abuses amounting to torture and CIDT in these settings are to be stopped, it is crucial to attend to the deprivations of liberty that both enable these abuses to take place and are occasioned by them.

Conclusion

While the preceding catalog of abuses is certainly not exhaustive, it exposes the types of widespread abuses amounting to torture and CIDT in health care settings and helps to refine the application of torture and CIDT standards to the health care context. As indicated above, these abuses range from forced or coerced medical interventions to denial of health care services, as well as provision of health care in a humiliating manner, often in environments where patients’ liberty is unduly restricted. This analysis, as well as the recent report by the Special Rapporteur on Torture, further highlights certain key themes:

- *The particular vulnerability of socially excluded and marginalized groups to abuse.* The Special Rapporteur critically recognizes that states have “a heightened obligation to protect vulnerable and/or marginalized individuals” as they are “generally more at risk of experiencing torture and ill-treatment.”¹⁵³ When populations are deeply marginalized, the power dynamic in their relationship with medical professionals is intensified, creating opportunities (and impunity) for abuse. The Special Rapporteur points out that this power imbalance, “exacerbated by stigma and discrimination, results in individuals from certain groups being disproportionately vulnerable” to violations of their informed consent.¹⁵⁴
- *The misuse of medical procedures as a form of social control.* In many cases of torture and CIDT perpetrated in health care settings, medical treatment is used to exclude marginalized persons from society (e.g., in the case of persons with mental disabilities) or to force them to conform to social norms, such as who is “allowed” to procreate, how biological males and females ought to appear and act, and the expectation that individuals be “drug free.” Discrimination in these contexts is often explicit, particularly with mistreatment or denial of treatment accompanied by derogatory and abusive remarks.
- *The intersection between torture in health care and the deprivation of liberty.* As outlined above, involuntary confinement breeds conditions that are ripe for abuse, and health care delivered in such

¹⁵² See, e.g., *Gelfmann v. France*, App. No. 25875/03 Eur. Ct. H.R. (2004); *Kudla v. Poland*, App. No. 30210/96 Eur. Ct. H.R. (2000); *Keenan v. United Kingdom*, App. No. 27229/95 Eur. Ct. H.R. (2001); *Mouisel v. France*, App. No. 67263/01/01 Eur. Ct. H.R. (2003); *Matencio v. France*, App. No. 58749/00 Eur. Ct. H.R. (2004); *Sakkopoulos v. Greece*, App. No. 61828/00 Eur. Ct. H.R. (2007); *Price v. United Kingdom*, App. No. 33394/96 Eur. Ct. H.R. (2001); *Papon v. France*, App. No. 64666/01 Eur. Ct. H.R. (2002); *McGlinchey and Others v. United Kingdom*, App. No. 50390/99 Eur. Ct. H.R. (2003).

¹⁵³ Special Rapporteur on Torture, *supra* note 8, ¶ 26.

¹⁵⁴ *Id.* ¶ 29; *supra* ¶ 32, 79.

settings should be examined with particular scrutiny. In most cases, as with persons with drug dependence, mental disabilities, or tuberculosis, a human rights approach calls for community-based treatment instead of institutional care.

Applying an anti-torture framework to health care settings helps to lift the shroud of darkness allowing these abuses to continue with impunity. For too long and in too many places, human rights violations committed in health care settings have remained invisible, taking place under the guise of “medical expertise.” The Special Rapporteur draws our attention to this insidious fallacy, recognizing that many abuses are wrongly justified in the name of “health” and on grounds such as “administrative efficiency, behaviour modification, or medical necessity.”¹⁵⁵ He further notes the “need to highlight the specific dimension and intensity of the problem, which often goes undetected.”¹⁵⁶ It is time to apply the well-developed monitoring and protection standards for torture and abuse in detention to health care settings, paying close attention to the severity of pain and suffering, lack of justification, and often their intentional and discriminatory nature. Addressing human rights abuses carried out in health care settings through an anti-torture lens is a powerful tool because it sets up an immediate and non-derogable obligation for states to remedy these abuses. Deploying this tool will help foster health care settings that genuinely serve as places of care for all people.

¹⁵⁵ *Id.* ¶ 13; *supra* ¶ 35.

¹⁵⁶ *Id.* ¶ 12.

The U.N. Committee Against Torture and Eradication of Torture in Health Care Settings

CLAUDIO GROSSMAN*

Abstract

This article explains that the United Nations Committee against Torture (hereinafter “the Committee”) has played a significant role in addressing the serious problem of torture in health care settings. In particular, the Committee’s Concluding Observations and Recommendations under Article 19 of the Convention against Torture have been an important tool in this area. The Committee has used these means to remind States parties of their obligation to provide adequate health care for persons held in detention centers and prisons, to address abuses and poor conditions in mental health institutions and psychiatric facilities, and to denounce the practice of punishing or denying care to women who seek post-abortion health services. Additionally, the substantive and procedural obligations outlined in the Committee’s recently adopted General Comment No. 3, which addresses the issue of redress and rehabilitation of victims of torture, are also identified as an important step in the quest to prevent torture and provide redress to all victims of torture, including those in health care settings.

Introduction

The Committee is a treaty body with ten independent experts elected by the States parties. Its mandate is to supervise compliance with the United Nations Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (“Convention”).¹ The Convention establishes obligations for States to prevent torture or ill-treatment inflicted by or at the instigation of or with the consent or acquiescence of a public official.² Accordingly, torture and ill-treatment can also take place in health care settings when a State fails to perform its duties of prevention or investigation and punishment if there is a violation of the Convention.

Health care settings present a highly sensitive situation as people could be placed in vulnerable settings that limit a person’s ability to consent. Additionally, individuals in places of detention must fully rely on a third party to provide any needed health care. The consequences of denial of

*Claudio Grossman is Dean of American University Washington College of Law, Chairperson of the United Nations Committee against Torture, and Chairperson of the UN human rights treaty bodies. The views expressed by Dean Grossman are his own and not necessarily those of the Committee against Torture or the other UN human rights treaty bodies.

¹ U.N. Convention against Torture, Dec. 10, 1984, 1465 U.N.T.S. 85, available at <http://www2.ohchr.org/english/law/cat.htm> [hereinafter *Convention*].

² *Id.*, arts. 1, 2 and 16.

health services in such a vulnerable situation are often devastating and dramatic. The Committee has addressed torture in health care settings mostly through its Concluding Observations and through the recently published General Comment No. 3: Implementation of Article 14 by States Parties that address the issue of redress and rehabilitation of victims of torture. This paper will highlight recent examples of the Committee's efforts.³

Concluding Observations and Recommendations under Article 19

The Committee's Concluding Observations and Recommendations are an important tool in addressing torture in health care settings. Article 19 creates an obligation for State party periodic reporting and is the Committee's primary tool to assess compliance with the Convention. The Committee considers and evaluates reports submitted by States parties and formalizes its findings in an official document known as the Committee's Concluding Observations. Through the process of adopting Concluding Observations, issues are identified, recommendations are formulated, and a participatory process is created that allows for dialogue and exchanges with government officials, NGOs, and the international community. In this context, the Committee has submitted observations and recommendations to States parties that deal directly with torture in health care settings.

The Committee has specifically addressed abuses and poor conditions in mental health institutions and psychiatric facilities. Patients with psychosocial, mental, or psychological disabilities are among the most vulnerable patient populations. The Committee's primary concerns include the deprivation of liberty and related fundamental safeguards, use of physical restraints, and lack of investigations when violations are denounced. The Committee has expressed concern, as in the case of the Czech Republic, that patients in these facilities are often deprived of liberty without free and informed consent.⁴ Likewise, the Committee identified that numerous persons with disabilities were held in mental and psychiatric institutions, for example in Russia and Japan, for extended periods of time and on an involuntary basis.⁵ The Committee has determined that consent to be treated is crucial to guarding a patient's fundamental rights; this also extends to the use of physical restraints. The Committee denounced the widespread use of physical restraints in the cases of Norway and the Czech Republic, including the use of cage-beds, net-beds, bed strapping, manacles, and solitary confinement.⁶ In all of the above examples, the Committee highlighted the need for independent monitoring and investigation and proper training in all psychiatric and mental health institutions. The Committee's views show that, in accordance with the Convention, it is crucially important that patients in these institutions be granted full rights of appeal and that state authorities provide clear regulations and training for medical and non-medical staff in order to safeguard and prevent torture or ill-treatment of patients. The Committee will continue to review

³ This paper provides an overview of recent efforts by the Committee and is by no means exhaustive. In addition to Article 19, the Committee has additional supervisory mechanisms including individual communications (Article 22) and confidential visits to States parties for which the Committee has received "reliable information which appears to it to contain well-founded indications that torture is being systematically practiced ..." (Article 20).

⁴ U.N. Committee against Torture [UNCAT], *Concluding Observations on the Czech Republic* [hereinafter *Czech Republic*], para. 21, U.N. Doc. CAT/C/CZE/CO/4-5 (2012).

⁵ UNCAT, *Concluding Observations on the Russian Federation Republic*, para. 22, U.N. Doc. CAT/C/RUS/CO/5 (2012); UNCAT, *Concluding Observations on Japan* [hereinafter *Japan*], para. 22, U.N. Doc. CAT/C/JPN/CO/2 (2013).

⁶ Czech Republic, *supra* note 4, at para. 21; UNCAT, *Concluding Observations on Norway*, ¶ 14, U.N. Doc. CAT/C/NOR/CO/6-7 (2012).

the issue of consent, clearly establishing that the existence of a disability, no matter how severe, does not negate the requirement of consent.

The Committee has also reminded States parties of their obligation to provide adequate health care for persons held in detention centers and prisons. For example, the Committee in the case of Madagascar called upon the state to ensure that prisoners have access to decent food and health care given the poor living conditions, malnutrition, and disease in state prisons.⁷ Japan, Belarus, and Chile were also reminded of their duties to ensure adequate health care in centers of detention, including access to mental health care for all prisoners.⁸ The Committee also specifically identified one community health center in Vienna, Austria that failed to provide privacy when administering mandatory exams for sex workers. The Committee recommended that Austria ensure privacy in all examination centers and safeguard the dignity of women.⁹ As noted above, detained persons must rely on state authorities for care, and as such, States parties are obligated to provide access to adequate health and medical services to those who need them.

The Committee denounced the practice of punishing or denying care to women who seek post-abortion health services, as well as the practice of extracting information from women for the purpose of prosecuting those providing abortion related services.¹⁰ The Committee has fallen short of endorsing abortion as a legal right. However, the Committee has expressed serious concerns that illegal abortions are one of the main causes of high maternal mortality and that overly restrictive interpretations of therapeutic and legal abortion in cases of medical necessity lead women to seek unsafe illegal abortions.¹¹ The Committee is also concerned, as noted to Chile, with the practice of requiring women suffering complications from illegal abortions to disclose information as a requirement to receive health care.¹² The Committee's Concluding Observations follow these concerns, stating that States parties should clarify legislation regarding therapeutic or legal abortions and ensure that patients in need of care are provided care without restriction.¹³ The doctor-patient relationship must be protected and no doctor or patient should be required to disclose information as a requirement of receiving or providing care.¹⁴ The Committee has further urged states to prohibit the practice of extracting confessions from women seeking emergency medical care for prosecution purposes.¹⁵ Additionally, the Committee has urged States to authorize abortions in the case of pregnancy resulting from rape or incest or for cases where the pregnancy threatens the life of the mother.¹⁶

⁷ UNCAT, *Concluding Observations on Madagascar*, para. 10., U.N. Doc. CAT/C/MDG/CO/1 (2011).

⁸ Japan, *supra* note 5, at para. 13; UNCAT, *Concluding Observations on Belarus*, para. 19, U.N. Doc. CAT/C/BLR/CO/4 (2012); UNCAT, *Concluding Observations on Chile* [hereinafter Chile], para. 22, U.N. Doc. CAT/C/CHL/CO/5 (2009).

⁹ UNCAT, *Concluding Observations on Austria*, para. 22, U.N. Doc. CAT/C/AUT/CO/4-5 (2010).

¹⁰ UNCAT, *Concluding Observations on Chile* [hereinafter Chile 2004], para. 6(j)-(m), U.N. Doc. CAT/C/CR/32/5 (2004); UNCAT, *Concluding Observations on Paraguay* [hereinafter Paraguay], para. 22, U.N. Doc. CAT/C/PRY/CO/4-6 (2011); UNCAT, *Concluding Observations on Ireland* [hereinafter Ireland], para. 26, U.N. Doc. CAT/C/IRL/CO/1 (2011); UNCAT, *Concluding Observations on Peru* [hereinafter Peru], para. 15, U.N. Doc. CAT/C/CO/5-6 (2013).

¹¹ Peru, *supra* note 10, at para. 15.

¹² Chile 2004, *supra* note 10, at para. 6(j)-(m).

¹³ Peru, *supra* note 10, at para. 15(a); Ireland, *supra* note 10, para. 26; Paraguay, *supra* note 10, para. 22.

¹⁴ Paraguay, *supra* note 10, at para. 22.

¹⁵ Peru, *supra* note 10, at para. 15(d); Chile, *supra* note 10, at para. 6(j).

¹⁶ Paraguay, *supra* note 10, at para. 22. The Committee echoes the recommendations of the Human Rights Council, the Human Rights Committee, the Committee on the Elimination of Discrimination against Women, and the Committee on Economic, Social and Cultural Rights.

General Comment No. 3 on Redress under the Convention

The Committee recently adopted General Comment No. 3 (December 2012), the aim of which is to interpret the obligations of States parties in accordance with Article 14 of the Convention to provide redress to victims of torture and ill-treatment. The General Comment clarifies the obligations of States parties in relation to Article 14 and also contributes to specifying states' obligations in individual cases of torture and other forms of cruel, inhuman or degrading treatment (hereafter "ill-treatment") that have been the object of communications to the Committee under Article 22. The Committee's experiences in dealing with redress to victims of torture led to the adoption of the General Comment; it was the Committee's goal to increase the impact of the Convention and provide guidance for all stakeholders involved that would assist them in evaluating the obligations under the Convention.

1. Substantive Obligations Outlined in General Comment No. 3

General Comment No. 3 explains that States parties have substantive obligations to ensure in accordance with Article 14 that victims of torture or ill-treatment shall obtain full and effective redress and reparations and be provided the means for as full rehabilitation as possible. These substantive obligations for the right to redress include restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition.¹⁷ The General Comment defines the term victim in relation to torture in paragraph three: "Victims are persons who have individually or collectively suffered harm, including physical or mental injury, emotional suffering, economic loss or substantial impairment of their fundamental rights, through acts or omissions that constitute violations of the Convention."¹⁸ In defining the term "victim" broadly, the Committee made it clear that torture is a pervasive evil that touches all aspects of the human society. This broad definition certainly encompasses victims of torture and ill-treatment in health care settings.

The Committee strongly emphasizes that victim participation is essential in the redress process. The right to redress is one that, by its nature, centers on the victim of torture. This point is specifically important in relation to health care settings as hospitals, doctors, and medical professionals are often a key component of any successful victim-centered rehabilitation. Additionally, state authorities have an affirmative obligation to prevent, prosecute, investigate, and punish non-state actors or private individuals who commit torture, which is of specific importance in health care settings as many hospitals, mental institutions, doctors' offices, and medical providers are often privately owned.¹⁹

Rehabilitation is a particularly relevant obligation of States parties in regard to torture in health care settings. General Comment No. 3 explains in detail States' affirmative obligation to provide means for as full of a rehabilitation as possible for victims of torture.²⁰ Health care institutions are a key component of any successful rehabilitation as victims of torture suffer life altering physical and mental harm. States parties are required to adopt a long-term integrated approach to rehabilitation that requires health care settings to be safe and free from abusive practices as well as to be

¹⁷ UNCAT, *General Comment No. 3: Implementation of Article 14 by States Parties*, para. 6, U.N. Doc. CAT/C/GC/3 (Nov. 16, 2012).

¹⁸ *Id.*, para. 3.

¹⁹ *Id.*, para. 7.

²⁰ *Id.*, paras. 11-15.

accessible, effective, and holistic.²¹ States parties must ensure that all health care settings are free from torture and ill-treatment, as well as ensure that both private and public health care facilities and personnel are trained, able, and ready to provide victims of torture means for as full a rehabilitation as possible, including direct health care, psychosocial services, re-integrative and social services, community and family assistance, and physical and mental rehabilitative services.²² This obligation for States parties to provide rehabilitation to victims of torture encompasses all individuals found within a State's territory.

States parties' other substantive obligations under Article 14 are also important in preventing torture and providing redress to victims of torture in health care settings, including restitution, compensation, satisfaction and right to truth, and guarantees of non-repetition. These obligations are important generally to all victims of torture, including those in health care settings, and also obligate state authorities to take specific measures to guarantee non-repetition. General Comment No. 3 explains that States parties must provide a guarantee of non-repetition, which in health care settings requires independent monitoring, training public servants and health care professionals on human rights law, promoting the observance of international standards for correctional, medical, psychological and social service public servants, and ensuring the availability of temporary services for victims of torture and ill-treatment.²³

2. Procedural Obligations Outlined in General Comment No. 3

As explained in the General Comment, States parties have several procedural obligations under Article 14 of the Convention. These procedural obligations include the obligation to enact domestic legislation, provide effective mechanisms for complaints and investigations, and ensure access to mechanisms for obtaining redress. States have an obligation under Article 14 to enact legislation that criminalizes torture and ill-treatment in all settings, including health care.²⁴ Domestic legislation should also incorporate health care providers and institutions in a holistic and integrated approach to provide victims of torture with full and effective redress. States parties are obligated to ensure that victims of torture have full access to institutions that are capable of investigating complaints and rendering enforceable final decisions in compliance with the Convention.²⁵ These mechanisms include judicial proceedings, state investigations, and proceedings under Article 22 of the Convention. Health care settings cannot be excluded from investigation or civil or criminal proceedings. General Comment No. 3 also highlights the importance of States parties affirmatively ensuring that victims of torture have full access to mechanisms for obtaining redress. Of specific relevance to health care settings, all medical staff dealing with victims of torture should receive special training, including training on the Istanbul Protocol.²⁶ These procedural obligations under Article 14, and the substantive obligations explained above, serve to prevent torture and provide redress to all victims of torture, including those in health care settings.

²¹ *Id.*, para. 13.

²² *Id.*, paras. 13-14.

²³ *Id.*, para. 18.

²⁴ *Id.*, para. 19.

²⁵ *Id.*, paras. 23-28.

²⁶ *Id.*, para. 35.

Conclusion

It is extremely difficult to accurately assess the impact of the Committee's work in terms of transformation of societal norms and practices. However, the Committee has taken an active role in advocating for the eradication of torture in health care settings through its Concluding Observations and the guidelines and obligations articulated in General Comment No. 3. By adopting General Comment No. 3, the Committee has provided governmental entities, civil society, and other international organizations with additional normative legitimacy. Through its activities, the Committee has shown that compliance with State obligations is not only a moral duty, but a legal requirement. Additionally, the constant dialogue that takes place between the Committee and the States, a dialogue that takes into account the views of civil society, creates a possibility of an ongoing supervision designed to achieve the vital goals of the Convention against Torture.

II.

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Torture or Ill-Treatment in Reproductive Health Care: A Form of Gender Discrimination

LUISA CABAL & AMANDA McRAE*

Abstract

This paper seeks to elaborate on the Special Rapporteur's report by illustrating how legal restrictions on essential reproductive health services, as well as discriminatory attitudes, stereotypes, and traditional beliefs about women, often place women in the hands of health care providers who level on them physical and verbal abuse that can amount to torture or CIDT. The paper explores how reproductive rights violations may amount to torture or CIDT, revealing the underlying systemic gender discrimination prevalent in the provision of health services across different regions of the world. It draws upon the ways in which these violations illustrate a pattern of mistreatment directed at women because of their gender, and sometimes compounded by other factors such as race, socioeconomic status, ethnicity, or disability. Section I of this paper briefly explores the scope of the concepts of torture and CIDT and how this framework applies to reproductive rights. Section II enumerates a series of reproductive rights violations and how those violations may amount to torture or CIDT, including what treaty bodies, special procedures, and regional courts have said about these violations. Section III concludes by drawing a connection between these abuses and the gender discrimination inherent when torture or CIDT occur in reproductive health care settings, services that only women need.

Introduction

Reproductive rights lie at the heart of human rights for women, which promise dignity, self-determination, non-discrimination, and equality. When a woman is denied her **reproductive rights**—when she is denied obstetric care, modern contraceptives, facts about her **reproductive health**, or safe **abortion**—she is denied the means to direct her own life, protect her health, and exercise many of her human rights as recognized by regional and international human rights bodies and international consensus documents. This denial of basic human rights can, under certain circumstances, constitute torture or cruel, inhuman, or degrading treatment (CIDT).

In his most recent report to the United Nations Human Rights Council, the Special Rapporteur on Torture broke new ground by illustrating how torture and CIDT can occur not only in detention and interrogation, but also in health care settings, including reproductive health care settings, establishing a new standard for states to prevent and prosecute such abuses. This paper seeks

* Luisa Cabal is the Vice President of Programs at the Center for Reproductive Rights. Amanda McRae is an Advocacy Adviser in the Global Advocacy Program at the Center.

to elaborate on the Special Rapporteur's report by illustrating how legal restrictions on essential reproductive health services, which are services that only women need, as well as discriminatory attitudes, stereotypes, and traditional beliefs about women often place women in the hands of health care providers who inflict physical and verbal abuse that can amount to torture or CIDT.

This paper will explore how reproductive rights violations may amount to torture or CIDT, revealing the underlying systemic gender discrimination prevalent in the provision of health services across different regions of the world. It draws upon the ways in which these violations illustrate a pattern of mistreatment directed at women because of their gender, and sometimes compounded by other factors such as race, socioeconomic status, ethnicity, or disability. Section I of this paper briefly explores the scope of the concepts of torture and CIDT and how this framework applies to reproductive rights. Section II enumerates a series of reproductive rights violations and how those violations may amount to torture or CIDT, including what treaty bodies, special procedures, and regional courts have said about these violations. Section III concludes by drawing a connection between these abuses and the gender discrimination inherent when torture or CIDT occur in reproductive health care settings.

A Short Primer on Torture and CIDT

The UN Convention against Torture prohibits torture and CIDT in all circumstances. Torture occurs when severe physical or mental suffering is intentionally inflicted on a person by a state official or with state authority, for an impermissible purpose, such as obtaining information or a confession, punishment, intimidation or coercion, or "for any reason based on discrimination of any kind."¹ According to the Convention, CIDT, a less severe but still absolutely prohibited human rights violation, occurs when a person experiences severe pain or suffering at the hands of a state actor or under state control, but without the need for intention or an impermissible purpose.²

A showing of severe pain or suffering is required to prove both torture and CIDT. While international human rights bodies, including the UN Committee against Torture and the Human Rights Committee, have not provided a clear definition of what type of pain or suffering qualifies as "severe," they have enumerated several factors to consider when making this assessment. International and regional human rights bodies measure the intensity of alleged conduct based on both objective factors, such as duration, physical and mental effects, and the manner and execution of the conduct, and subjective factors, including sex/gender, age, and the victim's state of health.³

Subjective factors, such as sex or health status, play an important role in determining the severity of the harm. Indeed, human rights bodies have begun to recognize that women experience pain and suffering in a particular way due to their sex or gender and that the consequences of such harm might also be different for these same reasons.⁴ In a case concerning denial of fetal health information to a pregnant woman, the European Court of Human Rights addressed gender specific elements (pregnancy) in support of its finding that the threshold for pain in the context

¹ Convention against Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment, art. 1, Dec. 10, 1984, 1465 U.N.T.S. 85.

² *Id.* art. 16.

³ AISLING REIDY, THE PROHIBITION OF TORTURE: A GUIDE TO THE IMPLEMENTATION OF ARTICLE 3 OF THE EUROPEAN CONVENTION OF HUMAN RIGHTS 11 (2002); CHIDI ODINKALU & FRANS VILJOEN, THE PROHIBITION OF TORTURE AND ILL-TREATMENT IN THE AFRICAN HUMAN RIGHTS SYSTEM: A HANDBOOK FOR VICTIMS AND THEIR ADVOCATES 40-41 (BORIS WIJKSTRÖM ED., 2006).

⁴ See *Miguel Castro-Castro Prison v. Peru*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 160 (Nov. 25, 2006).

of inhuman and degrading treatment was met. In particular, the Court noted “that the applicant was in a situation of great vulnerability. Like any other pregnant woman in her situation, she was deeply distressed by information that the foetus could be affected with some malformation . . . , [and] she had to endure weeks of painful uncertainty concerning the health of the foetus, her own and her family’s future and the prospect of raising a child suffering from an incurable ailment.”⁵ The current Special Rapporteur on Torture, Juan Mendez, made clear that the torture and CIDT rubrics apply in variety of settings, stating that “while the prohibition of torture may have originally applied primarily in the context of interrogation, punishment or intimidation of a detainee, the international community has begun to recognize that torture may also occur in other contexts,” including in public and private health care institutions.⁶

In order to prove torture, as opposed to CIDT, one must also show that the severe pain and suffering was specifically inflicted on the victim by a state official or on behalf of the state for an impermissible purpose as defined by the Convention against Torture.⁷ As noted above, the Convention lists four impermissible purposes: to obtain information or a confession, to punish a person for an act he or she committed, to intimidate or coerce a person, or “for any reason based on discrimination of any kind.”⁸ This latter category, discrimination, includes gender discrimination. Indeed, the former Special Rapporteur on Torture, Manfred Nowak, explicitly commented on the effect of gender-based discrimination in assessing the elements of torture, stating that the “[impermissible] purpose element is always fulfilled, if the acts can be shown to be gender-specific, since discrimination is one of the elements mentioned in the CAT definition.”⁹

Reproductive Rights Violations that May Amount to Torture or CIDT

There are many reproductive rights violations that occur in healthcare settings that may amount to torture or CIDT because of the severe pain and suffering they inflict. These violations fall roughly into two categories: violations that result from legal restrictions on access to reproductive health services; and abusive treatment of women when they do access those services. This section explores some of these violations, as well as the approach that regional and international human rights bodies have taken to classify the abuses as forms of torture or CIDT, illustrating the wide range of reproductive rights abuses that can cause severe mental or physical suffering for women.

⁵ R.R. v. Poland, App. No. 27617/04, Eur. Ct. H.R. 159 (2011).

⁶ U.N. Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, [hereinafter Special Rapporteur Juan Méndez’s 2013 Report] U.N. Doc. A/HRC/22/53 (2013) (by Juan E. Méndez).

⁷ Convention Against Torture, *supra* note 1, art. 1.

⁸ *Id.*

⁹ U.N. Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, para. 30, U.N. Doc. A/HRC/7/3 (2008) (by Manfred Nowak).

1. The Effects of Legal Restrictions on Reproductive Health Services

a. Laws that Restrict Access to or Ban Abortion

Unsafe abortion is one of the leading causes of maternal death and illness around the world, yet it is also one of the most preventable. Studies have demonstrated the correlation between a country's restrictive abortion law and high rates of maternal mortality and morbidity.¹⁰ Where access to safe and legal abortion is limited, women resort to unsafe abortion or are forced to carry pregnancies to term, even when facing devastating consequences for their health, lives, and human rights.¹¹

International and regional human rights bodies have recognized that restrictive abortion laws violate women's human rights and lead them to undergo clandestine abortions, which are often unsafe and pose risks to their lives and health.¹² They have also affirmed that in cases where abortion is legal it must be accessible.¹³

At least six countries ban abortion in all circumstances, even in cases of rape, incest or where necessary to protect the life or health of the pregnant woman.¹⁴ Complete bans on abortion and restrictive abortion laws can have grave consequences for pregnant women as many pregnant women are denied life-saving treatments when pregnancies endanger their health. The Committee against Torture has affirmed that denial of abortion can amount to torture or CIDT in certain circumstances.¹⁵ As the Committee against Torture noted in its 2006 review of Nicaragua, which passed a law banning all abortions, "there have been several documented cases in which the death of a pregnant woman has been associated with the lack of timely medical intervention to save her life, in clear violation of numerous ethical standards of the medical profession." In its report, the Committee urged Nicaragua to decriminalize therapeutic abortion, as recommended by the UN Human Rights Council, the Committee on the Elimination of Discrimination against Women (CEDAW Committee), and the Committee on Economic, Social, and Cultural Rights (ESCR Committee).¹⁶

Legal restrictions on access to abortion in other circumstances, including pregnancies caused by rape or incest, may also constitute torture or CIDT because of the severe physical or mental consequences of carrying an unwanted pregnancy. In its 2011 review of Paraguay, the Committee against Torture expressed concern about a law that outlawed abortion in cases of sexual violence, incest, or when the fetus is not viable. The Committee stated that under this law, women who become pregnant after sexual violence "are constantly reminded of the violation committed against them, which causes serious traumatic stress and carries a risk of long-lasting psychological problems, a situation which can amount to torture."¹⁷ The Committee made similar findings in its review of

¹⁰ See DEPARTMENT OF REPRODUCTIVE HEALTH AND RESEARCH & WORLD HEALTH ORGANIZATION [WHO], UNSAFE ABORTION: GLOBAL AND REGIONAL ESTIMATES OF THE INCIDENCE OF UNSAFE ABORTION AND ASSOCIATED MORTALITY IN 2008 (6TH ED. 2011).

¹¹ *Id.* at 23.

¹² See Center for Reproductive Rights, *Abortion and Human Rights*, BRINGING RIGHTS TO BEAR, OCT. 2008.

¹³ K.L. v. Peru, para. 6.1-9, U.N. Doc. CCPR/C/85/D/1153/2003 (Nov. 22, 2005) available at <http://reproductiverights.org/sites/crr.civicactions.net/files/documents/KL%20HRC%20final%20decision.pdf>; Tysiac v. Poland, App. No. 5410/03, Eur. Ct. H.R. para. 116 (2007) available at <http://hudoca.echr.coe.int/sites/eng/pages/search.aspx?i=001-79812>.

¹⁴ Center for Reproductive Rights, *The World's Abortion Laws Map 2011*, (2011) available at <http://reproductiverights.org/en/document/the-worlds-abortion-laws-map-2011>.

¹⁵ U.N. Comm. against Torture, *Concluding Observations: Paraguay*, para. 22, U.N. Doc. CAT/C/PRY/CO/4-6 (2011).

¹⁶ U.N. Comm. against Torture, *Concluding Observations: Nicaragua*, para. 16, U.N. Doc. CAT/C/NIC/CO/1 (2009).

¹⁷ U.N. Comm. against Torture, *Concluding Observations: Paraguay*, *supra* note 15, para. 22.

Nicaragua in 2009, stating that the Nicaraguan law that denies access to abortion in cases of sexual violence leads to “constant exposure to the violation ... and causes serious traumatic stress and a risk of long-lasting psychological problems such as anxiety and depression,” recommending that the country liberalize its laws to allow for abortion in cases of sexual violence as a means of relieving such trauma.¹⁸

b. Legal Restrictions on Access to Contraception, Including Emergency Contraception

Women’s and adolescents’ rights to contraceptive information and services is grounded in basic human rights protections. These human rights include the rights to equality and non-discrimination, to privacy, to determine the number and spacing of children, to life and health, to education and information, and to benefit from scientific progress.¹⁹ Indeed, the Special Rapporteur on Violence against Women characterized restrictions on access to contraception as a “form of violence” because such restrictions subject “women to excessive pregnancies and childbearing against their will, resulting in increased and preventable risks of maternal mortality and morbidity.”²⁰

Most human rights institutions have not yet recognized denial of access to contraception as a form of torture or CIDT, but evidence from countries where contraception access is restricted offer evidence of severe physical and mental effects of being denied contraception. In the Philippines, for example, a Manila City Executive Order effectively bans all modern contraception provision in public health facilities, an outcome that has a particularly devastating impact on poor women.²¹ Women in Manila City reported mental anguish, including fear and anxiety, at the thought of getting pregnant again because they could not afford unsubsidized contraception outside of the public health facilities.²² Even where another pregnancy would threaten the life or health of a woman, doctors at public health facilities were powerless to provide contraception, contributing to higher rates of maternal mortality and morbidity.²³ Some women who tried to avoid sex with their husbands because of fear of pregnancy and lack of adequate contraception reported that they were then subjected to sexual violence.²⁴ Alarmed by *de facto* bans on contraception in Manila City, civil society organizations have requested the CEDAW Committee to conduct an inquiry into this practice in the Philippines.

The Committee against Torture has taken initial steps towards recognizing that bans on one form of contraception, emergency contraception, and lack of implementation of existing laws that allow for emergency contraception can lead to severe physical and mental suffering. In its 2012 concluding observations for Peru, the Committee against Torture expressed concern at the lack of access to oral emergency contraception to victims of rape, classifying the practice as potential torture or CIDT. The Committee then called on Peru to remove legal restrictions on the distribution of emergency contraception to rape victims in order to protect its citizens from torture or CIDT.²⁵

¹⁸ See U.N. Comm. against Torture, *Concluding Observations: Nicaragua*, *supra* note 16.

¹⁹ CENTER FOR REPRODUCTIVE RIGHTS & UNITED NATIONS POPULATION FUND, *THE RIGHT TO CONTRACEPTIVE INFORMATION AND SERVICES FOR WOMEN AND ADOLESCENTS* 12-14 (2010).

²⁰ U.N. Special Rapporteur on Violence Against Women, *Its Causes and Consequences*, *Report of the Special Rapporteur on Violence against Women, Its Causes and Consequences*, paras. 57-58, U.N. Doc. E/CN.4/1999/68/Add.4, (1999) (by Radhika Coomaraswamy).

²¹ CENTER FOR REPRODUCTIVE RIGHTS, *IMPOSING MISERY: THE IMPACT OF MANILA’S CONTRACEPTION BAN ON WOMEN AND FAMILIES* 24 (2007, UPDATED 2010).

²² *Id.* at 27.

²³ *Id.* at 28-30.

²⁴ *Id.* at 31.

²⁵ U.N. Comm. against Torture, *Concluding Observations: Peru*, paras. 15-16, U.N. Doc. CAT/C/PER/CO/6 (2012).

The Committee against Torture's observations concerning Peru are a natural progression from what other human rights bodies have observed about the physical and mental effects of denying a woman access to emergency contraception. In particular, the Committee on the Rights of the Child (CRC Committee) has consistently called on states to allow access to emergency contraception for adolescent girls. The CRC Committee recommended that Costa Rica make emergency contraception available to victims of sexual violence, noting a high rate of such violence in the country.²⁶ The CRC Committee also raised the issue of access to emergency contraception more generally in Ecuador, where the distribution, sale, or commercialization of a specific form of emergency contraception was at that time illegal, stating that access to emergency contraception is an important part of preventing unsafe abortions or suicides and recommending that the state make all forms of emergency contraception available to adolescents.²⁷ The issues raised by the CRC Committee, including prevention of unsafe abortions and access to emergency contraception in cases of sexual violence, are all important in avoiding severe physical or mental suffering and thus preventing torture or CIDT.

2. Abuses When Accessing Reproductive Health Services

Even where reproductive health services are legal, women may still face abuses from health care providers or others when they access those services. This section outlines the contexts in which those abuses occur, including state failures to implement abortion laws, failure to regulate the use of conscientious objection, abuses when women seek post-abortion care, denial of access to needed reproductive health information, and detention and humiliation of women in health facilities.

a. Failure to Implement Abortion Laws

Some countries with restrictive abortion laws often have exceptions to their abortion bans in cases where the life or health of the pregnant woman are threatened, or in cases of sexual violence. These limited exceptions, however, are not applied in all relevant cases, as noted below, in part because of the lack of clarity of when abortion is legal, lack of regulation of conscientious objection, lack of training for providers, the stigma around performing abortion, criminal penalties attached to performing illegal abortions, and fear of prosecution for performing even legal abortions. Non-implementation of these laws then leads to severe abuses against women who wish to terminate their pregnancies, even when abortions are legal.

In Ireland, a law banning abortion has a limited exception when there is a real and substantial risk to the life of a pregnant woman. The law also provides, however, for severe criminal penalties for both women undergoing abortions for any other reason and for persons aiding in the performance of these other abortions.²⁸ The serious consequences for women that can result from Ireland's law, which can create confusion as to what procedures doctors can legally perform on pregnant women, became apparent in the recent case of Savita Halappanavar, a pregnant woman who died of septicemia in Ireland in November 2012 after doctors refused to perform an abortion during a prolonged miscarriage.²⁹

²⁶ Comm. on the Rts. of the Child, *Concluding Observations: Costa Rica*, paras. 63-64, U.N. Doc. CRC/C/CRI/CO/4 (2011).

²⁷ Comm. on the Rts. of the Child, *Concluding Observations: Ecuador*, paras. 60-61, U.N. Doc. CRC/C/ECU/CO/4 (2010).

²⁸ U.N. Comm. against Torture, *Concluding Observations: Ireland*, para. 26, U.N. Doc. CAT/C/IRL/CO/1 (2011).

²⁹ See Ben Quinn, *Scandal in Ireland as Woman Dies in Galway 'After Being Denied Abortion'*, THE GUARDIAN (Nov. 13, 2012), <http://www.theguardian.com/world/2012/nov/14/ireland-woman-dies-after-abortion-refusal>.

In its concluding observations for Ireland in 2011, the Committee against Torture, based on an earlier European Court of Human Rights decision, emphasized that the lack of clear guidelines for when to apply the life exception “leads to uncertainty facing women and their medical doctors, who are also at risk of criminal investigation or punishment if their advice or treatment is deemed illegal.” The Committee recognized that this lack of legal clarity “leads to serious consequences in individual cases” and urged Ireland to establish clear statutory guidelines for legal abortion and adequate service provision to ensure compliance with the Convention against Torture.³⁰ It is unclear the extent to which a new law on abortion adopted in July 2013, which seeks to more clearly articulate the parameters of Ireland’s life exception, will resolve these issues.

The European Court of Human Rights has also outlined the rights of women to be free from CIDT when legal abortions are denied and the obligations of states to prevent such denial. In the case of *R.R. v. Poland*, where a woman was denied needed prenatal genetic testing for fear that she might seek a legal abortion due to severe fetal impairment, European Court of Human Rights enumerated that once a state has allowed abortion in some circumstances, the state “must not structure its legal framework in a way which would limit real possibilities to obtain an abortion.”³¹ According to the Court, the state “is under a positive obligation to create a procedural framework enabling a pregnant woman to effectively exercise her right of access to lawful abortion,” additionally noting that, “in the context of access to abortion the relevant procedure should guarantee to a pregnant woman at least the possibility to be heard in person and to have her views considered.”³²

Many countries that restrict abortion in most circumstances but allow it in order to protect the life or physical health of the pregnant women often do not recognize the severe mental health consequences that many women will face in continuing unwanted pregnancies, and indeed their laws and practices restricting access to legal abortion may inflict further mental suffering. In the Human Rights Committee case of *K.L. v. Peru*, K.L., a 17-year-old girl, was pregnant with an anencephalic fetus—a fetal abnormality that is fatal in all cases—and doctors noted that continued pregnancy posed risks to the life and health of K.L. Although the doctors treating K.L. recognized the risks inherent in carrying the pregnancy to term and recommended that K.L. terminate the pregnancy, the state hospital authorities denied her request for an abortion, claiming it fell outside the life and health exceptions to Peru’s abortion ban. K.L. was forced to continue her pregnancy to term and gave birth to an anencephalic girl, whom she was then coerced to breastfeed during the four days that the child survived after birth. K.L. was subsequently diagnosed with severe depression requiring psychiatric treatment.³³

The Human Rights Committee found that the Peruvian government had violated its obligations under the ICCPR with respect to the right to be free from CIDT. The Committee noted that “article 7 of the Covenant relates not only to physical pain but also to mental suffering,” and determined that the depression and mental anguish that K.L. suffered as a result of having to carry the pregnancy to term was a foreseeable consequence and direct result of the State’s denial of an abortion.³⁴

Mental suffering is particularly acute for pregnant women who are victims of sexual violence and are unable to obtain abortions, even where they are legal. In the case of *P. and S. v. Poland*, a

³⁰ See U.N. Comm. against Torture, *Concluding Observations: Ireland*, *supra* note 28.

³¹ *R.R.*, App. No. 27617/04 para. 200, *supra* note 31.

³² *Id.* para. 191.

³³ *K.L. v. Perú*, para 2.1-6.3, U.N. Doc. CCPR/C/85/D/1153/2003 (Nov. 22, 2005) available at <http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/KL%20HRC%20final%20decision.pdf>

³⁴ *K.L. v. Peru*, para 6.3, U.N. Doc. CCPR/C/85/D/1153/2003 (Nov. 22, 2005) available at <http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/KL%20HRC%20final%20decision.pdf>

14-year-old girl who became pregnant after she had been raped faced numerous barriers to accessing a lawful abortion, including biased counseling, breach of confidentiality, the unregulated practice of conscientious objection, and removal from her mother's custody. The European Court of Human Rights, in finding that Poland had violated the right to be free from inhuman and degrading treatment, stated that "the general stigma attached to abortion and to sexual violence has been shown to deter women from seeking medical care, causing much distress and suffering, both physically and mentally."³⁵ As applied to the particular circumstances of this case, the Court noted that, "[w]hen medical personnel subjects a child to sustained and aggravated harassment with a view to getting her to continue an unwanted pregnancy she has already and repeatedly asked to terminate, this constitutes mental violence..."³⁶

i. Unregulated Conscientious Objection

In places where there is particular stigma attached to abortion, health care providers may decline to provide this service through a practice known as conscientious objection. International standards on medical ethics indicate that providers who wish to exercise conscientious objection must give notice of the services they decline to provide, appropriately refer patients who request such services, provide timely care when referral is not possible, and provide care regardless of personal objections in emergency situations.³⁷ But as the examples below illustrate, states often fail to regulate health care providers or hold them to these standards, thus failing in their obligation to protect women's access to reproductive health services to which they are legally entitled.

The European Court of Human Rights noted in *P. and S. v. Poland*, outlined above, that due to the use of insufficiently regulated conscientious objection by health care providers the applicants faced "procrastination and confusion," "did not receive appropriate and objective medical counselling which would have due regard to their own views and wishes," and that no set procedure was available to the applicants to challenge the objections, contributing to the pain and suffering the applicants endured.³⁸ Although the law in Poland requires medical professionals who wish to exercise conscientious objection to provide referrals to doctors who may be willing to provide reproductive health services, in practice, doctors often fail to provide such referrals.³⁹

The Human Rights Committee expressed concern under Article 6 (right to life) about the unregulated use of conscientious objection in Poland and noted with concern that safeguards put in place to ensure access to reproductive rights in cases of conscientious objection were not being adequately applied.⁴⁰ In his report following a mission to Poland, the Special Rapporteur on the Right to Health recognized conscientious objection as a barrier to prenatal testing, stating that there was a need for action to "reconcile the legitimate concerns of health providers exercising their right to conscientious objection with the legitimate and pressing interests of patients."⁴¹ The Special Rapporteur recommended that Poland "[i]ntroduce regulations that require physicians to

³⁵ *P. and S. v. Poland*, App. No. 57375/08, Eur. Ct. H.R. para. 76 (2012) available at <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-114098>.

³⁶ *Id.* para. 77.

³⁷ International Federation of Obstetrics and Gynecology, *Resolution on 'Conscientious Objection,'* (Nov. 2006) <http://www.figo.org/projects/conscientious>.

³⁸ *P. and S. v. Poland*, *supra* note 35, para. 107.

³⁹ *Id.* para. 81.

⁴⁰ U.N. Hum. Rts Comm., *Concluding Observations: Poland*, para. 12, U.N. Doc. CCPR/C/POL/CO/6 (2010).

⁴¹ U.N. Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover*, paras. 50-55, U.N. Doc. A/HRC/14/20/Add.3 (2010) (by Anand Grover).

provide timely prenatal examinations and termination of pregnancies as permitted by law, and which provide a thorough, fair, transparent and effective investigation process in circumstances where physicians fail to provide adequate and timely medical care.”⁴²

b. Abuses When Seeking Post-Abortion Care

In countries where access to abortion is restricted or criminalized, including where laws hold a penalty for a woman undergoing abortion or for those helping her, women are often denied or delayed lawful post-abortion care. Denial or delay of post-abortion care can lead to serious human rights violations, including health complications resulting in severe physical or mental suffering, and is one of the leading causes of maternal mortality and morbidity.⁴³

Abortion is criminalized without any clear exceptions in the Philippines. A 2010 report by the Center revealed that women in the Philippines often die or suffer grave complications from unsafe abortion procedures and are frequently denied emergency post-abortion care—which is legal—due to the stigma surrounding abortion and the chilling effect of the criminal prohibition of abortion.⁴⁴ The Center documented similar abuses under the restrictive abortion law in Kenya.⁴⁵

The Committee against Torture has consistently classified violations of reproductive rights that occur in post-abortion care as forms of CIDT. In its 2011 review of Paraguay, in the context of a law banning abortions in almost all circumstances, the Committee against Torture expressed that it was “concerned about the denial of medical care to women who have decided to have an abortion, which could seriously jeopardize their physical and mental health and could constitute cruel and inhuman treatment.”⁴⁶ In its recommendations to Chile on access to post-abortion care, the Committee called upon the government to “ensure immediate and unconditional treatment of persons seeking emergency medical care,” in line with World Health Organization Guidelines.⁴⁷

Denial of post-abortion care may in some circumstances, however, amount to torture rather than CIDT. As noted above, the Convention against Torture specifically enumerates that one of the impermissible purposes that can classify an act as torture, rather than CIDT, is “punishing him for an act he or a third person has committed or is suspected of having committed.”⁴⁸ The Convention against Torture also provides that another impermissible purpose that can classify an abuse as torture is when state authorities or those acting under state control inflict severe pain and suffering for the purpose of obtaining information or a confession.⁴⁹ Women seeking post-abortion care in different parts of the world face abuse at the hands of health care workers for both of these purposes, acts that under international law may constitute not only CIDT but torture.

For instance, denial of post-abortion care is sometimes used as a form of punishment by health care workers, acting within the context of countries that have restrictive abortion laws, and thus can amount to torture. In a 2004 study of practices in Rosario, Argentina, women reported suffering harassment and inferior care when seeking post-abortion medical services, as a form of

⁴² *Id.* para. 85(m).

⁴³ See DEPARTMENT OF REPRODUCTIVE HEALTH AND RESEARCH & WORLD HEALTH ORGANIZATION [WHO], UNSAFE ABORTION: GLOBAL AND REGIONAL ESTIMATES OF THE INCIDENCE OF UNSAFE ABORTION AND ASSOCIATED MORTALITY IN 2008 (6TH ED. 2011).

⁴⁴ See CENTER FOR REPRODUCTIVE RIGHTS, FORSAKEN LIVES: THE HARMFUL IMPACT OF THE PHILIPPINE CRIMINAL ABORTION BAN (2010).

⁴⁵ See CENTER FOR REPRODUCTIVE RIGHTS, IN HARM’S WAY: THE IMPACT OF KENYA’S RESTRICTIVE ABORTION LAW (2010).

⁴⁶ U.N. Comm. against Torture, *Concluding Observations: Paraguay*, *supra* note 15, para. 22.

⁴⁷ U.N. Comm. against Torture, *Concluding Observations: Chile*, para. 7(m), U.N. Doc. CAT/C/CR/32/5 (2004).

⁴⁸ Convention against Torture, *supra* note 1, art. 1.

⁴⁹ *Id.*

punishment by health care providers and even cleaning staff because those women had undergone an abortion.⁵⁰ Physical and mental pain and suffering can be closely associated with the denial of care or the provision of inferior care. This pain and suffering is often exacerbated by overt acts of discrimination by medical care providers, as women seeking post-abortion care may be subjected to verbal and physical abuse, delays or denials of treatment or pain medication, extortion or unreasonably high user fees, and threats of being reported to law enforcement for violation of criminal abortion laws.⁵¹

Women may also be denied post-abortion care until they confess or give authorities information about who provided the service. For instance, the Committee called upon the Chilean government to “eliminate the practice of extracting confessions for prosecution purposes from women seeking emergency medical care as a result of illegal abortion.”⁵² Where such confessions were subsequently used in legal proceedings against both the women and the abortion providers, the Committee urged the government to “investigate and review convictions where statements obtained by coercion in such cases have been admitted into evidence, and take remedial measures including nullifying convictions which are not in conformity with the Convention [against Torture].”⁵³ The Committee made similar recommendations to Peru in 2012, in the context of a law that obliges women to report physicians from whom they sought abortions to the authorities.⁵⁴ The Center also documented this phenomenon in the Philippines, where women seeking post-abortion care reported verbal abuse, threats of criminal sanctions, and at times were coerced into confessing that they underwent an illegal abortion.⁵⁵ A 2004 study out of Rosario, Argentina, documented verbal and physical abuse targeted at women seeking post-abortion care, as well as pressure from police or doctors to provide the names of abortion providers before they would receive treatment.⁵⁶

c. Denial of Reproductive Health Information

In order for women to be able to exercise their reproductive autonomy and make informed decisions about their lives, they must have access to information about their reproductive health. Prenatal testing, for example, is imperative to a woman's ability to exercise her rights to information, to health and to physical integrity, and to also make decisions concerning continuation or termination of a pregnancy, where the law allows abortion in cases of fetal impairment. The European Court of Human Rights found that denial of such information can cause mental suffering that can amount to CIDT.

Poland has a restrictive abortion law that only allows abortion in certain circumstances, including fetal impairment. An ultrasound performed on R.R., a Polish woman, during her 18th week of pregnancy detected a cyst on the fetus's neck. To determine whether this was indicative of a severe fetal malformation, genetic tests were needed. R.R. repeatedly faced obstructions in receiving these further tests, often with the purpose of pushing her beyond the time period allowed for abortion. It

⁵⁰ Cynthia Steele & Susana Chiarotti, *With Everything Exposed: Cruelty in Post-Abortion Care in Rosario, Argentina*, 12 REPROD. HEALTH MATTERS 39, 43 (2004).

⁵¹ See CENTER FOR REPRODUCTIVE RIGHTS, IN HARM'S WAY: THE IMPACT OF KENYA'S RESTRICTIVE ABORTION LAW, SUPRA NOTE 40; SEE CENTER FOR REPRODUCTIVE RIGHTS, FORSAKEN LIVES: THE HARMFUL IMPACT OF THE PHILIPPINE CRIMINAL ABORTION BAN, SUPRA NOTE 44.

⁵² U.N. Comm. against Torture, *Concluding Observations: Chile*, supra note 47.

⁵³ *Id.*

⁵⁴ U.N. Comm. against Torture, *Concluding Observations: Peru*, supra note 25, para. 15(d).

⁵⁵ See CENTER FOR REPRODUCTIVE RIGHTS, FORSAKEN LIVES: THE HARMFUL IMPACT OF THE PHILIPPINE CRIMINAL ABORTION BAN, SUPRA NOTE 44.

⁵⁶ Steele, supra note 50, at 42-43.

was only in her 23rd week of pregnancy that she was able to undergo the genetic testing, the results of which came only after the timeframe in which Poland allows abortion for fetal impairment⁵⁷

In 2011, the European Court of Human Rights found in *R.R. v. Poland* that Poland had violated the Article 3 prohibition on inhuman or degrading treatment.⁵⁸ The Court found that R.R.'s access to genetic testing was "marred by procrastination, confusion and lack of proper counselling and information given to the applicant."⁵⁹ In support of its finding that the threshold of pain and suffering for CIDT was met, the Court recognized in the applicant's particular situation, access to information was imperative. The Court stated: "Like any other pregnant woman in her situation, she was deeply distressed by information that the foetus could be affected with some malformation ..., [and] she had to endure weeks of painful uncertainty concerning the health of the foetus, her own and her family's future and the prospect of raising a child suffering from an incurable ailment."⁶⁰ In addition to her status as a pregnant woman, the Court noted that her suffering was increased "by the fact that the diagnostic services which she had requested early on were at all times available and that she was entitled as a matter of domestic law to avail herself of them."⁶¹ The Court also ruled that Poland needed to ensure that the exercise of conscientious objection does not inhibit women's access to lawful reproductive health care services and that women have access to complaint mechanisms that can respond in a timely manner when they are denied services.⁶²

Similarly, the Human Rights Committee in its 2010 concluding observations for Poland noted concerns about lack of access to needed prenatal testing, as a violation of Article 6 of the ICCPR (right to life) and called for legal changes to regulate the use of conscientious objection and to improve response times from the medical commission in cases related to abortion.⁶³

d. Detention and Humiliation of Women in Health Facilities

Women suffer mistreatment at the hands of health care providers in many other aspects of reproductive health care. In his recent report to the Human Rights Council on torture and CIDT in health care settings, the current Special Rapporteur on Torture, Juan Mendez, highlighted the humiliation of women in reproductive health care settings as a potential form of torture or CIDT.⁶⁴ Moreover, according to the former Special Rapporteur on Torture, Manfred Nowak, to prove CIDT it is sufficient to show that the act was aimed at humiliating the victim, regardless of whether severe pain was inflicted.⁶⁵

The Committee against Torture has recognized some other violations in reproductive health care settings as forms of CIDT. The Committee recently expressed concern in concluding observations to Austria regarding "reports of alleged lack of privacy and humiliating circumstances amounting to degrading treatment during medical examinations" at a community health center, where registered sex workers are required to undergo weekly medical checkups, including gynecological

⁵⁷ *R.R.*, App. No. 27617/04, paras. 6-55, *supra* note 5

⁵⁸ *Id.* para. 161.

⁵⁹ *Id.* para. 153.

⁶⁰ *Id.* para. 159.

⁶¹ *Id.* para. 160.

⁶² *Id.* para. 206.

⁶³ U.N. Hum. Rts Comm., *Concluding Observations: Poland*, *supra* note 40.

⁶⁴ Special Rapporteur Juan Méndez's 2013 Report, *supra* note 6, para. 46.

⁶⁵ U.N. Special Rapporteur on Torture, Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, para. 35, U.N. Doc. E/CN.4/2006/6 (2005) (by Manfred Nowak).

exams, and to take regular blood tests for sexually transmitted diseases.⁶⁶ The Committee called upon the state to ensure that the “medical examinations are carried out in an environment where privacy is safeguarded and in taking the greatest care to preserve the dignity of women being examined.”⁶⁷

In 2007, the Center and FIDA Kenya published *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities*, which documented systemic and widespread problems with the provision of reproductive healthcare services in Kenya.⁶⁸ The findings included the physical and verbal abuse and humiliation of women seeking maternity services and detention of women and their babies shortly after birth for unpaid medical bills, documenting the physical and emotional toll placed on these women who suffered verbal harassment, were detained in poor conditions, and were separated from their families. In its 2013 concluding observations for Kenya, the Committee against Torture noted concern “about ill-treatment of women who seek access to reproductive health services, in particular the on-going practice of post-delivery detention of women unable to pay their medical bills, including in private health facilities,” classifying the practice as potential torture or ill-treatment. The Committee then called on Kenya to “strengthen its efforts to end the practice of forcible detention” of women post-birth.⁶⁹

Connecting the Dots: The Underlying Systemic Discrimination against Women in the Provision of Reproductive Health Care

As illustrated above, women are subjected to a wide range of violations that may constitute torture or CIDT when they access reproductive health services in contexts where those services are both legal and where they are criminalized. Human rights bodies are increasingly recognizing reproductive rights violations as forms of torture or CIDT. It is important, however, that these institutions connect the dots between the wide range of reproductive rights abuses they classify as torture or CIDT and a wider problem: systemic discrimination against women. Indeed, reproductive rights violations that amount to torture or CIDT are violations that only women can experience. By calling attention to the linkages between these abuses, human rights institutions can draw further attention to the violations and push states to urgently address this gendered form of torture or CIDT.

According to the Convention on Elimination of all forms of Discrimination against Women (CEDAW), “discrimination against women” occurs when there is “any distinction, exclusion or restriction made on the basis of sex which has the *effect or purpose* of impairing or nullifying the recognition, enjoyment, or exercise by women ... of human rights or fundamental freedoms....”⁷⁰ This definition sets out that discrimination against women can occur when not only the *purpose* of a law or practice is to discriminate against women but also when the *effect* of laws or practices is to nullify women's rights. By this understanding, legal restrictions that many states impose and unlawful abuses that many states fail to prevent or punish in the context of reproductive health services are forms of discrimination against women, even if the purpose of the law is not discrimination.

⁶⁶ U.N. Comm. against Torture, *Concluding Observations: Austria*, para. 22, U.N. Doc. CAT/C/AUT/CO/4-5 (2010).

⁶⁷ *Id.*

⁶⁸ See CENTER FOR REPRODUCTIVE RIGHTS & FEDERATIONS OF WOMEN LAWYERS—KENYA [FIDA], *FAILURE TO DELIVER: VIOLATIONS OF WOMEN'S HUMAN RIGHTS IN KENYAN HEALTH FACILITIES* (2007).

⁶⁹ U.N. Comm. against Torture, *Concluding Observations: Kenya*, para. 27, U.N. Doc. CAT/C/KEN/CO/2 (2013).

⁷⁰ Convention on Elimination of All Forms of Discrimination Against Women, art. 1, (Dec. 18, 1979).

Laws and practices that limit women's access to reproductive health services and result in torture or CIDT are very often the result of direct or indirect discrimination against women, based on stigma, beliefs about their traditional roles, and disregard for their health, lives, and personal choices. Indeed, the CEDAW Committee has emphasized that legal and policy restrictions on access to reproductive health services discriminate against women by denying them health services that only they need.⁷¹ As the Special Rapporteur on Torture points out in his most recent report, "[d]iscrimination plays a prominent role in an analysis of reproductive rights violations as forms of torture or ill-treatment because sex and gender bias commonly underlie such violations."⁷²

Indeed, discrimination against women in the context of reproductive health care is enshrined in law and in practice in many countries throughout the world. As noted above, six states in the world have banned access to abortion in all circumstances, while many others restrict access to only a few defined circumstances, and women who seek unsafe, illegal abortions are at higher risk of injury or death. Experts have noted that many steps taken to deny women abortions, including following sexual violence, or to deny women post-abortion care are grounded in pervasive discriminatory beliefs which are often based on stereotypes and traditional views that a woman's primary role is to bear children and that women lack the moral agency to make responsible decisions about reproduction.⁷³

A recent case out of El Salvador, a country that prohibits abortion without exception, illustrates the often callous disregard for women's health and lives in the context of reproduction. Beatriz, a pregnant woman who suffers from lupus, sought to terminate her pregnancy, a course of treatment with which her doctors agreed, as her kidneys began to fail and it became clear that the pregnancy threatened her life and health. Meanwhile, she was informed that she was carrying an anencephalic fetus, a condition in which the brain of the fetus is only half formed and where the fetus will not survive beyond a few days after birth.⁷⁴ Despite a situation that put Beatriz's life at grave risk, the Salvadoran authorities, including the Supreme Court, declined to protect her and her doctors from prosecution should she seek an abortion, citing the absolute prohibition on the procedure and stating that the rights of pregnant women could not be privileged over those of a fetus.⁷⁵

In a letter to El Salvador, the UN Special Rapporteurs on Torture, Health, and Violence against Women, as well as the chair of the UN Working Group on the issue of discrimination against women in law and practice, classified the forced continuation of Beatriz's pregnancy as a form of CIDT, stating that "[t]his case exemplifies the urgent need to launch a national dialogue on abortion legislation, in order to consider the introduction of exceptions to its general prohibition, especially in cases of therapeutic abortion and pregnancy resulting from rape or incest."⁷⁶ On May 29, 2013, the Inter-American Court of Human Rights ordered El Salvador to urgently take measures

⁷¹ Comm. on the Elimination of Discrimination against Women, *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, General Recommendation No. 24*, para. 22, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008).

⁷² Special Rapporteur Juan Méndez's 2013 Report, *supra* note 6, para. 37.

⁷³ REBECCA J. COOK & SIMONE CUSACK, GENDER STEREOTYPING: TRANSNATIONAL LEGAL PERSPECTIVES 85 (2009).

⁷⁴ See Karla Zabudovsky & Gene Palumbo, *Salvadoran court Denies Abortion to Ailing Woman*, N.Y. TIMES, MAY 29, 2013, <http://www.nytimes.com/2013/05/30/world/americas/salvadoran-court-denies-abortion-to-ailing-woman.html>.

⁷⁵ *Id.*

⁷⁶ Joint Statement of the U.N. Special Rapporteurs on Torture, Violence against Women, and Health and UN Working Group on Issue of Discrimination Against Women in Law and Practice, *El Salvador: UN Rights Experts Appeal to Government to Provide Life-Saving Treatment to Woman at Risk* (Apr. 26, 2013).

to protect the rights to life and bodily integrity of Beatriz.⁷⁷ After at 14-week ordeal and during Beatriz's 27th week of pregnancy, Salvadoran authorities in early June permitted Beatriz to undergo a caesarian section, an alternative to abortion but one that posed additional risks to Beatriz's health, and her baby died a few hours later⁷⁸

This case is not just an illustration of an individual instance of CIDT targeted at a pregnant woman in El Salvador. The fact that the law exists in El Salvador, and that Salvadoran courts have found that the rights of pregnant women cannot be "privileged" over those of fetuses, illustrates that in El Salvador a pregnant woman's value to society lies solely in her ability to reproduce. When a woman is placed in a situation where, because of legal restrictions stemming from discriminatory beliefs about the traditional roles of women, she cannot make a decision to save her own life, that is a clear illustration of discrimination, and the result may be torture and not just CIDT.

As part of their obligations to prevent and remedy violations of the prohibition on torture or CIDT, states must take action to ensure that women have access to sexual and reproductive health services, on the basis of free and informed consent and without discrimination. States should eliminate laws and practices that deny women access to information and services related to abortion and contraception, while prosecuting those who subject women to abuse when they seek out those services. Most urgently of all, states need to take steps to address the systemic discrimination, stereotypes, and stigma that exist in medical communities and beyond about women's sexuality and about the services they most need to protect their lives and health. Ending this discrimination starts with investing in human-rights based training of health personnel and continues with empowering national human rights institutions and the judiciary to uphold the rights of women in all areas of their lives, thereby fulfilling their obligations to protect all persons, including women, from torture or CIDT.

⁷⁷ See El Salvador Matter of B, Provisional Measures, Order of the Court, "Having Seen" (Inter-Am. Ct. H.R. May 29, 2013) available at http://www.corteidh.or.cr/docs/medidas/B_se_01_ing.pdf.

⁷⁸ *Baby Born to El Salvador Woman Denied Abortion Dies After C-Section*, THE GUARDIAN (JUNE 4, 2013), <http://www.theguardian.com/world/2013/jun/04/baby-el-salvador-woman-abortion-dies>.

Poor Access to Comprehensive Prenatal Care, Including Opiate Substitution Treatment: A Form of Ill-Treatment for Women With Drug Dependence During Pregnancy

MIKHAIL GOLICHENKO & SANDRA KA HON CHU*

Abstract

The vulnerability of people who use drugs (“PWUD”) to human rights violations is well documented.¹ Amongst PWUD, women are the most vulnerable for many reasons, including strong prejudice and stigma, which often result in gender-based discrimination and violence.² In many countries, there is an absence of gender-sensitive services for women who use drugs, including the lack of services for pregnant women who use drugs, the lack of education of medical practitioners regarding special needs of women who use drugs during pregnancy, and the presence of stigma and prejudice among medical staff toward women who use drugs during pregnancy.³ Medical practitioners often give women who use drugs incorrect information regarding the possible harms of substance misuse, and the negative effects on their health and the health of their babies.⁴ In countries where governments promote stigma against PWUD users by way of “zero tolerance”

* Mikhail Golichenko and Sandra Ka Hon Chu are Senior Policy Analysts with the Canadian HIV/AIDS Legal Network, a non-governmental organization which promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally, through research and analysis, advocacy and litigation, public education and community mobilization. www.aidslaw.ca

¹ Joanne Csete and Jonathan Cohen, *Lethal Violations: Human Rights Abuses Faced By Injection Drug Users In The Era Of HIV/AIDS*, in *WAR ON DRUGS, HIV/AIDS AND HUMAN RIGHTS* 212-226 (K. Malinowska-Dempruch & S. Gallagher eds., 2004); Anya Sarang et al., *Policing Drug Users in Russia: Risk, Fear, and Structural Violence*, 45 *SUBSTANCE USE MISUSE* 813-864 (2010); Tim Rhodes, *Street Policing, Injecting Drug Use and Harm Reduction in a Russian City: A Qualitative Study of Police Perspectives*, 83 *J. OF URBAN HEALTH* 911-925 (2006); Human Rights Watch, *Fanning the Flames: How Human Rights Abuses Are Fueling the AIDS Epidemic in Kazakhstan* (2003); Human Rights Watch, *Abusing the User: Police Misconduct, Harm Reduction and HIV/AIDS in Vancouver* (2003); Human Rights Watch, *Rhetoric and Risk: Human Rights Abuses Impeding Ukraine’s Fight Against HIV/AIDS*, (2006); Human Rights Watch, *Lessons Not Learned: Human Rights Abuses and HIV/AIDS in the Russian Federation* (2007); Human Rights Watch, *Rehabilitation Required: Russia’s Human Rights Obligation to Provide Evidence-based Drug Dependence Treatment* (2007); R. Saucier, ed., *Treated With Cruelty: Abuses in the Name of Drug Rehabilitation* (Open Society Foundations, June 2011).

² *Women Who Use Drugs, Harm Reduction And HIV*, THE GLOBAL COALITION ON WOMEN AND AIDS, <http://womenandaids.net/CMSPages/GetFile.aspx?guid=b59f24b2-6f04-4592-b78e-cea9813f6aef>.

³ Open Society Institute: Public Health Program, *Women, Harm Reduction and HIV: Key findings from Azerbaijan, Georgia, Russia and Ukraine* (2009)(by Katya Burns), http://www.opensocietyfoundations.org/sites/default/files/wmhreng_20091001.pdf.

⁴ *Id.*

policies, there is considerable pressure on pregnant drug-dependent women to undergo abortion. This pressure is of a particular intensity in countries where, on the one hand, drug dependence is stipulated in Ministry of Health regulations as a contraindication to pregnancy, and on the other hand, there is no access to evidence-based maintenance therapy—such as opioid substitution therapy (“OST”)—for pregnant women with drug dependence.⁵ Methadone substitution treatment is the currently recommended standard of care for drug-dependent pregnant women. OST reduces illicit drug use, withdrawal symptoms and pregnancy-related complications.⁶ In countries where OST is legally banned or effectively restricted due to economic, geographical or other systemic reasons, drug-dependent pregnant women face imminent risks to their health and life as well as to the health and life of their fetuses.⁷

Introduction

In this article, we argue that policy leading to poor access to comprehensive prenatal care and OST for women with drug dependence during pregnancy, along with the deliberate or negligent use of misinformation against pregnant women with drug dependence, constitutes ill-treatment in violation of Articles 1 and 16 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (“Convention Against Torture”) (respectively, the prohibitions against torture and against other acts of cruel, inhuman or degrading treatment or punishment.

Elements of Torture and Other Cruel, Inhuman or Degrading Treatment

In many settings, the four essential elements reflected in the definition of torture provided in Article 1(1) of the Convention against Torture can be found in cases of poor access to prenatal care for pregnant women with drug dependence: (1) an act inflicting severe pain or suffering, whether physical or mental; (2) the element of intent; (3) a specific, improper purpose; and (4) the involvement of a State official, at least by acquiescence.

The Threshold of Severe Pain or Suffering

The jurisprudence of international human rights bodies, including the U.N. Committee against Torture, demonstrates that different types of suffering of different origins can potentially constitute torture or ill-treatment, including suffering arising from: the military burning down a person’s house; a failure to protect a person from environmental pollution; a government’s failure to adequately investigate a reported disappearance; a failure to protect a person from domestic violence; and a failure to address mistreatment and neglect of children by their parents.⁸

According to the well-established case law of the European Court of Human Rights, ill-treatment must attain a minimum level of severity if it is to fall within the scope of the prohibition of torture and other forms of ill-treatment. The assessment of this minimum level of severity is rel-

⁵ Nalaya Vershinina, *People Shall Not be Segregated in This Way*, ANDREY RYLKOV FOUNDATION (2012), <http://rylkov-fond.org/blog/lichnye-svidetelstva/vershinina/>.

⁶ World Health Organization, *Clinical Protocol for the WHO European Region: Protocol 10: Prevention of HIV Transmission from HIV-Infected Mothers to their Infants* [hereinafter *WHO Clinical Protocol*], at 376 (2007).

⁷ Vershinina, *supra* note 5.

⁸ Joseph Amon & Diederik Lohman, *Denial of Pain Treatment and the Prohibition of Torture, Cruel, Inhuman or Degrading Treatment or Punishment*, 16 INTERRIGHTS BULLETIN 173 (2011).

ative; it depends on the many circumstances of the case, such as the duration of the treatment, its physical and mental effects and, in some cases, the victim's sex, age and state of health.⁹

The special vulnerability of women during pregnancy, with regards to states' responsibility to prevent acts of torture, inhuman, or degrading treatment, was recognized by the European Court of Human Rights in the case of *R.R. v. Poland*, where the applicant faced obstacles in accessing medical help related to her pregnancy.¹⁰ With reference to its case law, the Court noted that "it cannot be excluded that the acts and omissions of the authorities in the field of health care policy may in certain circumstances engage their responsibility under Article 3 [prevention of ill-treatment] by reason of their failure to provide appropriate medical treatment."¹¹ Pointing to the applicant's great vulnerability, the European Court asserted:

*"Like any other pregnant woman in her situation, [the applicant] was deeply distressed by information that the fetus could be affected with some malformation. It was therefore natural that she wanted to obtain as much information as possible so as to find out whether the initial diagnosis was correct, and if so, what was the exact nature of the ailment. She also wanted to find out about the options available to her. As a result of the procrastination of the health professionals, she had to endure weeks of painful uncertainty concerning the health of the fetus, her own and her family's future and the prospect of raising a child suffering from an incurable ailment."*¹²

Ultimately, the Court concluded that there was a violation of Article 3 of the European Convention (the prohibition of torture, inhuman, or degrading treatment).

The particular vulnerability of pregnant women can be many times greater in cases where women are drug-dependent. They can experience the same, if not stronger distress, uncertainty and anguish as in *R.R. v. Poland*, all as the result of the lack of information or misleading information, lack of access to appropriate medical care, and an inadequate legal framework that gives rise to these. The suffering caused by these factors can be much exacerbated in cases when pregnant women experience pain because of withdrawal syndrome. According to the U.N. Special Rapporteur on Torture, "[t]here can be no doubt that withdrawal symptoms can cause severe pain and suffering if not alleviated by appropriate medical treatment."¹³

The Involvement of a State Official, at Least by Acquiescence

In many countries, the absence of specific protocols of prenatal care for women with drug dependence, as well as the existence of official drug policy aimed at stigmatizing PWUD, and even in some cases the legal prohibition of services (such as opioid substitution therapy for pregnant women or for the population in general), can all serve as indicators that the state authorities are aware of—or willfully blind to—the suffering of pregnant women with drug dependence. In some states, the legal framework is the primary reason that pregnant women with current or past drug use are subjected to the sole "option" of undergoing abortion. In such cases the element of involvement of state officials in such ill-treatment is clear—at the least they are acquiescent to the abuse women experience, but in fact it could also be said that they are directly inflicting or instigating such pain and suffering when it is the clearly foreseeable consequence of the legal framework

⁹ *Price v. the United Kingdom*, 2001-VII Eur. Ct. H.R. No. 33394/96, at § 24.

¹⁰ *R.R. v. Poland*, Eur. Ct. H.R. 27617/04 (2011).

¹¹ *Id.* at para. 152.

¹² *Id.* at para.159.

¹³ U.N. Special Rapporteur On Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment [hereinafter *SRT 2009*], *2009 Report*, A/HRC/10/44, at para. 57 (2009).

they have created with the deliberate objective of stigmatizing PWUD and prohibiting certain evidence-based medical care. This involvement of public officials is even more evident when considering the failure of state authorities to effectively investigate such cases and undertake necessary measures to prevent similar future cases. As emphasized by the Special Rapporteur on torture, “the State’s obligation to prevent torture applies not only to public officials, such as law enforcement agents, but also to doctors, health-care professionals and social workers, including those working in private hospitals, other institutions and detention centres.”¹⁴ The Special Rapporteur further points to the state’s “heightened obligation to protect vulnerable and/or marginalized individuals from torture, as such individuals are generally more at risk of experiencing torture and ill-treatment.”¹⁵ Pregnant women are often under the significant control of doctors due to their special medical needs during pregnancy. Arguably, stronger control extends to pregnant women whose pregnancy is complicated because of other health conditions (HIV, hepatitis C, drug dependence).

State involvement in ill-treatment, at least in the form of acquiescence, is evident in cases where, despite ample evidence of the effectiveness of a particular type of health care intervention, authorities maintain a legal ban on such an intervention. One such example is the restriction of OST, whether authorities impose an outright blanket ban, or make it practically unavailable via economic obstacles and poor program-design, including the failure to consider specific needs of women, including during pregnancy.

The Special Rapporteur on torture asserts that the denial of methadone maintenance treatment is a violation of the right to be free from torture and ill-treatment in certain circumstances, including in a non-custodial context, particularly in instances where governments impose a complete ban on substitution treatment and harm reduction measures.¹⁶ The Special Rapporteur further stresses that “[by] denying effective drug treatment, State drug policies intentionally subject a large group of people to severe physical pain, suffering and humiliation, effectively punishing them for using drugs and trying to coerce them into abstinence, in complete disregard of the chronic nature of dependence and of the scientific evidence pointing to the ineffectiveness of punitive measures.”¹⁷ When State drug policies further subject drug-dependent people to the additional pain and suffering of an unwanted abortion (thereby contravening their right to found a family), the violation of the right to be free from torture and ill-treatment is even more flagrant.

The Elements of Intent and a Specific, Improper Purpose

In some cases the improper discriminatory purposes of policies and practices are evident on the side of the government officials, law makers, doctors, and private actors. One example of such cases is an official state drug policy which is pursuing the goal of purging drug use from the society by way of draconian law enforcement and the denial of access to harm reduction services for PWUD, regardless of the chronic nature of drug dependence.¹⁸ In other cases it is only possible to speculate on a doctor’s intent in providing drug-dependent pregnant women with misleading information regarding their health and the health of their babies. It is possible that the doctors sincerely wish to

¹⁴ *Id.* at para. 24.

¹⁵ *Id.* at para. 26.

¹⁶ *Id.* at para. 73.

¹⁷ *Id.* at para. 74.

¹⁸ Mikhail Golichenko and Anya Sarang. *Atmospheric Pressure: Russian drug policy as a driver for violations of the UN Convention against Torture and the International Covenant on Economic, Social and Cultural Rights*. HEALTH AND HUMAN RIGHTS. AN INTERNATIONAL JOURNAL. Volume 15 (2013)

help, but have been prevented from doing so because of stigma and prejudice, lack of training, an absence of protocols, the legal ban on OST, etc., and so had no other option but to pressure drug-dependent pregnant women to abort. The UN Special Rapporteur on torture accepts that ill-treatment contrary to the Convention Against Torture may occur where the purpose or intention of the state's action or inaction was not to degrade, humiliate or punish the victim, but where this nevertheless was the result.¹⁹ Regardless of the true intentions, if the result of a doctor's actions and inaction was degrading treatment and humiliation, it is legitimate to categorize such treatment as ill-treatment.

The element of intent is also satisfied when private or parastatal authorities administering dubious care and treatment practices where the State's law or regulation permits a given practice, or the practice is known and acquiesced to by public authorities (e.g. ministry of health, justice or interior or local officials with such responsibilities)²⁰. The legal ban on OST for pregnant women and/or the lack of treatment and care protocols for pregnant patients with drug dependence are explicit examples where the element of intent is satisfied.

Discrimination, Including Structural Violence against Women, as an Element of a Gender-Sensitive Definition of Torture

According to the Special Rapporteur on torture,

*"[d]iscrimination plays a prominent role in an analysis of reproductive rights violations as forms of torture or ill-treatment because sex and gender bias commonly underlie such violations ...the purpose element is always fulfilled when it comes to gender-specific violence against women, in that such violence is inherently discriminatory and one of the possible purposes enumerated in the Convention [in defining torture] is discrimination."*²¹

Pregnancy is a health condition that can only be experienced by people with uteruses, and discriminatory treatment based on pregnancy is well established in law as discrimination based on sex. In order for health services to be equally accessible, available and effective without such discrimination, health-care providers must take into account the special needs of women in pregnancy. When such needs are not addressed, there is a legitimate concern that women in pregnancy experience discrimination. The Committee on the Elimination of Discrimination against Women ("CEDAW Committee") emphasizes that "[m]easures to eliminate discrimination against women are considered to be inappropriate if a health care system lacks services to prevent, detect and treat illnesses specific to women."²²

When services concerning pregnancy are not designed to meet the specific needs of women who use drugs, including drug-dependent women, there are legitimate concerns about the government's ability to fulfill its obligations under the Convention on the Elimination of All Forms of Discrimination against Women ("CEDAW Convention"). In particular this is the case where there are no medical protocols related to pregnancy that address drug dependence and no medical protocols related to drug dependence treatment to address the issue of pregnancy (e.g., where OST, the most effective and evidence-based treatment for drug-dependent women during pregnancy, is legally banned or effectively inaccessible; where the state promotes stigmatizing policies towards

¹⁹ Supra note 13 para. 18.

²⁰ Treatment or Torture? Applying International Human Rights Standards to Drug Detention Centers. Open Society Foundations. (2011). Page 11

²¹ Supra note 13 para. 37.

²² CEDAW Comm., *General Recommendation No. 24*, 1999. at para. 11 (1992).

people who use drugs; and where there is a lack of training for medical practitioners regarding the special needs and health-care services for women whose pregnancy is complicated by such health conditions as drug-dependence, HIV, and hepatitis C).

According to the CEDAW Committee, the definition of discrimination provided in the CEDAW Convention includes gender-based violence (i.e., violence that is directed against a woman because she is a woman or that affects women disproportionately, including acts that inflict physical, mental or sexual harm or suffering). Gender-based violence may breach specific provisions of the CEDAW Convention, regardless of whether those provisions expressly mention violence.²³

The U.N. Special Rapporteur on violence against women, its causes and consequences (“SRVAW”) has identified two broad categories of violence against women: interpersonal and institutional (or structural), with synergies and links between them.²⁴ According to the SRVAW, the term “institutional violence” includes laws and policies that maintain one group’s advantage over another in access to government services and benefits, as well as societal beliefs that claim one group of people is superior to another.²⁵

When it comes to pregnant women with drug dependence, repressive and stigmatizing drug policies, in particular those underpinned by a “zero tolerance” policy towards drug use and people who use drugs, are the main causes for this violence. Such policies institutionalize stigma and discrimination against people who use drugs, and allow violence against them to flourish. Among the most vulnerable members of this group are pregnant women with drug dependence, including due to an extra special stigma against women who use drugs as being bad mothers if they become pregnant or if they have children. This stigma prevents health care providers and public health officials from recognizing the special vulnerability of pregnant woman with a history of drug use, and from providing them with appropriate health care, especially when these women wish to maintain their pregnancy and do not want to undergo abortion.

In settings where there are legal prohibitions or other barriers to the use of methadone and buprenorphine for drug dependence treatment, and the absence of protocols for medical care, these can be considered additional strong causes of structural violence. Due to inaccessibility of OST in such settings, health care providers have no options for maintenance therapy and therefore often press drug-dependent pregnant women toward abortion. The lack of protocols for medical care also contributes to structural violence by leaving medical practitioners ill-equipped to provide women with appropriate care, in addition to conscripting them, even unwillingly, into withholding medically-indicated treatment.

Arguably among the consequences of the legal barriers to OST, the “zero tolerance” policy towards drug use and drugs users, as well as the lack of training of medical practitioners, are cases where medical doctors deliberately or negligently provide pregnant women with misleading health-related information. Where the direct or indirect intent in providing such misinformation is to coerce drug-dependent pregnant women into abortion against their will, the acts of a medical practitioner can be seen as a form of gender-based structural violence.

²³ CEDAW Comm., *General Recommendation No. 19*, 1992. at para. 6 (1992).

²⁴ U.N. Special Rapporteur on Violence Against Women, its Causes and Consequences, 2011 *Report*, A/HRC/17/26, at para. 24 (2011).

²⁵ *Id.* at para. 27, 28.

The U.N. Special Rapporteur against torture includes the right to informed consent in the contextual analysis of torture and other forms of ill-treatment in health-care settings.²⁶ According to the Committee on Economic, Social and Cultural Rights (“CESCR”), access to information related to reproductive health is one of the underlying determinants of the right to health,²⁷ and CESCR lists the withholding or the intentional misrepresentation of health-related information among the violations of that right.²⁸ According to the Special Rapporteur on the right to health, “guaranteeing informed consent is a fundamental feature of respecting an individual’s autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services.”²⁹ The U.N. Special Rapporteur on the right to health emphasizes that due to stigma and discrimination, women from marginalized communities are particularly vulnerable to violations of the right to informed consent.³⁰

In the case of *Szijjarto v Hungary*,³¹ the CEDAW Committee held that the failure to ensure that a pregnant woman was able to make an informed choice before signing her consent for a sterilization procedure amounted to a violation of Article 12 of the CEDAW Convention.³² Pregnant women with a history of drug dependence could be in situations similar to *Szijjarto* where they are provided with misleading information, in particular the erroneous opinion that because of their history of drug use and frequent co-morbidities (HIV and hepatitis C) they cannot expect to have healthy babies, and are therefore pressured into aborting.

Moreover, in countries where there is no access to essential maintenance treatment such as OST for pregnant women with drug dependence, the consent of pregnant women is, *a priori*, not completely informed due to incomplete information and an incomplete list of choices to support their pregnancy with the best available evidence-based medical care.

Positive Obligation to Prevent Acts of Ill-Treatment of Drug-Dependent Pregnant Women

According to the UN Convention against Torture, the protection of marginalized individuals or populations especially at risk of torture is a part of the obligation to prevent torture or ill-treatment.³³ Health status is specifically mentioned by the Committee against Torture as one of the possible reasons for discrimination in the context of torture.³⁴ According to the European Court of Human Rights, vulnerable individuals, in particular, are entitled to state protection against such serious breaches of personal integrity as torture and inhuman or degrading treatment.³⁵ Both drug dependence and the condition of pregnancy make women especially vulnerable to gender-based structural violence and discriminatory ill-treatment. Thus, in respect of this vulnerability, states

²⁶ U.N. Special Rapporteur On Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2013 Report, A/HRC/22/53, at paras. 27-30 (2013).

²⁷ Comm. on Economic, Social, and Cultural Rights [hereinafter *CESCR 2000*], *General Comments No. 14*, E/C.12/2000/4, at para. 11 (2000).

²⁸ *Id.* at para. 50.

²⁹ *Id.* at para. 18.

³⁰ U.N. Special Rapporteur On The Right Of Everyone To The Enjoyment Of The Highest Attainable Standard Of Physical And Mental Health, 2009 Report, A/64/272, at para. 55 (August 10, 2009).

³¹ Comm. on the Elimination of Discrimination Against Women, *Szijjarto v Hungary*, Communication No. 4/2004, U.N. Doc. A/61/38, at 366 (2006).

³² Comm. on the Elimination of Discrimination Against Women, *Communication No.4/2004*, CEDAW/C/36/D/4/2004 (2006) http://www2.ohchr.org/english/law/docs/Case4_2004.pdf.

³³ Comm. Against Torture, *General Comments*, No 2. CAT/C/GC/2, at para. 21 (2008).

³⁴ *Id.*

³⁵ *A. v. the United Kingdom*, Eur. Ct. H.R., No 100/1997/884/1096, at § 223 (1998).

have a special positive obligation to take all reasonable steps to ensure that pregnant women who use drugs are protected from ill-treatment, including by way of ensuring comprehensive prenatal care. In the context of ill-treatment in health-care settings, states should follow the guidelines given by the CESCR with regards to states' positive obligation to fulfill the right to health. The CESCR lists as a core obligation under the right to health the state's obligation "to provide essential drugs, as from time to time defined under the World Health Organization [("WHO")] Action Program on Essential Drugs."³⁶ Both methadone and buprenorphine are in the WHO list of essential medicines for treatment of drug dependence³⁷ and WHO recommends methadone substitution treatment as a standard of care for drug-dependent pregnant women.³⁸ As obligations of comparable priority, the CESCR includes obligations "to ensure reproductive, maternal (pre-natal as well as post-natal) and child health care," and "to provide appropriate training for health personnel, including education on health and human rights."³⁹ As core principles closely related to the right to non-discrimination, these obligations should be considered as "obligations of immediate effect."⁴⁰

Conclusion

As demonstrated above, poor access to comprehensive prenatal care for women with drug dependence, including lack of access to opiate substitution treatment, and deliberate misinformation from health-care providers, could be categorized as ill-treatment in violation of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Falling under the category of ill-treatment in health-care settings, these violations should be prevented by states through adherence to the guidance of the Committee on Economic, Social and Cultural Rights, specifically the states' core obligations to fulfill the right to health. In order to ensure that the fulfillment of these obligations has an immediate effect with the best possible outcome, states should pay particular attention to appropriate WHO recommendations and clinical protocols, including those related to prenatal care, opioid substitution therapy, and the prevention of mother-to-child HIV transmission. Particular attention should be given to the seriousness of these violations when states design and deliver training for health-care professionals.

³⁶ CESCR 2000, *supra* note 28, at para. 43(d).

³⁷ World Health Organization, *WHO Model List of Essential Medicines*: 17th list, at para. 24.5 (2011), http://whqlibdoc.who.int/hq/2011/a95053_eng.pdf.

³⁸ WHO Clinical Protocol, *supra* note 6, at 376.

³⁹ CESCR 2000, *supra* note 28, at para. 44(a,e).

⁴⁰ *Id.* at para. 30.

Consent Signed with Invisible Ink: Sterilization of Trans* People and Legal Gender Recognition

MICAH GRZYWNOWICZ*

Abstract

Forced sterilization against stigmatized groups, bodies, and identities has been commonly used by state actors as a form of social control. International human rights jurisprudence has rightfully condemned these practices against women, Roma women and women with disabilities in particular.

Trans people are also routinely subjected to this abusive practice as it is commonly set as a requirement if one wants to change their legal gender. Most Council of Europe member states, and several countries worldwide, make sterilization mandatory; this ignores the will and preferences of trans* people, many of whom wish to opt-out from surgically altering their bodies.*

In 2013 Mr. Juan E. Mendez, U.N. Special Rapporteur on Torture published a thematic report on forms of torture, cruel, inhuman, and degrading treatment or punishment in health care settings and called on states to immediately abolish the forced sterilization of trans people worldwide. Although a number of domestic courts and international human rights actors have recognized the practice as a human rights violation, the report marks a milestone in acknowledging that it amounts to torture and ill-treatment. The right to be free from torture and ill-treatment is an absolute right—therefore, states have no option to suspend or restrict them in any way.*

It is now upon international human rights bodies, as well as states, to take note of the Special Rapporteur's recommendations and implement them on the ground in order to take a stand against this abusive practice affecting trans people globally.*

Micah Grzywnowicz is a trans activist and human rights expert focused on issues of sexual orientation and gender identity and works to advance the rights of trans* persons globally. Grzywnowicz has worked at the Office of the Commissioner for Human Rights of the Council of Europe assisting in publication of the report *Discrimination of Grounds of Sexual Orientation and Gender Identity in Europe*. Contact: Johannesgatan 10, 111 38 Stockholm, Sweden. micah.grzywnowicz@gmail.com

Introduction

The statement, “trans*¹ people are being legally sterilized around the world,” is usually met with shock and disbelief. The procedure, now recognized in international human rights jurisprudence as constituting torture, cruel, inhuman or degrading treatment or punishment,² is still applied to trans* people worldwide as one of the requirements for obtaining legal gender recognition. Even though the coercive and irreversible nature of the procedure results in profound physical and psychological effects, the procedure seems to be accepted and states turn a blind eye or actively support human rights violations against this group. Throughout history, forced sterilization has been used against several marginalized groups; however, little attention has been directed at trans* persons in international torture prevention jurisprudence. This article contributes to filling this gap by outlining how forced sterilization has been applied against trans* people worldwide and examining the potential of the groundbreaking 2013 report of Mr. Juan E. Méndez, the U.N. Special Rapporteur on Torture in changing the situation on the ground.³ The report is a turning point in the discourse around forced sterilization of trans* people—for the first time, a U.N. body has recognized it as a form of torture, cruel, inhuman or degrading treatment or punishment. The burden shifts onto states now to prevent such human rights violation of trans* people. No excuses can be made as the right to be free from torture is an absolute right.

Trans* People and Law

Trans* people have a gender identity that is different from the sex assigned to them at birth. They also wish, choose, or prefer to express their gender identity in a different way than expected by the societal norms, which are based on their biological sex.

Some trans* people, usually identifying as transsexual, wish to surgically alter their bodies to live and be perceived as the sex opposite to the one assigned to them at birth. Some wish to fully transition and go through “gender reassignment therapy,” composed of several different elements including hormonal treatment, psychiatric assessment and diagnosis of “transsexualism,” and various surgeries aiming at altering the body to match that of “the opposite sex” both on the outside and inside. This includes hysterectomy⁴ and mastectomy⁵ for transgender men, and vaginoplasty⁶ and breast augmentation for transgender women. Other trans* people would like to be able to choose only some elements of the treatment, and not forcibly undergo all of them against their

¹ Trans* will be used by the author throughout the article as an umbrella term to be inclusive of a wide spectrum of gender identities.

² Convention to Eliminate All Forms of Discrimination Against Women [CEDAW], *Violence Against Women*, para. 22, General Recommendation No. 19 (1992); U.N. Office of the High Comm’r on Human Rights [OHCHR], *Equality of rights between men and women*, General Comment No. 28 (2000); OHCHR, Concluding Observations on Slovakia, para. 12, CCPR/CO/78/SVK (2003); Concluding Observations on Slovakia, para. 13, CCPR/C/SVK/CO/3 (2011); OHCHR, Concluding Observations on Japan, para. 31 CCPR/C/79/Add.102 (1998); OHCHR, Concluding Observations on Peru, para. 21, CCPR/CO/70/PER (2000); OHCHR, Concluding Observations on Czech Republic, para. 10, CCPR/C/CZE/CO/2 (2007); OHCHR, Concluding Observations on Switzerland, para. 20, CCPR/C/CHE/CO/3 (2009); *see also* U.N. Comm. against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment [UNCAT], Concluding Observations on Peru, para. 23, CAT/C/PER/CO/4 (2006); UNCAT, Concluding Observations on Slovakia, para. 14, CAT/C/SVK/CO/2 (2009); UNCAT, Concluding Observations on Czech Republic, para. 6, CAT/C/CR/32/2 (2004).

³ Special Rapporteur on Torture and Other Cruel, Inhumane or Degrading Treatment or Punishment, *2013 Report*, U.N. Doc. A/HRC/22/53 (by Juan E. Méndez).

⁴ Removal of ovaries.

⁵ Breast removal.

⁶ Penis removal and creating a vagina.

will—they may opt out of surgical procedures altogether. They may wish to only transition socially, which may include name change, changing clothing style, mannerism, etc. However, those who want to change their legal gender in their documents are in most countries today required to go through “gender reassignment treatment,” including surgeries that result in permanent sterility and irreversible changes to the body.

Out of 47 member states of the Council of Europe, 24 States forcibly require a sterilization procedure to recognize legal gender of trans* people.⁷ In the U.S., 20 states require a trans* person to undergo “gender-confirming surgery,” or “gender reassignment surgery,” before being able to change their gender marker in their documents.⁸ In Canada, nine out of ten provinces (with the exception of Ontario) enforce “transsexual surgery” in order to rectify the recorded sex on birth certificates.⁹

Forced sterilization is a form of social control that aims to fit trans* people into the gender binary and prevent them from reproducing. However, the practice is routinely disguised as medically necessary, and therefore, legitimate.

Medical Necessity

The sterilization of trans* people is not medically necessary as most recently affirmed by the Swedish Administrative Court that struck down the abusive practice in 2013.¹⁰ A loosely understood meaning of “medically necessary” would indicate the procedure is to either keep one as healthy as possible, or to detect and treat harmful condition, or to improve one’s health condition. In other words, “medically necessary” treatment should make one feel better but “[g]enital surgeries are not recommended: medical treatment for all transgender people.”¹¹

Forced sterilization practices however affect *all* trans* people, who want to change their gender identity and have this reflected in their legal documents, including those who do not wish to go through any surgeries, such as mastectomy or breast augmentation, or hormonal treatment. Being recognized as the preferred gender only by the means of going through a severe, forced, and irreversible intrusion into one’s own physical integrity amounts to torture, cruel, inhuman or degrading treatment or punishment. As one trans* person stated: “I know that there is no alternative. I will not manage any other way.”¹²

It is essential that trans* people who do want to undergo gender reassignment treatment have access to it. However, such a procedure must be carried out with the free and informed consent of the person concerned—for the well-being and fulfillment of trans* persons’ needs for their identities and bodies.

⁷ Media Release, Transgender Europe, 24 Countries in Europe Still Require Sterilization of Trans People, at http://www.tgeu.org/TGEU_Media_Release_IDAHOT_2013; TRANSGENDER EUROPE (June 10, 2013), http://www.tgeu.org/sites/default/files/Trans_Rights_Europe_Map_2013.pdf.

⁸ Dean Spade, *Documenting Gender*, 59 HASTINGS L. J. 731, 830-831 (2008).

⁹ XY v. Ontario (Government and Consumer Services), 2012 CanLII 01326-1 (Can. Ont. HRTO).

¹⁰ See *Kammarrätten i Stockholm* [Administrative Court of Appeals], Mål nr 1968-12, Avdelning 03, (Swed.), at http://du2.pentagonvillan.se/images/stories/Kammarrattens_dom_-_121219.pdf. (“The person needs to go through an extensive procedure, which results in sterilization, which is not medically necessary and often not wished by the person concerned”).

¹¹ Dean Spade, *Medicaid Policy & Gender Confirming Healthcare for Trans People: An Interview with Advocates*, 8 SEATTLE J. FOR SOC. JUST. 498 (2010).

¹² SIGNE BREMER, *KROPPSLINJER: KÖN, TRANSSEXUALISM OCH KROPP I BERÄTTELSE OM KÖNSKORRIGERING* [Lines of the Body: Gender, Transsexualism and Body in Stories of Gender Corrections] 192 (Micah Grzywnowicz trans., Gothenburg) (2011).

However, in most countries there is no option to freely make such a choice—one either takes the whole package, or is unable to change their legal gender.

Social Control

Forced sterilization is a form of social control against stigmatized bodies and identities. It has been common practice in many regions, the most known example being the eugenics program of the early 20th century that aimed to ensure only the “fit” and “productive” were a part of societies and others do not exist and/or reproduce. In the case of trans* people, it is a tool to forcibly fit people into a gender binary, despite their wishes to do so, and even at the cost of severe intrusions into their physical integrity.

Its purpose is also to deprive trans* people from their reproductive rights, as it has been the case against other excluded groups, such as Roma women and women with disabilities in many countries globally. Trans* people are often barred to freeze their sperm or eggs before undergoing forced sterilization, and are thereby stripped from yet another option of ever having their biological children. Such a restriction implies that it is not in the best interest of a child to have trans* parents—an argument used for other marginalized groups, such as LGBTQ persons or women with disabilities.

The practice is based on the false presumption that trans* people are by definition heterosexual after they transition. For instance, a transgender man, who was assigned female at birth, is presumed to be attracted to women only and therefore not needing his reproductive organs. Trans* people however can have any sexual orientation.

Law as Violence

The practice of sterilization creates paradoxical situations where trans* people apply “voluntarily” for a grave human rights violation, i.e. to be forcibly altered in their bodies and prevented to reproduce, in order to obtain their new legal gender marker. It is well described by a trans* person from Sweden:

It's been five months since I signed the application documents to be sterilized, castrated and get my legal gender changed to male, but when I came to RR (Legislative Council), I had not recovered yet after my top surgery (mastectomy) which I had almost two months ago ... And now I was there to be thrown into yet another surgery tangle. I have applied for it myself, of course. In order to have it over with. Because the law requires it.¹³

The forced sterilization requirement can be seen as a legalized violence against a specific group of people, who challenge normative binary gender system. Even though, such arguments have never been expressed openly in favor of the law, a violence-oriented interpretation is hard to avoid, especially if taken from a human rights perspective.

Putting words like “law” and “violence” next to each other in an expression indicating that the violence is a result of the existing laws creates a sense of a paradox and insecurity.

This violence emerges from a profound desire to keep the order of binary gender natural or necessary, to make of it a structure, either natural or cultural, or both, that no human can oppose, and still remain human. If a person opposes norms of binary gender not just by having a critical point of view about them, but by incorporating norms critically, and that stylized opposition is legible, then it seems that

¹³ *Id.* at 193-194 (emphasis added).

*violence emerges precisely as the demand to undo that legibility, to question its possibility, re render it unreal and impossible in the face of its appearance to the contrary...To counter that embodied opposition by violence is to say, effectively, that this body, this challenge to an accepted version of the world is and shall be unthinkable.*¹⁴

The forced sterilization of trans* people is a violation of the right to be free from torture, cruel, inhuman, or degrading treatment, but it also leads to a number of other human rights being undermined. These include the right to physical and mental integrity; the right to respect for private and family life; the right to be free from discrimination and; the right to health, including and in particular, sexual and reproductive health.

Free Consent and Impact on Trans* People's Health

Free and informed consent would take place if there was a range of choices that trans* people could make when it comes to their individual transition path. There are opinions that trans* people consciously agree to the procedures and they are not forced by anyone—it is them who made a decision on being trans* and going through gender reassignment. It is trans* people signing the consent forms to start the necessary process in order to have their preferred legal gender approved by authorities. “A common feature of most gender recognition procedures is the combination of legal and medical requirements, (...) the borderlines of which are often blurred. Lengthy processes of psychological, psychiatric, and physical tests are characteristic features of such procedures.”¹⁵ As a result, often trans* people do not enter the official procedures at all and they choose to self-medicate using illegally purchased hormones or injecting illegal industrial silicone. This exposes them to serious health risks¹⁶ and leaves them without safe and proper access to health care, which has serious impact on other spheres of their life. Such persons will often be socially perceived as belonging to the “opposite sex,” but this will not be reflected in their legal documents. This means that they are forced to live in a legal limbo, where their body and documents do not match, exposing them to harassment, and difficulties in accessing basic services, such as education, transportation, and health care.

*It is up to the judge to decide whether a first name is appropriate. In my case, this particular judge decided that for me it was inappropriate to have a male first name, because in the eyes of the law I'm still female. I can't change my registered gender because I don't yet meet the infertility requirement, and I can't change my name because I can't change my registered gender. These judges thus accord primacy to people's registered gender, ignoring the social reality of the people in question, and their own expressly stated wish to adopt a forename that is appropriate for their gender identity. In this way, judges make forename changes for trans people conditional on SRS [(sex reassignment surgery)] and infertility, requirements that are not in fact provided by law.*¹⁷

Choices made in these procedures cannot be considered of free consent. Persons who are forced to choose between receiving documents reflecting their gender identity or having their physical

¹⁴ JUDITH BUTLER, UNDOING GENDER 35 (2004).

¹⁵ Council of Europe Comm. For Human Rights, *Issue Paper on Human Rights and Gender Identity*, CommDH/IssuePaper(2009)2, p. 16.

¹⁶ See *Health Impact of Adulterated Silicone on Transgender Health: Call for Education and Awareness about Adulterated Injection Silicone Use*, SOCIETY FOR PUB. HEALTH EDUC. 1 (Feb. 9, 2012), http://www.sophe.org/Sophe/PDF/transgender_policy_approved_letterhead.pdf (injecting industrial silicone may result in respiratory embolism, infections, scleroderma, toxic shock syndrome, granuloma, neuropathy, lymphadenopathy, rheumatic symptoms, severe autoimmune and connective tissue disorders, and death.).

¹⁷ HUMAN RIGHTS WATCH, CONTROLLING BODIES, DENYING IDENTITIES 6 (2011).

integrity violated by unnecessary, and unwanted procedures, are merely given a free choice. It is a system regulating how one is allowed to perform their gender, and what type of a body is allowed to follow that specific gender expression. According to a report prepared by the Human Rights Watch, it became clear that those individuals, living under jurisdictions requiring sterilization, would never be able to alter their legal documents, unless they follow all outlined regulations. It is crucial to realize that the consequences of it would last a lifetime.

A woman who did not want gender reassignment treatment, who had lost her own business once she started living as a woman, and who had then suffered countless indignities when applying for jobs said in April 2011: "I have even thought about having the operations after all, just to be done with all the crap. But if I come to regret the operations later on, I'll be deeply unhappy for the rest of my life."¹⁸

Under no circumstances such a process can be considered within the definition of free consent.

In order to put this issue into a specific context, one should think about cosmetic surgeries performed for cisgender¹⁹ individuals for so called "beauty reasons." For instance, cisgender women wanting breast augmentation surgeries are never questioned about the reasons for those procedures. They are never forced to undergo psychological tests, or are given a diagnosis of being mentally ill. When cisgender men suffer from a condition called gynecomastia, which results in breast tissue growing in "abnormal amounts,"²⁰ they are provided, without any additional tests or diagnosis, with chest reconstruction operations in order to create a masculine, flat chest. Moreover, reconstruction surgeries, for cisgender individuals, of breasts, penises, or testicles lost (due to illness or accident) are also performed without any further diagnosis. At the same time, no one questions those people's gender identity or gender markers in their legal documents, in case they choose not to go through those procedures. In that case, one could question: is a man who lost his testicles in an accident still a man? Or is a woman who lost her breasts due to cancer still a woman? The only difference between trans* and cisgender individuals is that trans* people seem to be challenging accepted gender norms, whereas cisgender persons seem to try to "fix" their bodies to fit those gender norms. Challenging gender norms is not met with acceptance and therefore the access to those procedures is safe-guarded and available to the privileged few. At the same time the extreme surgery of sterilization is only performed on trans* bodies to make sure they fit in "properly gendered body" norm, no matter what it takes. The strictly structured and controlled treatment of trans* people, their (un)ability to make decisions about their own bodies, and the right to self-determination illustrate absurdity of those procedures and how unjust the system is.

Sterilization as Torture, Cruel, Inhuman or Degrading Treatment or Punishment

The sterilization of women without their free and informed consent has been recognized in international human rights law as constituting torture, cruel, inhuman or degrading treatment or punishment, due to the coercive and irreversible nature of the procedure, which results in profound physical and psychological effects.²¹ The European Court of Human Rights has further rec-

¹⁸ HUMAN RIGHTS WATCH, CONTROLLING BODIES, DENYING IDENTITIES 7 (2011).

¹⁹ People whose gender identity and gender expression are conforming to that of the norm of the sex they were assigned at birth.

²⁰ Spade, *supra* note 11, at 501.

²¹ CEDAW, *Violence Against Women*, *supra* note 2, at para. 22; OHCHR, General Comment no 28, *supra* note 2; OHCHR, Observations on Slovakia, CCPR/CO/78/SVK, *supra* note 2 at para. 12; OHCHR, Observations on Slovakia, CCPR/C/SVK/CO/3, *supra* note 2 at para. 13; OHCHR, Observations on Japan, CCPR/C/79/

ognized the forced sterilization of Roma women as a violation under Article 3 of the Convention.²² Mr. Manfred Nowak, the previous U.N. Special Rapporteur on Torture, and Mr. Paul Hunt, former U.N. Special Rapporteur on Health, have expressly affirmed that the involuntary sterilization of women with disabilities, even if agreed by their legal guardians, constitutes torture, cruel, inhuman, or degrading treatment or punishment.²³ The U.N. Development Program's ("UNDP") Global Commission on HIV and the Law recommended, in its latest report, that the states must ensure that "transgender people are able to have their affirmed gender recognized in identification documents, without the need for prior medical procedures such as sterilization, sex reassignment surgery or hormonal treatment."²⁴

Not only have LGBTQI movements questioned forced sterilization against trans* people, but the practice has also been challenged by the Council of Europe, as well as domestic and international courts. The Commissioner for Human Rights of the Council of Europe, Mr. Nils Muižnieks stated in December 2012:

*It is my position that legal recognition of the preferred gender should not require infertility or compulsory medical treatment which may seriously impair the autonomy, health or well-being of the individuals concerned. Any requirement of a medical diagnosis should be reviewed with a view to eliminating obstacles to the effective enjoyment by transgender persons of their human rights, including the right to self-determination.*²⁵

Muižnieks' opinion fell well into the Council of Europe position on forced sterilization of trans* people expressed already in March 2010. The Committee of Ministers of the Council of Europe recommended to its 47 member states that, "requirements, including changes of a physical nature, for legal recognition of a gender reassignment should be reviewed in order to remove abusive elements." The Committee of Ministers stated that the member states should take appropriate measures "to guarantee the full recognition of a person's gender reassignment in all areas of life, in particular by making possible the change of name and gender in official documents in a quick, transparent and accessible way."²⁶

In February 2009, the Austrian Administrative High Court held that mandatory gender reassignment, as a condition for legal recognition of gender identity, was unlawful.²⁷ In January 2011, the Constitutional Court in Germany ruled that the gender reassignment surgery violated the right

Add.102, *supra* note 2 at para. 31(1998); OHCHR, Observations on Peru, *supra* note 2, at para. 21 (2000); OHCHR, Observations on Czech Republic, CCPR/C/CZE/CO/2, *supra* note 2 at para.10; OHCHR, Observations on Switzerland, CCPR/C/CHE/CO/3, *supra* note 2 at para. 20; *see also* UNCAT, Observations on Peru, *supra* note 2 at para. 23; UNCAT, Observations on Slovakia, *supra* note 2 at para. 14; UNCAT, Observations on Czech Republic, *supra* note 2 at para. 6.

²² *V.C. v. Slovakia*, Application No. 18968/07, Eur. Ct. H.R. para. 120 (2011); *I.G. and Others v. Slovakia*, Application no. 15966/04, Eur. Ct. H.R. para. 124, 126 (2012).

²³ Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 2008 Report, para. 38, U.N. Doc. A/63/175 (by Manfred Nowak); Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 2008 Report, paras. 9, 12, U.N. Doc. A/HRC/7/11/Add.1 by Paul Hunt).

²⁴ U.N. Development Program [UNDP], *HIV and Law: Risks, Rights and Health* 54 (2012).

²⁵ Council of Europe Comm. For Human Rights, Letter dated Dec. 06, 2012 from Nils Muižnieks addressed to Joan Burton, Minister for Social Protection of Ireland, CommDH (2012)37, (Dec. 06, 2012).

²⁶ *Recommendation of the Committee of Ministers to member states on measures to combat discrimination on grounds of sexual orientation or gender identity*, COM (2010) 5, at paras. 20-21 (Mar. 31, 2010).

²⁷ Verwaltungsgerichtshof [VfGH][Administrative High Court] February 27, 2009, No. 2008/17/0054, at Bundeskanzleramt Rechtsinformationssystem [BKA/RIS] http://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Vwgh&Dokumentnummer=JWT_2008170054_20090227X00.

to physical integrity and self-determination.²⁸ Most recently, on December 19, 2012 the Swedish Administrative Court ruled in a case where the applicant wanted to challenge the forced sterilization requirement before his transition that such a procedure is indeed not based on a voluntary basis. The Court established that “the requirement to intrude into someone’s physical integrity cannot be seen as voluntary,” i.e. of free consent.²⁹ The Court ruled that the forced sterilization of trans* people is a violation of their right to privacy and non-discrimination, and violates the European Convention on Human Rights. The Court also established that such procedures are not medically necessary. In all three mentioned countries, the court decisions resulted in changes to the law regulating legal gender recognition.

The World Professional Association for Transgender Health (“WPATH”) also addressed the issue of forced sterilization in 2010 stating, “no person should have to undergo surgery or accept sterilization as a condition of identity recognition. If a sex marker is required on an identity document, that marker could recognize the person’s lived gender, regardless of reproductive capacity.”³⁰

The Report of U.N. Special Rapporteur on Torture

The 2013 report of Mr. Juan Mendez a milestone for the rights of trans* people. Taking into account all previous statements made in regards to forced sterilization of trans* persons, the U.N. Special Rapporteur on Torture went one step further and called on all states to: repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances.³¹

This statement is ground-breaking for the rights of trans* people. It also has a potential of being a very strong tool for trans* advocates in the fight against forced sterilization requirement. The report is crucial because no court or human rights body has argued before that the practice against trans* people amounts to torture, cruel, inhuman or degrading treatment or punishment. The report recognized parallels between forced sterilization of trans* people and other vulnerable groups, such as Roma women or women with disabilities and it makes it explicit that such treatment can amount to ill-treatment and should be abolished. The position expressed by the U.N. Special Rapporteur on Torture should translate into stronger arguments used both in advocacy as well as court cases. The report emphasizes that a trans* person must have the right to decide over their own body and it is not the task of a state to force its citizens into bodies and identities they do now want.

²⁸ Press Release No. 7/2011, Bundesverfassungsgericht (BVerfG)[Federal Constitutional Court], Jan. 28, 2011, 1 BVerfGE3295/07(Ger.), at http://www.bundesverfassungsgericht.de/entscheidungen/rs20110111_1bvr329507.html.

²⁹ Mål nr 1968-12, Kammarrätten i Stockholm, Avdelning 03, http://du2.pentagonvillan.se/images/stories/Kammarrttens_dom_-_121219.pdf, page 4. “The Chamber’s assessment is that the sterilization requirement can no longer be justified with reference to today’s values [...], it is not based on a voluntary basis and that it is discriminatory in relation to the Group of transsexuals. The requirement is not therefore compatible with the prohibition of forced physical intervention in Chapter 2. para. 6 of the form of Government and articles 8 and 14 of the European Convention concerning the right to respect for private and family life and the prohibition of discrimination.”

³⁰ World Professional Association for Transgender Health [WPATH], Identity Recognition Statement (June 16, 2010), at http://www.wpath.org/publications_public_policy.cfm.

³¹ Special Rapporteur on Torture and Other Cruel, Inhumane or Degrading Treatment or Punishment, 2013 Report, para. 88, U.N. Doc. A/HRC/22/53 (by Juan E. Mendez).

This is one of the most important developments for the human rights of trans* people globally. It confirms that these are unjust procedures that violate an absolute right. It also acknowledges that trans* people worldwide are subjected to medical treatments and interventions that are performed without their consent.

What Next?

The Special Rapporteur has taken a pioneer role in taking a stand for the rights of trans* people worldwide. The report, however, is not legally binding and states are under no obligation to implement it. Yet, the report has already left its mark on the jurisprudence of the Council of Europe. The Rapporteur, Ms. Maury Pasquier, urged the Council of Europe member states to “revise their laws and policies to ensure that no one can be coerced into sterilization or castration in any way for any reason.”³² In her “Explanatory Memorandum”³³ to the 2013 report “Putting an end to coerced sterilizations and castrations”³⁴ to the Parliamentary Assembly, she cited Mr. Mendez’s report and reaffirmed the standard established by it. There is an urgent need for states to follow suit and promptly change existing laws regulating legal gender recognition. There is a serious need for political will and leadership as well as public discussion about trans* identities and education thereof. Documents, such as the thematic report of the U.N. Special Rapporteur, are tools, which could be used to educate policy and lawmakers, as well as advocates and trans* individuals themselves.

³² *Putting an End to Coerced Sterilisations and Castrations*, Explanatory Memorandum, EUR. PARL. DOC. 13215, para. 7.1 (2012)

³³ *Id.* at para. 50.

³⁴ *Id.*

When Healing and Comforting Hands Turn Hostile and Harmful: Homophobia and Transphobia in Health Care Centers

RAFAEL MAZIN*

Abstract

The social expectations about provision of health care are not limited to the mere administration of curative procedures and healing interventions. People need and want to be comforted and treated with compassion and respect during the difficult times of their own, or their dear one's disease and infirmity. Unfortunately, there are many circumstances that prevent providers from effectively responding to the demands for compassionate care. One of the barriers is the quest for increased productivity by the health sector that has led to certain degree of "dehumanization" of medical practice. Another form of dehumanization occurs when providers stigmatize and mistreat the members of certain groups or populations due to their ethnicity, race, age, sexual orientation or gender identity. This paper discusses some bad practices observed in the health sector that are based in the ignorance, prejudices, and disdain against homosexual and trans persons (homophobia and transphobia); analyzes the damaging effects on individual and community health and wellbeing and; proposes some general avenues for action to correct the situation.

Introduction: Not Caring for Persons is Bad Quality Care

As an art based on knowledge, medicine's ultimate purpose has always been, and still is, to alleviate distress, anxiety, pain and suffering and to console persons in need for care (or "patients") under any circumstances. The provision of comforting support and authentic compassionate words and touch¹ is an equally important social expectation placed on all members of health care teams, as is their taking the necessary steps to favor cure and healing of ailments and diseases. Doctors, nurses, psychologists, dentists, and social workers enjoy an elevated social regard because they are considered truly devoted to others' wellbeing. Successful providers base their practice on the commitment to try to understand the thoughts, needs, and emotions of their patients.² It is a well-documented fact that a warm and comforting interaction between providers and health care service users has a very pronounced effect in reducing distress, anxiety, suffering, and even levels of pain. This alleviating effect does not result from the administration of a sugar pill ("placebo effect") but from the sense of wellness related to the sense of connectedness and trust that causes

*Senior Advisor on HIV, STI and hepatitis; Pan American Health Organization, Regional Office of the World Health Organization (PAHO/WHO)

¹ Sadhu Charan Panda, *Medicine: Science or Art?*, 4 MENS SANA MONOGR. 127-138 (2006) available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3190445/>.

² Andrew Moscrop, *Empathy: A Lost Meaning?* 175 WESTERN J. OF MED. 59-60 (2001).

reduction in stress (“healing effect”). Thus, trust, and connectedness with providers seem to be essential elements in the processes of attaining, recovering, and maintaining health and wellness.

The evolution of scientific knowledge, use of evidence, and technological developments are contributing to greater efficacy in treatments conducive to cure and healing. It may also be transforming social interactions and shaping new personal needs, desires and aspirations in terms of health care. Yet, the need for sympathetic and warm interactions with trusted providers does not go, and will not go away, even in the most developed environments.

Scientific and technological progress should—in theory—permit a larger access to the benefits associated with biomedical discoveries and developments, and to augment the access to the highest attainable standards of health care for all. However, along with such developments there is a constant quest for maximum efficiency. There is hardly anything objectionable about an augmentation in productivity with lower investment of material resources in most areas of human labor. However, efficiency in processes intended to foster and restore health and wellness should never reach a level in which critical elements of the art of medicine (such as empathy),³ compassion, respect and “comforting, healing words, gestures and hands” are reduced to insignificant amounts or absolutely dispensed with.

The application of an industrial paradigm in which increased productivity becomes a goal in itself usually forces health systems to increase the number of persons seen per time unit. As a result, in many places the demand for increased efficiency in health care has limited the personal interaction between providers and users of services, or “patients,” and deviates the efforts of the former ones to mere removal of symptoms and complaints through quick, substandard and incomplete fixes. At the point in which the symptoms of a disease become more relevant than the persons in need of health care,⁴ the health care service becomes a space in which persons are being denied receipt of a warm and comforting treatment and, at the end, despoiled of their humanness. The service is more like a factory or a repair shop and the person is a “diseased machine (body).”

Members of the healthcare force who see “patients” as cases, diseases, or a hospital bed number instead of as real persons with feelings, emotions, and values, contribute to the dehumanization of medical practice. Dehumanization would serve the purposes of medicine if it was just a for-profit business and health care would be a mere industry. However, dehumanization of health care is at the end an aberrant, perverse concept if one stops to reflect on the principle enunciated at the beginning of this section: the ultimate purpose of medicine and public health is the relief of human suffering and pain and the improvement of the wellness of human communities. Modernization and efficiency should never mean lack of care for persons.

Insult to Injury: Dehumanization and the Destructive Four I's

If dehumanization of patients in the quest for efficiency is unacceptable, dehumanization resulting from prejudice, contempt, disdain and hatred is execrable and condemnable. Any person in distress or pain being denied of the “warm, comforting and healing touch” by any member of the health care workforce is also being mistreated. If on top of that, the “patient” is victimized by any

³ Andrew Moscrop, *Empathy: A Lost Meaning?* 175 WESTERN J. OF MED. 59-60 (2001); Elliot M Hirsch, *The Role of Empathy in Medicine: A Medical Student's Perspective*, 9 VIRTUAL MENTOR 423-427 (2007).

⁴ Paul Rousseau, *quoted in Has Medicine Lost Its Compassion and Humanism?*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/education-careers/graduate-medical-education/question-of-month/medicine-lost-compassion.page>.

member of the health care team, without any doubt, the ailing person is receiving an inhumane treatment comparable to torture. Indubitably, the presence of any of the Four Destructive I's (indifference, insult, indignity or injury) in health care services generate mistrust and disconnectedness which are not conducive to cure, healing and wellness, but rather to further distress and suffering. Moreover, if a person, in addition to her health condition has been stigmatized, bullied, discriminated against, or endured violence in her environment, any of the Four Destructive I's expressed or perpetrated by members of the health care team becomes an extra burden in her already heavy and difficult existence, and an aggravating factor in her already impoverished quality of life. In such a case, the providers, far from being providers of care, are causers of inexcusable harm.

Services users (patients) who belong to groups and populations on the fringes of society frequently have to face the stereotypes, unfounded fears, and prejudices of providers and other staff. Hostility, aggression, humiliation, and outright denial of attention are common outcomes of preconceptions that have to be endured by persons with mental illness,⁵ members of ethnic minorities and⁶ persons whose sexual orientation or gender identity do not conform with hegemonic heteronormativity nor with the predominant binary model of masculinity and femininity (lesbians, gay, bisexual or trans persons or *LGBT*).

A stereotype is harmful because it ascribes negative characteristics to members of certain groups and marks them with pernicious stigmatizing attributes. For example, the Roma People (traditionally referred to with derogatory terms such as "gypsies," "gitanos," or "tziganes") are described by prejudiced bigots in a stereotypical manner as "people prone to theft", "pickpockets by nature", "blackmailers", "dirty" or "plainly lazy."⁷ The stigma is accepted as "the real nature" of the stigmatized person or group by people from outside (the exogroup) and their attitudes and behaviors will be shaped by their biased and prejudiced misconceptions.⁸ Stigma devalues the human person and the mores and culture of the group to which she belongs and the devaluation becomes a disruptive element in the individual, family and community life of those who are stigmatized. The devaluation may reach a level in which the individual's social identity is spoiled and they are not seen anymore as human, but as animals or objects, and treated accordingly. When a person or a group is deprived of their humanness through stereotyping and stigmatization, the violation of their human rights becomes a harsh reality they have to face. Persons from Roma (or Romani) populations are rejected in health care services or receive substandard attention. Coerced sterilization has been among the most flagrant violations of Romani women's rights.⁹ Not only these persons are deprived of their right to decide about number and spacing of children but are treated literally as subhuman, as "cattle."

⁵ Aikaterini Arvaniti et al., *Health Service Staff's Attitudes Towards Patients With Mental Illness*, 44 *SOC. PSYCHIATRY AND PSYCHIATRIC EPIDEMIOLOGY* 658-665 (2009).

⁶ Elena Gorolova (from the Group of Roma Women Harmed by Sterilization), mentioned in Maja Siatovic Jovanovic et al., *Discrimination at its Worst: The State of Healthcare for Europe's Roma is Appalling*, EUROPEAN VOICE (June 6, 2013), <http://www.europeanvoice.com/article/2013/april/discrimination-at-its-worst/76889.aspx>.

⁷ *MP Publishes Inflammatory Article Against the Roma*, BULGARIAN HELSINKI COMMITTEE (May 22, 2003), <http://www.bghelsinki.org/en/news/bg/single/mp-publishes-inflammatory-article-against-the-roma/>.

⁸ Monica Biernat & John F. Dovidio, *Stigma and Stereotypes*, in *THE SOCIAL PSYCHOLOGY OF STIGMA* (Todd F. Heatherton et al. eds., 2000).

⁹ Elena Gorolova (from the Group of Roma Women Harmed by Sterilization), mentioned in Maja Siatovic Jovanovic et al., *Discrimination at its Worst: The State of Healthcare for Europe's Roma is Appalling*, EUROPEAN VOICE (June 6, 2013), <http://www.europeanvoice.com/article/2013/april/discrimination-at-its-worst/76889.aspx>.

Despite that idea that societies have moved towards being more pluralistic and tolerant, the fact of the matter is that like many ethnic minorities LGBT persons and communities continue facing prejudice and discrimination.¹⁰ In a study among HIV+ males 25% to 35% of gay men in the sample experienced anxiety and depression as a result of personal hardship related to their sexuality, rather than their serostatus.¹¹ Unfortunately, many health practitioners not only lack the necessary skills to provide the necessary support to these persons, but also have negative attitudes that contribute to worsen the overall sense of discomfort and suffering the depressed men endure.

In fact, for many LGBT—perhaps the majority—the experience of attending a health care service might be traumatic due to their fear of being refused, of having to openly talk about their sexuality to providers who are perceived as unsympathetic. Thus, many LGBT face harassment expressed as disqualifying slurs and remarks, or disdainful and contemptuous body language, as well as prejudiced attitudes and behaviors from one or more of the members of the health care force.

Indifference is a common homophobic/transphobic reaction of providers and other persons in health services (guards, receptions, lab technicians, pharmacists, etc.) before a LGBT person requiring care. Indifference may adopt various forms that include: very limited verbal and non-verbal communication, hesitation or delay in provision of essential care,¹² denial in the provision of comforting words and touch, refusal to admit the partners in the same space or to give her/him visitation rights and, finally, total and complete denial of attention.

Insult may occur in cases in which the provider feels disturbed by the sexual orientation or gender identity of the person being treated (“patient”).¹³ The provider or staff may start having a cold and distant interaction with the “patient,” use derogatory expressions to refer to her/his sexuality and to his/her partner’s. They may even confront the service users and lecture them trying to impose on them ideological and/or religious dogmas about their sexuality being “devious,” “abnormal,” “harmful,” or “sinful.”

Indignity is present whenever a patient is submitted to humiliating and degrading treatment because of her/his sexual orientation and/or gender identity. The service user can be humiliated in private or publicly, and make him/her feel deeply disqualified and put down. Some practitioners and other members of health care teams may infuse and/or increase a sense of shame and guilt in LGBT patients by expressing disapproval, repugnance, disdain, or rejection for the gender identity and sexuality of the latter. For many people who find a solace in religious beliefs to the hardship they have to deal with in intolerant environments, it can be disturbing to hear lectures on how “despicable” their sexuality or gender identity must be for a deity or superior force from a person, or team, who are supposed to give comfort and support. This is not only out of place in moments in which comfort and support is expected, but also a cruel behavior. If the notion of “spiritual health” (the status of wellness associated to sense of connection with the force or forces central to one’s beliefs that give sense, direction and meaning to the personal life project)¹⁴ was more extended, threatening persons about being rejected by the divinity or any higher forces would be considered malpractice of medicine because of potential damage to the “spiritual wellbeing” of the person. While the expressions of eternal doom uttered by fuss-making religious zealots (i.e., “God hates

¹⁰ Mark L. Hatzenbuehler et al., *The Impact of Institutional Discrimination on Psychiatric Disorders in Lesbian, Gay, and Bisexual Populations: A Prospective Study*, 100 AM. J. PUB. HEALTH 452-459 (2010).

¹¹ Linmin Mao et al., *Social Factors Associated With Major Depressive Disorder In Homosexually Active, Gay Men Attending General Practices In Urban Australia*. 33 AUSTL. N.Z. J. PUB. HEALTH 83-6 (2009).

¹² Martin Christensen, *Homophobia in Nursing: A Concept Analysis*, 40 NURSING FORUM 60-71 (2005).

¹³ Roxane Henrici, *Homophobia: Does It Affect the Quality of Care?* 1 THE J. OF UNDERGRAD. NURSING WRITING (2007).

¹⁴ Rafael Mazin, *Spiritual Health: A Concept That Requires Serious Attention* (unpublished).

homosexuals” or “gays will burn in hell”) may have little impact if any on resilient people, the same expressions said by a provider may have a devastating effect on a patient.

Injury can result from disregard for the person and lack of care in the provision of services, but can also be the result of intentional desire to cause harm out of cruelty and hatred. Forced sterilization has been reported as a “requisite” for Trans persons to initiate their transition into the other sex. There is personal report by a Trans man to the author that after one of his surgeries in the transition process he had the stitches removed in a rather blunt manner and without any analgesic medication so “he could learn what it means to be a real man.” LGBT person refer stories of being shoved, pushed down, slapped or submitted to painful procedures in a rather vicious manner. These very traumatic experiences may occur in any health care center, but they are particularly common in places in which the so-called “reparative therapies” are given to LGBT persons.

“Reparative *therapies*” or “conversion *treatments*” are interventions purported to change sexual orientation or gender identity of LGBT persons. No rigorous scientific studies demonstrate any efficacy of efforts to change sexual orientation. However, there are many testimonies about the severe harm to mental and physical health that such “services” can cause. Repression of sexual orientation has been associated with feelings of guilt and shame, depression, anxiety, and even suicide. The methods and approaches used by the “providers” of these “services” are very often brutal, abusive, and equivalent to torture. There have been a growing number of reports about degrading treatments, and physical and sexual harassment under the guise of such “therapies,” which are often provided illicitly. In some cases, adolescents have been subjected to such interventions involuntarily and even deprived of their liberty, sometimes kept in isolation for several months.¹⁵ This way of treating a human being is unacceptable under any circumstance.

Unwanted Outcomes: Physical, Emotional, Psychological and Community Damage

Very few physicians and other health care providers currently in practice have been introduced, during their formal education, to the particular situation and needs of LGBT patients.¹⁶ It is therefore no surprise that practitioners may experience discomfort with the unknown when meeting patients whose sexual orientation and/or gender identity/expression does not correspond with heterosexist norms or binary models. Furthermore, practitioners may have acquired misinformation or been raised in rigid, intolerant, and prone to stereotyping and stigmatizing environments, which may hamper their capacity of providing optimal care to LGBT patients. For many insecure, highly prejudiced or fearful members of health care teams, getting close to persons they have preconceived ideas about tends to be a very difficult experience. These staff members have a tendency to establish a “protective distance” and do not want, under any circumstance, to display any manifestations of social or emotional proximity. They may see the “transgressors” of their own vision of “right and wrong” as “morally tainted” and thus “dirty” (“filthy”), “contaminating” and “unworthy of human touch.” In so doing, they are disfiguring the essence of health care that is first, and foremost, to provide help and support rather than to make moral judgments about the character of the person in need. The most radical homophobic/transphobic staff may even refuse to admit the

¹⁵ “*Therapies*” to Change Sexual Orientation Lack Medical Justification and Threaten Health, PAN AMERICAN HEALTH ORGANIZATION (May 17, 2012), http://www.paho.org/hq/index.php?option=com_content&view=article&id=6803&Itemid=1.

¹⁶ Adalberto Campo-Arias & Edwin Herazo, *Homofobia En Estudiantes De Medicina: Una Revisión De Los Últimos Diez Años*, 11 MEDUNAB 120-123 (2008) (Colomb.).

person in the premises and use as a “justification” to their attitude a supposed “congruence with the moral principles” or “personal objection to *certain lifestyles*” or other similar explanations.

There is also the case of staff members who may not have any particular fear, prejudice or particular ideological posture that would limit their interactions with LGBT patients. However, the normative pressures in the environment force them to “align with the *moral majority*.” Even providers who are LGBT have to remain “hidden in the closet,” lest their gender and sexuality becomes a pretext for harassment, ostracism, and denial of opportunities for professional development by the “majority.”¹⁷

Out of fear or concern of homophobic/transphobic attitudes and practices in medical centers, members of the LGBT populations may not feel motivated to utilize health care services, or procrastinate attending them. The result has been largely documented: late diagnosis of conditions that could have been prevented or successfully treated if detected early. Delay in seeking professional help should never be caused by fear to face unsympathetic, hostile, or even aggressive providers. It is a paradox that professionals and services that should be perceived as safe and comforting havens for ailing or sick people and their dear ones turn into characters and places that are scary and even threatening.

Many members of LGBT populations may be becoming more resilient and therefore more assertive, even if they do not live in an accepting environment. For these persons the full integration of their identities and sexuality into their whole self becomes an affirmation of their sense of worth that further propels their quest for health, wellbeing, and ultimately happiness.

In contrast, persons who have personal reasons to hide their identity or sexual orientation most probably experience difficulties communicating with providers because of the fear that they need to disclose “very personal things” during the clinical interactions. As a result, they may end being treated as if they were heterosexuals who conform to the binary system of gender, and their real needs and demands would go unattended or poorly treated. If the provider happens to find out that the patient failed to communicate relevant details about her gender identity, sexual orientation, or practices, the provider may have a negative reaction to the “incomplete disclosure” and express anger, frustration, or frank hostility, instead of trying to understand the difficulties the patient has to “come out.” Some patients may be reluctant to have their sexuality recorded in their histories due to the fear that others may gain access to their records.

One of the most damaging reductionist and pervading stereotypes about LGBT persons is that their whole lives gravitate around sexual activity. Such an idea is present among health care providers too.¹⁸ LGBT persons, like any other human being, establish relationships, have attractions and desires, and fall in love with someone special to them. Like anyone else too, the experience of falling in love can be very intense. Also, ruptures can be very traumatic experiences and they have to endure love sorrows and unrequited love. Many times these experiences, whether joyful or sad, are lived in silence. Anxiety and depression may be present without opportunities to vent the need for emotional support given that LGBT persons feel that there is no competency in service to understand their specific situations. The distressed LGBT persons who have the courage to express their emotional health issues may end up treated for her gender identity, or sexual orientation, and not for the specific suffering or sorrow she is going through. Many health care services may claim

¹⁷ Mark Schuster, *On Being Gay in Medicine: A Leading Harvard Pediatrician's Story*, WBUR's COMMON HEALTH: REFORM AND REALITY (March 30, 2012), <http://commonhealth.wbur.org/2012/03/being-gay-in-medicine>.

¹⁸ Alan Sheard, *Personal View: Homophobia in Medicine*. 317 BRITISH MED. J. (1998).

they treat “everybody with the same standards,” but this usually means that they treat everyone according to the rigid models of the *status-quo*.

The right to provide “medical consent” or even visitation rights may be refused to same sex partners, which is a situation that generate further stress and suffering for both partners. The patient may remain socially isolated and without any connections with persons emotionally significant to her. For the partner who is denied the opportunity to be with her dear one, the situation generates unnecessary pain and suffering. The system intended to alleviate human pain and sorrows is creating new ones and intensifying the problems of two or more persons.

If health system demands “hard evidence” that homophobic/transphobic attitudes and practices in health care services are damaging, the data that needs to be collected and reported would be in the following areas:

- Deaths attributable to denial or delay in providing services to LGBT persons.
- Late diagnosis of preventable or treatable conditions associated to delay to attend a service for fear of being insulted, humiliated or abused.
- Abandonment by LGBT patients of health care services and treatments as a consequence of bad experiences with staff.
- Complaints about physical or sexual abuse consummated by health care services staff.
- Complaints about degrading or humiliating treatment by health services staff.
- Existence of any type of centers or providers who claim to “cure” non-heterosexual orientation or non-dyadic gender identities.
- Documented cases of vicious and premeditated harm or damage caused by members of the health team to any patient because of her sexual orientation or gender identity.
- Reports by family members and/or partners of LGBT patients of being treated in a humiliating, degrading, or aggressive manner, or of being denied the right to visit a LGBT hospitalized person.
- Reports by staff of health care centers of being harassed, bullied or mistreated because of their gender identity or sexual orientation.

Physical, emotional, and mental health issues of LGBT people do not need to be treated in special premises or with highly differentiated approaches; they just need treatment that is respectful, compassionate, considerate, warm, and effective. The treatment any human being deserves has as its main goal the removal of suffering and pain to enable her potential to enjoy physical, emotional, mental, social, and even spiritual wellness and happiness.

Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment

ANNE TAMAR-MATTIS*

Abstract

People worldwide born with intersex conditions, or variations of sex anatomy, face a wide range of violations to their sexual and reproductive rights, as well as the rights to bodily integrity and individual autonomy. Beginning in infancy, and continuing throughout childhood, children with intersex conditions are subject to irreversible sex assignment and involuntary genital normalizing surgery, sterilization, medical display and photography of the genitals, and medical experimentation. In adulthood, and sometimes in childhood, people with intersex conditions may also be denied necessary medical treatment. Moreover, intersex individuals suffer life-long physical and emotional injury as a result of such treatment. These human rights violations often involve tremendous physical and psychological pain and have been found to rise to the level of torture or cruel, inhumane, or degrading treatment. We offer recommendations for states working to address torture and inhuman treatment in medical settings.

Introduction

People worldwide born with intersex conditions, or variations of sex anatomy, face a wide range of violations to their sexual and reproductive rights, as well as the rights to bodily integrity and individual autonomy. Beginning in infancy and continuing throughout childhood, children with intersex conditions are subject to irreversible sex assignment and involuntary genital normalizing surgery, sterilization, medical display and photography of the genitals, and medical experimentation. In adulthood, and sometimes in childhood, people with intersex conditions may also be denied necessary medical treatment. Moreover, intersex individuals suffer life-long physical and emotional injury as a result of such treatment. These human rights violations often involve tremendous physical and psychological pain and have been found to rise to the level of torture or cruel, inhumane, or degrading treatment (“CIDT”).

* Anne Tamar-Mattis, JD, Executive Director, Advocates for Informed Choice, POB 676, Cotati, CA 94931, USA. Email: director@aiclegal.org. Thanks to Christina Winship, JD, for significant assistance in drafting. This report drew heavily on the Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment, by the Association of Intersexual People / XY Women and Humboldt Law Clinic: Human Rights, available at http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf.

This report focuses on the most egregious abuses affecting people with intersex conditions in medical settings, and on claims that can be readily documented in the medical literature or in official publications. The injuries suffered by intersex people worldwide have not been adequately documented, and additional research is needed in this area to document widespread anecdotal reports of additional harm stemming from torture or CIDT in medical treatment, as well as in other settings, and to summarize those reports that have been documented.

What are Intersex Conditions?

Intersex conditions, also called differences of sex development (“DSD”), have been defined by medical sources as congenital conditions that cause atypical development of chromosomal, gonadal and/or anatomical sex.¹ The terms “intersex” and “DSD” are umbrella terms for many different medical conditions, including androgen insensitivity syndrome, virilizing congenital adrenal hyperplasia (“CAH”), Klinefelter’s syndrome, Turner’s syndrome, hypospadias, bladder exstrophy, and many others. Many children born with intersex conditions have genitals that seem “ambiguous” to caregivers. Others have genitals that seem to be clearly male or clearly female, but are atypical in some way, such as a very large clitoris, a penis that is very small or has a urethra somewhere along the underside of the penis. Others have typical male or female genitals, but they may have atypical sex chromosomes or internal sex organs (such as testes inside the abdomen of a child with female genitals), and/or they may have atypical sex development at puberty.² The frequency of intersex births is not well-established, but common estimates are between one in 1,000 and one in 2,000 live births.³

Violations Experienced by People with Intersex Conditions in Health Care Settings

When a child is born with an intersex condition, parents and doctors alike are frequently unsettled by the child’s atypical genitals and the possibility of “gender uncertainty.” There is a great sense of urgency about making a quick gender assignment, despite the fact that from 8.5–20% (or more depending on the specific condition) of these children ultimately reject their gender assignment.⁴ Genital surgery is commonly performed in the first two years of life, often by six months.⁵ Removal of internal sex organs is also a common practice. Children with intersex conditions may have medical photographs taken of their genitals and may experience a large number of genital exams throughout childhood, which can be psychologically damaging.⁶ Because of their unique conditions, these children are often used as human research subjects, and concerns have been

¹ IA Hughes et al., *Consensus Statement on Management of Intersex Disorders*, 91 ARCHIVES OF DISEASE IN CHILDHOOD 554-63 (2006).

² Intersex Society of North America, *Intersex Conditions*, <http://www.isna.org/faq/conditions>, accessed Dec. 7, 2012. *Shifting the Paradigm of Intersex Treatment*, <http://www.isna.org/compare>, accessed September 27, 2012.

³ M Blackless et al., *How Sexually Dimorphic Are We? Review and Synthesis*, 12 Am. J. of Human Biology 151-166 (2000); C Phornphutkul, et al., *Gender Self-Reassignment in an XY Adolescent Female Born With Ambiguous Genitalia*, 106 PEDIATRICS 135 (2000).

⁴ K Karkazis, *FIXING SEX: INTERSEX, MEDICAL AUTHORITY, AND LIVED EXPERIENCE* (2008); IA Hughes et al., *supra* note 2; PS Furtado et al., *Gender Dysphoria Associated with Disorders of Sex Development*, NAT. REV. UROL. (2012).

⁵ S Creighton, et al., *Timing and Nature of Reconstructive Surgery for Disorders of Sex Development*, JOURNAL OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.001>; IA Hughes et al., *supra* note 1.

⁶ K Karkazis, A Kon & A Tamar-Mattis, *Shared Decision-Making and Children with DSD*, 23 J. of Pediatric Endocrinology and Metabolism 789-806 (2010); IA Hughes et al., *supra* note 1.

raised about whether standard human research protections have been consistently used. In adulthood, intersex people may have more difficulty accessing needed medical care, and there have been reports of denial of care for discriminatory reasons.

1. Irreversible Sex Assignment and Genital Normalizing Surgery

It is widely recognized that there is insufficient data on surgical and sexual outcomes to support any particular recommendation about the timing of genital surgery or to predict gender identity outcomes with confidence in many conditions.⁷ Nonetheless, doctors around the world continue to perform infant genitoplasty in children with intersex conditions. Genital surgery is not necessary for gender assignment, however, and atypical genitals are not in themselves a health issue.⁸

While there are a few situations where some surgery is necessary for medical reasons, such as to create an opening for urine to exit the body, most procedures commonly performed on children with intersex conditions are cosmetic, not necessary in childhood, and/or done for gender-related social reasons such as “to achieve an unobstructed, sex-typical manner for urination (i.e. standing for males).”⁹ Rationales often provided for such surgery for minors include reducing gender confusion for the child and parents; responding to parental concerns that the child be “normal” and accepted and promoting the child’s social integration and happiness.¹⁰ However, evidence that surgery provides these benefits is lacking.¹¹ No studies have linked early genital surgery to successful gender outcome.¹²

In addition to the usual risks of anesthesia and surgery in infancy, genital normalizing surgery carries a number of known risks of harm. Vaginoplasty, a procedure undertaken to create a vaginal opening or to elongate a vagina that is inadequate for sexual intercourse has many risks and complications, including scarring at the introitus and growth of abnormal tissue (“neoplasia”), necessitating repeated intervention.¹³ Regular vaginal dilation is often imposed on the child after vaginoplasty. The repeated forcing of a solid object into the vagina of a child has been described as extremely painful, highly traumatic, and comparable to sexual abuse in terms of the patient’s experience.¹⁴ Clitoral reduction is a cosmetic procedure used to reduce the size of a clitoris that is considered too large. It carries significant risk of loss or impairment of sexual function. “Adult women who have undergone clitoral surgery in infancy report reduced sexual sensation, and poorer sexual function, when compared to normal controls and also to women with clitoromegaly who had not undergone surgery.”¹⁵ Other risks of genital-normalizing surgery include scarring

⁷ P Lee, et al., *Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>; L-M Liao et al., *Determinant Factors of Gender Identity: A Commentary*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.09.009>.

⁸ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 1.

⁹ S Creighton, et al., *supra* note 5.

¹⁰ SURGICALLY SHAPING CHILDREN: TECHNOLOGY, ETHICS AND THE PURSUIT OF NORMALITY (E Parens, ed., 2006); K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6.

¹¹ S Creighton, et al., *supra* note 5; IA Hughes et al., *supra* note 1.

¹² S Creighton, et al., *supra* note 5; K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6.

¹³ IA Hughes et al., *supra* note 1.

¹⁴ T Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse*, Intersex Soc. of North Am. (1997), <http://www.isna.org/articles/analogue>; Association of Intersexual People, *Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment* (2011), http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf.

¹⁵ S Creighton, et al., *supra* note 5.

and incontinence.¹⁶ In one study, of “57 46XY DSD adults who had undergone genital surgery, 47.1% were dissatisfied with functional results, 47.4% with clitoral arousal and 37.5% with overall sex life; 44.2% had sexual anxieties, 70.6% had problems with desire and 56.3% reported dyspareunia [painful intercourse].”¹⁷

Many providers believe that surgical advances have reduced the risk of genital surgery, and that modern techniques may preserve sexual sensation.¹⁸ However, any cutting of the genitals carries the risk of harm and nerve damage.¹⁹ Furthermore, surgeons have been confidently announcing improvements in genital normalizing surgery for decades,²⁰ without producing meaningful long-term follow-up studies to demonstrate this success. In fact, there is still “much debate but little data on all aspects of clitoral surgery” including where and when it is safe to cut the clitoris and surrounding tissue, and what size and shape of genitals are acceptable.²¹

Psychological as well as physical harm can result from involuntary genital normalizing surgery. Patient advocacy groups around the world have called for an end to the practice of conducting these surgeries in early childhood²² and there have been numerous reports of patient dissatisfaction. One recent study of 50 pediatric patients concluded, “[t]he quality of life of pediatric patients with DSDs was impaired to varying degrees following reparative surgery.”²³ Another study found elevated rates of self-harming behavior and suicidal tendencies among intersex people comparable to those among women who have experienced physical or sexual abuse.²⁴ The trauma and psychological harm resulting from this practice has been compared to that of female genital mutilation (“FGM”) and childhood sexual abuse.²⁵

Furthermore, there are higher rates of gender dysphoria in intersex individuals than the general population.²⁶ As many as 20% of children with intersex conditions may be forced to undergo irreversible genital surgeries in order to achieve a gendered appearance that ends up being inconsistent with their gender identity. Gender dysphoria has been related to behavioral and emotional problems, with a potential link to increased risk of suicide.²⁷

In spite of these risks, genital normalizing surgery remains widespread around the world for children with intersex conditions. In 2009, for example, the United States’ federally-sponsored KIDS Inpatient Database reported 680 hypospadias repairs and 59 instances of “Operations on clitoris, amputation of clitoris, clitoridotomy, [or] female circumcision.”²⁸ In regions with less access

¹⁶ P Lee, et al., *supra* note 7.

¹⁷ J Yang & D Poppas, *Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability*, 178 J. OF UROLOGY 1598-1601 (2007).

¹⁸ S Creighton, et al., *supra* note 5.

¹⁹ SJ Kogan, et al., *Subtunic Total Reduction Clitoroplasty: A Safe Modification of Existing Techniques*, 130 J. UROLOGY (1983); P Mollard et al., *Clitoroplasty In intersex: A New Technique*, 53 BRITISH J. UROL (1981).

²⁰ S Creighton, et al., *supra* note 6; P Lee, et al., *supra* note 7.

²¹ K Karkazis, *supra* note 4.

²² D Zhu et al., *Quality Of Life Evaluation In Juveniles With Disorders Of Sexual Development*, 28 PEDIATRIC SURG INT’L 1119-23.(2012); S Creighton, et al., *supra* note 5.

²³ Schützmann et al., *Psychological Distress, Suicidal Tendencies, and Self-Harming Behaviour in Adult Persons with Different Forms of Intersexuality*, 38 ARCH SEX BEHAV. 16-33 (2009).

²⁴ Alexander, *supra* note 14; N Ehrenreich, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of “Cultural Practices,”* 40 HARV. C.R.—C.L. L. REV. 71 (2005).

²⁵ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6; PS Furtado et al., *Gender Dysphoria Associated with Disorders of Sex Development*, NAT. REV. UROL. (2012);

²⁶ PS Furtado et al., *supra* note 25.

²⁷ *KIDS Inpatient Database*, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY: UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES, <http://hcupnet.ahrq.gov/> (These reported numbers do not include all US hospitals.)

²⁸ OD Osifo & TI Amusan, *Female Children with Ambiguous Genitalia in Awareness-Poor Subregion*, 13 African Journal of Reproductive Health 130 (2009).

to up-to-date medical treatment, genital normalizing surgery is still practiced, although it may not be provided until a later age if discovery or diagnosis is delayed. In such cases, physician-imposed gender reassignment at a late age has been reported.²⁹

Some specialists have claimed that those who protest their involuntary genital-normalizing surgery are in the minority, and that there is a “silent majority” of patients who are glad of the treatment they received. However, not one such person has ever come forward publicly despite investigations by ethics committees, human rights bodies, and media around the world. The limited follow-up studies that do exist continue to demonstrate high rates of gender dissatisfaction, sexual dysfunction, and surgical complication among patients who have had involuntary childhood genital-normalizing surgery. Even fewer studies exist of intersex people who have not had genital-normalizing surgery, and no studies have demonstrated that growing up with atypical genitals causes any harm.

Genital normalizing surgery may be done with or without the consent of parents and without taking into consideration the views of the children involved.³⁰ Misinformation and directive counseling frequently prevent parents from learning about options for postponing permanent interventions.³¹ Parents often consent to surgery on their children in circumstances where full information is lacking; pressure may be applied by clinicians; or parents themselves may feel discomfort with their child’s bodily difference.³² Further, ethical and human rights standards dictate that the child’s interests, not parents’, must be the primary consideration in decisions regarding major invasive medical procedures. Postponing surgery until a child is sufficiently mature to make an informed decision has been recommended to ensure the child could participate in decision-making and consent.³³ However, this recommendation has not been widely implemented.

2. Involuntary Sterilization and Gonadectomy

People with intersex conditions may be subjected to involuntary sex-assignment treatments as infants or during childhood that, in some cases, terminate or permanently reduce their reproductive capacity. While some intersex people are born infertile, and some retain their fertility after medical treatment, many undergo removal of viable gonads or other internal and external reproductive organs,³⁴ leaving them with permanent, irreversible infertility and causing severe mental suffering.

²⁹ A Wisniewski & T Mazur, 46, *XY DSD with Female or Ambiguous External Genitalia at Birth Due to Androgen Insensitivity Syndrome, 5-Reductase-2 Deficiency, or 17-Hydroxysteroid Dehydrogenase Deficiency: A Review of Quality of Life Outcomes*. INT’L J. OF PEDIATRIC ENDOCRINOLOGY (2009); High Commissioner for Human Rights, *Annual Report to the UN General Assembly: Discriminatory Laws and Practices and Acts of Violence Against Individuals Based on their Sexual Orientation and Gender Identity* (2011).

³⁰ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6.

³¹ K Karkazis, *supra* note 4; C Murphy et al., *Ambiguous Genitalia in the Newborn: An Overview and Teaching Tool*, 24 J. PEDIATR ADOLESCENT GYNECOL 236-250 (2011).

³² NS Crouch & SM Creighton, *Long-Term Functional Outcomes In Female Genital Reconstruction In Childhood*, 100 BJU INT’L 403-7 (2007); C Murphy et al., *supra* note 31; Swiss National Advisory Commission on Biomedical Ethics, *On the Management of Differences of Sex Development: Ethical Issues Relating to “Intersexuality,”* Opinion No. 20/2012 (2012); Intersex Society of North America. *Intersex Conditions*, <http://www.isna.org/faq/conditions>, accessed Dec. 7, 2012. *Shifting the Paradigm of Intersex Treatment*, <http://www.isna.org/compare>, accessed September 27, 2012; European Commission, Directorate-General for Justice, *Trans and Intersex people, Discrimination on the Grounds of Sex, Gender Identity, and Gender Expression* (2012).

³³ A Wisniewski & T Mazur, *supra* note 29; IA Hughes et al., *supra* note 1.

³⁴ IA Hughes et al., *supra* note 1.

Medical procedures which might result in sterility have sometimes been rationalized by the reduction of cancer risk.³⁵ Such treatments are often recommended, however, on the basis of weak evidence and insufficient justification.³⁶ When sterilizing procedures are imposed on children to address a low or hypothetical risk of cancer, the fertility of intersex people is not being valued as highly as that of non-intersex people.³⁷

Other rationales for gonadectomy are that it will prevent emergence of undesired (to caregivers) secondary sex characteristics, such as facial hair, or that there will be an unspecified “psychological benefit” to removing structures discordant with sex assignment.³⁸ Such justifications are discriminatory because they would never prompt a procedure that would lead to sterilization in a non-intersex child. Furthermore, where the prevention of undesired secondary sex characteristics is the goal of gonadectomy, the procedure could be postponed until puberty, at which time the child can have input and it will be clearer whether or not the characteristics are indeed undesired by the patient. If retention of potential fertility causes distressing cross-sex changes at puberty, puberty-suppressing agents are a viable option.³⁹

Many doctors also do not see sterilizing surgeries as sterilization if the child would not have been fertile in the mode expected for the assigned gender. For example, one published article says: “At the present time fertility is challenging, but not impossible, for individuals with PAIS raised male. In contrast, fertility is not possible for individuals raised female.”⁴⁰ PAIS is a condition in which the child has ambiguous genitals, and has testes that are often functional. There is still controversy and uncertainty about gender assignment in these cases, and it can go either way, depending largely on the doctor’s judgment.⁴¹ However, clearly the fertility does not depend on whether the child is raised as a boy or a girl. The authors quoted see fertility as impossible for a child with PAIS raised as female because they assume that raising her as female will include removing her testes. This concept is so entrenched in the medical literature as to go unspoken.

The impact that involuntary sterilization has on the physical health and psychological and social well-being of those individuals who are subject to such violations has been widely recognized. Gonadectomy also causes the end of natural hormone production, which prevents the body from changing the way it naturally would have during puberty. Life-long hormone replacement therapy is required for those who have been gonadectomized.⁴²

3. Medical Display, Genital Photography, and Excessive Genital Exams

In addition to the physical and emotional problems that can be caused by surgical intervention, many intersex individuals suffer lasting psychological effects as a result of repeated genital examinations in childhood. “Repeated examination of the genitalia, including medical photography, may be experienced as deeply shaming. ... Medical interventions and negative sexual experiences

³⁵ M Cools et al., *Germ Cell Tumors In The Intersex Gonad: Old Paths, New Directions, Moving Frontiers*, 27 *Endocrine Reviews* 468–484 (2006); A Tamar-Mattis, *Sterilization and Minors with Intersex Conditions in California Law*, 3 *CAL. L. REV. CIRCUIT* 126-135 (2012); K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6; GA Hauser, *Testicular Feminization*, in *Intersexuality* 255-276 (C Overzier ed., 1966).

³⁶ A Tamar-Mattis, *supra* note 35.

³⁷ C Murphy et al., *supra* note 31;

³⁸ PT Cohen-Kettenis, *Psychosocial And Psychosexual Aspects Of Disorders Of Sex Development*, 24 *BEST PRACTICE & RESEARCH CLINICAL ENDOCRINOLOGY & METABOLISM* 325-334 (2010).

³⁹ A Wisniewski & T Mazur, *supra* note 29.

⁴⁰ A Wisniewski & T Mazur, *supra* note 29; IA Hughes et al., *supra* note 1.

⁴¹ IA Hughes et al., *supra* note 1.

⁴² IA Hughes et al., *supra* note 1.

may have fostered symptoms of posttraumatic stress disorder and referral to a qualified mental health professional may be indicated."⁴³ While some genital exams are deemed necessary for diagnosis or monitoring of medical conditions, others are done without specific indication, sometimes to satisfy provider curiosity or for purposes of training providers.⁴⁴ Complications and follow-up of genital surgery can make additional exams necessary.

A leading patient advocacy group has likened such procedures to child sexual abuse (CSA):

*[C]hildren with intersex conditions are subjected to repeated genital traumas which are kept secret both within the family and in the culture surrounding it... These children experience their treatment as a form of sexual abuse, and view their parents as having betrayed them by colluding with the medical professionals who injured them. As in CSA, the psychological sequelae of these treatments include depression, suicidal attempts, failure to form intimate bonds, sexual dysfunction, body image disturbance and dissociative patterns.*⁴⁵

4. Human Experimentation

Several researchers have referred to people with intersex conditions as "experiments of nature," and indeed this population has attracted a great deal of attention from researchers interested in sex and gender, even as surgical outcomes and other physical and psychological problems identified by the intersex community have gone largely unexamined.

Bioethicists and physicians have raised alarms about the longstanding practice of giving the powerful steroid dexamethasone to women pregnant with a child who might have virilizing congenital adrenal hyperplasia without adequate clinical trials or the protections normally afforded to human research subjects. The treatment is intended to prevent "masculinizing" effects of the condition, including atypical gender development, "tomboy" behaviors, and lesbianism. While the pregnant women were told for decades that the treatment was the standard of care and had been shown to be "safe and effective," researchers in the United States were enrolling the prenatally treated children in research studies after treatment, in order to determine if it was in fact safe.⁴⁶ Recently a Swedish study of the same treatment was shut down after high rates of birth defects were noted in the treated population, prompting study authors to state, "We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-up."⁴⁷

Concerns have also been raised about the activities of an American surgeon and researcher whose published studies recounted attempts to answer questions about genital sensitivity after clitoral surgery by applying a medical vibratory device to the genitals of conscious girls as young as six years old, and asking them to report on the sensation. Subjects in that study were apparently not afforded human research subject protections before the intervention, and institutional review board approval was only sought for the chart review after the tests had been done.⁴⁸ While a United States Office of Human Research Protection investigation determined that the vibratory tests were

⁴³ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6.

⁴⁴ Alexander, *supra* note 14.

⁴⁵ A Dreger, EK Feder EK & A Tamar-Mattis, *Prenatal Dexamethasone for Congenital Adrenal Hyperplasia*, 9 J. OF BIOETHICAL INQUIRY 277-294 (2012).

⁴⁶ T Hirvikoski et al., *Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint*, 97 THE J. OF CLINICAL ENDOCRINOLOGY AND METABOLISM (2012).

⁴⁷ J Yang & D Poppas, *Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability*, 178 J. OF UROLOGY 1598-1601 (2007); A Dreger A & EK Feder, *Bad Vibrations*. BIOETHICS FORUM (2010), available at <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4730>.

⁴⁸ U.N. Committee Against Torture, *General Comment No. 2, CAT/C/GC/2* (2007).

part of surgical follow-up and did not constitute research, no other surgeon has reported or recommended this procedure as part of follow-up patient care.

5. Denial of Needed Healthcare

While children with intersex conditions may suffer from an excess of medical attention and treatment, adults with intersex conditions often have a difficult time finding providers who are educated about their needs. Additionally, some have reported discrimination in health care settings and denial of care once their atypical anatomy is known. Reports have been made to AIC of an adult intersex man who died of vaginal cancer in the United States after being refused treatment at several centers due to discrimination based on him being a man who had a vagina, and of a newborn infant in Egypt who was refused life-saving treatment at a hospital due partly to discrimination based on his intersex condition.

How Medical Treatment of People with Intersex Conditions Fits into the Torture and CIDT Framework

Many of the violations visited on people with intersex conditions have already been recognized as torture or CIDT. Various human rights bodies have recognized that coerced sterilization can constitute torture and CIDT, and that states' obligations to protect persons from such treatment extends into the private sphere, including where such practices are committed by private individuals.⁴⁹ The U.N. Special Rapporteur on Torture and the U.N. Special Rapporteur on Violence against Women have made it clear that FGM constitutes torture⁵⁰ and that, from a human rights perspective, the medicalization of FGM—its performance in clinical surroundings—does not make this practice more acceptable.⁵¹ No exception has been mentioned for cutting girls' genitals for social or cultural reasons when the girl happens to have an intersex condition. The U.N. Committee on the Rights of the Child has specifically addressed involuntary sterilization of persons with disabilities under the age of 18 as a form of violence, which violates the right of the child to physical integrity and has life-long effects on physical and mental health effects.⁵² The Committee has called upon States to prohibit by law the involuntary sterilisation of children on grounds of disability.⁵³ Again, no exception has been mentioned for children whose medical condition happens to cause atypical sex characteristics.

Article 16 of the Convention Against Torture ("CAT"), and interpretations by the European Court of Human Rights and the mandate of the Special Rapporteur on Torture ("SRT") suggest that, at a minimum, CIDT covers "treatment as deliberately causing severe suffering, mental or physical, which in the particular situation is unjustifiable."⁵⁴ The U.N. Special Rapporteur on Torture has pointed out:

⁴⁹ *Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences*, U.N. Doc. E/CN.4/2002/83 (2002).

⁵⁰ *Report of the Special Rapporteur on Torture on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, U.N. Doc. A/HRC/7/3 (2008).

⁵¹ U.N. Committee on the Rights of the Child, *General Comment No. 13: The Right of the Child to Freedom from All Forms of Violence* (2011).

⁵² U.N. Committee on the Rights of the Child, *supra* note 51; U.N. Committee on the Rights of the Child, *General Comment No. 9: The Rights of Children with Disabilities* (2007).

⁵³ M Nowak, *What Practices Constitute Torture?*, 28 HUMAN RIGHTS QUARTERLY 821 (2006), (quoting Human Rights Watch, *Torture and Cruel Treatment in Health Settings*).

⁵⁴ *Interim Report of the Special Rapporteur on Torture on the Question of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, U.N. Doc. A/63/175 (2008).

*Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned.*⁵⁵

Under these interpretations, the medical practices described above constitute torture or CIDT in violation of Article 1(1) of the Convention. These procedures are intentional and performed for discriminatory and non-medical purposes; are performed with state control, custody or consent; can cause severe physical and psychological pain or suffering; and involve children who are powerless to refuse.

1. Intent and Purpose

The purpose of genital-normalizing surgery is not medical, in that it is not intended to preserve physical health. Instead, the purposes are social and cosmetic. Genital-normalizing surgery is intended to enforce gender norms, and risky medical treatment is imposed as a response to social stigma. Doctors and other healthcare personnel who perform, participate in, and approve these procedures generally believe that what they are doing is best for the child. However, determining intent and purpose do not require a subjective inquiry into the motivation of the perpetrators, but rather an objective determination under the circumstances.⁵⁶ The Special Rapporteur on Torture has pointed out that intent can be inferred where the act had a specific purpose, such as where a person has been discriminated against on the basis of disability.⁵⁷ The Rapporteur emphasizes this in the context of medical treatment, where such discriminations are often “masked as ‘good intentions’ on the part of health professionals.”⁵⁸

Clearly, the actions of the doctors in conducting genital-normalizing surgery, sterilizing procedures, genital exams, medical display and medical experimentation are intentionally performed. Promoters of these procedures are aware of the severe consequences for patients. The physical and mental suffering caused by cosmetic clitoral surgery and other genitoplasty, vaginal dilation, loss of fertility, and dependency on hormone substitution is well-established in medical literature, as noted above. The psychological suffering caused by excessive genital exams and photography is also widely recognized in the field, as demonstrated by its inclusion in an international consensus statement on treatment of intersex conditions.⁵⁹

The medical treatment of children with intersex conditions is done with discriminatory purposes, in that these children undergo cosmetic genital-normalizing surgery so that their bodies conform to dominant ideas of what constitutes a “male” or “female” body.⁶⁰ These surgeries are acknowledged in the medical literature to be cosmetic and intended to ensure the child develops with conformity to sex and gender norms.⁶¹ Enabling heterosexual intercourse is often an import-

⁵⁵ U.N. Committee Against Torture, *supra* note 48.

⁵⁶ *Interim report of the Special Rapporteur on Torture*, *supra* note 54.

⁵⁷ *Interim report of the Special Rapporteur on Torture*, *supra* note 54.

⁵⁸ IA Hughes et al., *supra* note 1.

⁵⁹ Association of Intersexual People, *Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment* (2011), http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf.

⁶⁰ S Creighton, et al., *supra* note 5.

⁶¹ S Creighton, et al., *supra* note 5.

ant goal,⁶² and in doing so surgeons may eradicate options for other forms of sexual expression. The focus of the limited outcome studies that are available on genital-normalizing surgeries belie their purpose, as most emphasize marriage rates, heterosexual intercourse, gendered behavior, and genital appearance.⁶³ Very few focus on psychological well-being, patient satisfaction, or sexual pleasure or function.⁶⁴ The goals and mode of treatment also differ according to what sex the doctors think the patient should be. In children assigned as girls, female fertility is prioritized even if treatment may damage sexual function and enjoyment. In children assigned as boys, the ability to penetrate a partner and stand to urinate is considered crucial; if the phallus is considered “inadequate” for these functions, the child may be assigned female and male fertility will be eradicated.⁶⁵

In considering intent, it is particularly noteworthy that doctors who perform genital-normalizing surgery are well aware that many of the children they operate on will ultimately reject their assigned sex. For example, one published review recognized that 10% of CAH cases have been shown to develop gender dysphoria, but concluded that “assigning female gender and performing premature surgery is safe in the majority of cases.”⁶⁶ In other words, the authors support removing or reducing the phallosclitoris and performing irreversible feminizing genitoplasty on infants with CAH, in spite of the fact that one in 10 of those infants will grow to identify as male. These authors further recognize rates of gender dysphoria as high as 8.5-20% in intersex conditions generally, yet maintain that early surgery remains safe.⁶⁷ A recent international consensus statement on treatment of intersex conditions reaches similar conclusions, even while recognizing rates of gender change as high as 40% in some conditions.⁶⁸

Doctors are also aware that there is usually no medical necessity for genital-normalizing surgery, and offer social justifications, believing that these procedures are necessary to prevent future discrimination against children with bodies that challenge the norm. However, just as it is a violation of the child's human rights to address parental discomfort through surgery on the child, it is a violation to address societal discomfort by the same means. This is discrimination on the basis of social stigma. The unavoidable pain of surgery and the high risk of severe lifelong physical and mental suffering—from loss of sexual sensation and function, pain caused by scarring, infertility, castration, violation of bodily integrity, and irreversible surgical assignment to the wrong sex—would never be accepted by doctors or parents if the child did not have an intersex body. The belief that such high risk is acceptable for a child with an intersex condition is the discriminatory attitude that drives these human rights violations. The fact that there is no medical justification for the ill-treatment means that good intentions cannot prevent the treatment from constituting torture.

Where medical justifications are offered for specific procedures, such as to prevent risk of cancer or to prevent future urinary tract infections, the risk/benefit analysis should be the same for children with intersex conditions as it would be for other children. So, for example, no ethical doctor would suggest removing a healthy infant girl's breast buds to protect her from breast cancer in the future. Similarly, it is not ethical to remove non-malignant gonads from a child with an intersex condition to protect against a low or hypothetical risk of cancer, especially where monitoring is an

⁶² L-M Liao et al., *Determinant Factors of Gender Identity: A Commentary*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.09.009>; A Wisniewski & T Mazur, *supra* note 29.

⁶³ L-M Liao et al., *supra* note 62; PT Cohen-Kettenis, *supra* note 38.

⁶⁴ A Tamar-Mattis, *supra* note 36.

⁶⁵ PS Furtado et al., *supra* note 4.

⁶⁶ *Id.*

⁶⁷ IA Hughes et al., *supra* note 1.

⁶⁸ *Id.*

option.⁶⁹ Using an extreme and invasive procedure to address a minor or hypothetical risk is discrimination if the risk would not be considered to justify such treatment in a non-intersex person.

Government bodies considering the question of genital-normalizing surgery have noted the potential for discrimination and human rights violations. The Swiss National Advisory Commission on Biomedical Ethics recently found:

*An irreversible sex assignment intervention involving harmful physical and psychological consequences cannot be justified on the grounds that the family, school or social environment has difficulty in accepting the child's natural physical characteristics. The harmful consequences may include, for example, loss of fertility and sexual sensitivity, chronic pain, or pain associated with dilation (bougie-age) of a surgically created vagina, with traumatizing effects for the child. If such interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child's welfare.*⁷⁰

The Colombian Constitutional Court, in considering a case involving genital-normalizing surgery on a child, opined that some “parents who consent to surgery may actually be discriminating against their own children.”⁷¹

2. State Control, Custody, or Consent

In general, the state-action component of the medical treatment of children with intersex conditions does not differ from that of other medical treatments being explored by the SRT, so we will not address this issue in great detail here. However, there are a few salient points worth raising.

The Committee Against Torture has noted that state parties must make sure that with respect to the Convention, their laws are in practice applied to all persons, “regardless of...gender, sexual orientation, transgender identity, mental or other disability, health status...”. This includes fully prosecuting and punishing all acts of violence and abuse against these individuals and implementing positive prevention and protection measures.⁷² The Special Rapporteur on Torture has emphasized that the obligation to prevent torture extends “to doctors, health professionals and social workers, including those working in private hospitals [or] other institutions.”⁷³ This indicates that people with intersex conditions must be treated without discrimination based on their perceived sex or gender difference or physical condition, and that doctors in private as well as state-run medical facilities have the responsibility to protect them from torture and CIDT.

In the case of FGM, a procedure similar in its particulars and in its social justification to the genital surgery endured by children with intersex conditions, the Rapporteur has specifically pointed out that where this is performed in private clinics and physicians carrying out the procedure are not being prosecuted, the State de facto consents to the practice and is therefore accountable.⁷⁴ We are unaware of any nation that prosecutes its own FGM laws in cases where the girl undergoing clitoral cutting has an intersex condition. Laws protecting people from involuntary sterilization are also not being enforced where the person being sterilized is a child with an intersex condition.⁷⁵

⁶⁹ Swiss National Advisory Commission on Biomedical Ethics, *supra* note 32.

⁷⁰ A Tamar-Mattis, *Exceptions To The Rule: Curing The Law's Failure To Protect Intersex Children*, 21 BERKELEY J. OF GENDER, L. & JUST. 59 (2006); A Tamar-Mattis, *supra* note 36.

⁷¹ U.N. Committee Against Torture, *supra* note 48.

⁷² *Interim report of the Special Rapporteur on Torture*, *supra* note 54.

⁷³ *Interim report of the Special Rapporteur on Torture*, *supra* note 54.

⁷⁴ A Tamar-Mattis, *supra* note 70.

⁷⁵ Report of the Special Rapporteur on Torture, U.N. Doc. E/CN. 4/1996/35 (1996).

3. Infliction of Severe Pain or Suffering

The U.N. Special Rapporteur on Torture has pointed out that children are more vulnerable to the effects of torture as they are in the critical stages of physical and psychological development where they may suffer graver consequences than similarly ill-treated adults.⁷⁶ The medical interventions imposed on children with intersex conditions may be all the more terrifying to them because they are unable to understand what is happening or to resist. This includes genital exams, the repeated catheterization that often follows complications of genital surgery, and vaginal dilation, in addition to the severe pain and suffering resulting from genital surgery and sterilization as outlined above. Young children may be unable to distinguish these procedures from intentional sexual abuse. Older children, having grown up with repeated genital interventions and exams, may find themselves unable to voice resistance. The pain and suffering experienced by these children is comparable to that of rape or sexual abuse, or of some forms of FGM.⁷⁷

In addition, genital-normalizing surgery and gonadectomy cause the physical and psychological pain attendant to any major surgery, along with specific long-term problems. These include genital scarring and pain, diminished or absent sexual function, incontinence, vaginal stenosis, urinary tract fistulas, dyspareunia (painful sexual intercourse), depression, poor body image, dissociation, social anxiety, suicidal ideation, shame, self-loathing, difficulty with trust and intimacy, post-traumatic stress disorder, and the wide-ranging consequences of a surgical attempt at sex assignment that often fails and cannot be undone.⁷⁸ Many intersex people report a level of trauma and fear of doctors that renders them unable to access even ordinary medical care.⁷⁹ The pain and suffering associated with medical treatment of intersex conditions clearly rises to the level of other acts considered to be torture or CIDT.

4. Powerlessness of the Victim

As with children undergoing female genital mutilation ("FGM"), children with intersex conditions undergoing surgery at an early age are in a situation of powerlessness, as they are under the complete control of their parents and medical personnel and have no means of resistance. The parents themselves also often report a sense of powerlessness.⁸⁰ Soon after the birth of a child with an atypical body, they are confronted with an alleged need for quick medical intervention. They may be threatened with scenarios of ostracism and cancer, and are pushed to make decisions that will affect their child forever, usually without complete information about the limitations and risks of these procedures or the option to postpone decisions until the child can participate.⁸¹ We have received numerous reports of parents who question the need for early genital surgery and are pressured by doctors with scenarios of suicide, cancer, "gender confusion," and ostracization, or even threatened with loss of medical care or reports to child abuse authorities.

⁷⁶ Alexander, *supra* note 14; N Ehrenreich, *supra* note 24.

⁷⁷ S Creighton, et al., *supra* note 5; San Francisco Human Rights Commission, *A Human Rights Investigation Into The Medical "Normalization" Of Intersex People* (2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf; P Lee, et al., *supra* note 16.

⁷⁸ San Francisco Human Rights Commission, *supra* note 77; K Karkazis, *supra* note 4.

⁷⁹ K Karkazis, *supra* note 4.

⁸⁰ K Karkazis, *supra* note 4; K Karkazis, A Kon & A Tamar-Mattis, *supra* note 6.

⁸¹ S Creighton, et al., *supra* note 5.

Conclusion and Recommendations

Intersex people suffer significant violations of their human rights to dignity, bodily integrity, control of reproduction, and privacy in medical settings. These violations include cosmetic genital-normalizing surgery in childhood, involuntary sterilization, excessive genital exams and medical display, human experimentation, and denial of needed medical care. We have argued that such treatment meets the threshold requirements of intent and discriminatory purpose, state control, pain and suffering, and powerlessness of the victim to constitute torture under Article 1 of the Convention Against Torture, and to meet the definition of cruel, inhuman or degrading treatment as prohibited by Article 16.

We welcome the recognition of such mistreatment in the Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, which states:

Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, 'in an attempt to fix their sex', leaving them with permanent, irreversible infertility and causing severe mental suffering.

And that:

These procedures [genital-normalizing surgeries] are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma.

We especially welcome the Special Rapporteur's call for an end to such treatment:

The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, "reparative therapies" or "conversion therapies", when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.

For the SRT to recognize that the childhood genital-normalizing surgery, involuntary sterilization, unethical experimentation, and medical display experienced by intersex people rises to the level of torture and CIDT represents an enormous step forward in ending these abuses. Currently these treatments are widely recognized as "controversial" and are promulgated by a small cadre of specialist providers. Non-surgeons on treatment teams may feel uncomfortable challenging surgical decisions.⁸² Recognizing these procedures as torture and CIDT gives support to the many medical providers who already question these treatments.

Our recommendations for states working to prevent torture and ill-treatment of intersex people in health care settings are:

1. **Cease all involuntary gonadectomies on children** unless there is clear and reliable medical evidence of a severe risk of tumor development, both in public and in private settings.
2. **Cease all involuntary cosmetic surgery on children's genitals**, both in public and in private settings.

⁸² S Creighton, et al., *supra* note 6.

3. Where genital surgery on a minor is deemed medically necessary, **require independent oversight by a court or other body** competent to weigh the evidence impartially and to independently consider the child's best interest.
4. **Provide for truly informed consent** of parents, young and adult patients, both in public and in private settings: Provide full information, orally and in writing, on the quantity and quality of the evidence suggesting the treatment; on the alternatives to the suggested intervention, including non-intervention, and their likely effects; on necessary follow-up treatment such as hormone substitution for gonadectomy or dilation for vaginoplasty, including physical and psychological side-effects and long-term effects; on the legal situation regarding parental consent including the child's right to an open future; and on the existence of support groups.
5. **Avoid situations of powerlessness** in hospitals, both public and private: Make sure parents know that there is no time pressure on a decision except in cases of true medical emergency; allow for parents to adapt to the condition of their child; provide financial and structural support for intersex self-help groups and outreach activities to young parents in hospitals.
6. Include **specific vocational training** of medical professionals on intersex conditions in all medical and psychological disciplines.
7. **Enforce existing laws relating to involuntary sterilization and female genital mutilation** where children with intersex conditions are involved.
8. **Ensure that all medical professionals know that medically unjustified gonadectomy and feminising surgery amount to the infliction of torture or CIDT** and constitute a punishable offense.
9. **Ensure that research involving intersex people complies with all legal requirements for protection of human research subjects**, and that ethical oversight of such research is informed by members of the intersex community.
10. **Ensure that medical professionals are educated about the harm caused by medical display and photography** and that they are able to distinguish genital exams necessary for treatment from those that do not benefit the patient.
11. Provide **access to needed medical treatment without discrimination**, including hormone substitution corresponding with the individual's gender identity.
12. Ensure that any intersex person who alleges they have been subjected to torture has the right to complain to, and to have their case promptly and impartially examined by, competent authorities and **ensure in the legal system that an intersex victim of an act of torture obtains redress** and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible:
 - a. Ensure each individual's **full access to the entirety of their medical files** in practice.
 - b. Review the specific problems encountered by intersex people in the pursuit of their rights with respect to the **statute of limitations**.
 - c. Establish an **aid and compensation fund** for affected persons.

Torturous “Treatment”? Assessing Government and Donor Responsibilities for Abuses in Drug Detention Centers From a Human Rights Perspective

REBECCA SCHLEIFER & RICHARD ELLIOTT*

Abstract

Human rights abuses against people in compulsory drug detention centers have been increasingly documented in recent years. Despite calls for the closure of such centers, hundreds of thousands of people who use drugs continue to be detained in centers throughout East and South East Asia, and subjected to abusive treatment in violation of international legal obligations, including the prohibition against torture and other cruel, inhuman, or degrading treatment. Abusive treatment includes the use of forced labor, including child labor; judicial, state-sanctioned corporal punishment and other forms of physical, psychological, and sexual violence; inadequate conditions of detention; and a deprivation of liberty without due process. Street children, people with psychosocial disabilities, and sex workers are also frequently detained against their will, and many centers fail to separate juveniles from adults in detention. The denial of medical care, as well as the performance of involuntary medical procedures, are common abusive practices. Nevertheless, drug detention centers receive extensive international support from U.N. agencies, other international donors, and governments in the form of financial and technical assistance, which exacerbates abusive practices. Despite increased criticism of drug detention centers and recent pledges by international organizations and national agencies to ensure respect for human rights when providing such assistance, donors continue to provide support for both existing and new facilities. Accordingly, U.N. agencies, as international organizations, and donor States may be complicit in violations of international law through their ongoing support of drug detention centers.

*Rebecca Schleifer, J.D., M.P.H., is a fellow with the Yale Global Health Justice Partnership. Richard Elliott, B.A. (Hons.), LL.B., L.L.M., is the Executive Director of the Canadian HIV/AIDS Legal Network.

Introduction¹

Around the world, a growing chorus—governments, U.N. organizations, international drug and health experts—have been calling for drug users to be considered “patients” rather than “criminals.” The Organization of American States’ 2013 report on drug law reform, for example, notes “[T]he fundamental change in perspective has been to shift from viewing drug users as criminals or accomplices of drug traffickers to seeing them as victims and chronic addicts.”² Thailand’s *Narcotic Addict Rehabilitation Act* officially considers “drug addicts” as “patients,” not criminals.³ In Lao PDR, the national drug law states that “[drug addicts] are to be considered as victims,”⁴ and Chinese law requires that drug users be rehabilitated.⁵

On its face, to many, this might seem a good idea—better drug treatment than prison, right? However, in these countries—like many in the region—the “treatment” or “rehabilitation” may be compulsory detention in locked facilities, entailing forced, unpaid labor, psychological abuse, and physical and sexual violence. In many countries, people who seek treatment voluntarily are subjected to similar abuses. And regardless of whether residential treatment is voluntary or coerced, it is often the case that evidence-based medical care to manage drug dependence, or to prevent or treat HIV, tuberculosis and other medical conditions, is denied or limited.

It is not sufficient to simply reclassify people who use drugs (whether dependent or not) as “patients not criminals.” Rather, whatever label is attached, it is critical to ensure that human rights obligations are brought to bear: governments, U.N. organizations, donors, drug and health experts, and non-governmental organizations—including human rights groups—must recognize people who use drugs as having fundamental human rights that must be respected, protected, and fulfilled.

In recent years, there has been increasing attention to human rights abuses in compulsory drug detention centers and calls for their closure. But there has been limited progress toward ending these abuses. U.N. agencies and international donors continue to support drug detention centers in some countries, in some cases supporting practices that they themselves consider morally reprehensible or illegal.

In this paper, we consider a number of practices commonly reported in drug detention centers to show how they might be considered torture or other cruel, inhuman or degrading treatment, contrary to the most basic international legal standards. We also provide specific examples of U.N. and international donor involvement in, and support to, these centers. Finally, we discuss related legal obligations and offer recommendations to address this situation.

¹ The authors note that portions of this text draw, with permission, on a number of publications they have previously authored or co-authored, in particular: Richard Elliott et al., *Treatment or Torture? Applying International Human Rights Standards to Drug Detention Centers*, CAMPAIGN TO STOP TORTURE IN HEALTH CARE (2011); J. J. Amon et al., *Compulsory Drug Detention In East And Southeast Asia: Evolving Government, U.N., And Donor Responses* [hereinafter *Compulsory Drug Detention in East and Southeast Asia*], INT’L J. OF DRUG POL’Y (2013).

² Organization of American States, *The Drug Problem in the Americas* 103 (2013).

³ Narcotic Addict Rehabilitation Act, B.E. 2545 (2002), available at <http://www1.oncb.go.th/document/narcotics%20addict%20rehabilitation%20act%20B.E.2545%20p91-103.pdf>.

⁴ Human Rights Watch [HRW], *Somsanga’s Secrets: Arbitrary Detention, Physical Abuse, and Suicide inside a Lao Drug Detention Center* (2011), available at <http://www.hrw.org/reports/2011/10/11/somsanga-s-secrets-0>.

⁵ HRW, “Where Darkness Knows No Limits”: *Incarceration, Ill-Treatment and Forced Labor as Drug Rehabilitation in China* (2010), available at <http://www.hrw.org/reports/2010/01/07/where-darkness-knows-no-limits-0>.

Drug Detention: An Overview

More than 350,000 people are estimated to be detained in over 1000 compulsory drug detention centers in East and South East Asia, ostensibly for drug “treatment” or “rehabilitation,”⁶ including in China, Vietnam, Cambodia, Lao PDR, Thailand, Burma, and Malaysia.

In Vietnam, “labor therapy” is stipulated as part of drug treatment by law, and drug detention centers are little more than forced labor camps where detainees are forced to work for private companies, processing cashews, sewing garments, or manufacturing other items. Detainees can be held for up to four years for “treatment,” and held in punishment or isolation cells for violating center rules. According to the government of Vietnam, at the beginning of 2011, there were 40,000 people in 123 drug detention centers, with the capacity to hold 70,000.⁷ In China, where the “Wind and Thunder Sweeping Narcotics” campaign allows police to arrest and test the urine of suspected drug users without consent,⁸ hundreds of thousands of people who use drugs are detained in compulsory detoxification centers run by the Public Security Bureau, where they can be held for up to 5 years. Detainees have been subjected to forced labor, beatings, withholding of food, and sleep deprivation. In Cambodia, detainees have reported forced labor for the benefit of detention centers or center staff, as well as being shocked with electric batons or whipped with wire cable.⁹ In Thailand, detainees have also reported overcrowding, inadequate food and beatings.¹⁰

In many other parts of the world, including Russia, South Africa, Mexico, and India, private centers also detain people against their will and provide punishment in the guise of rehabilitation. Detainees report receiving unknown tranquilizers, “flogging therapy,” “bread and water treatment,” and being subject to a regime of daily prayer and fasting.¹¹ Some die while detained.¹² In Peru, Kazakhstan, and Russia, detainees have died in fires as they struggled against locked windows and doors.¹³

Physical violence—being beaten, whipped and shocked—is a routine part of life inside some drug detention centers. Detainees have reported being beaten for violating center rules (including failing to work quickly enough or keep pace with exercises), smoking cigarettes or playing cards. Especially harsh punishments were given for trying to escape.¹⁴

⁶ B. Mathers et al., *HIV Prevention, Treatment and Care for People who Inject Drugs: A Systematic Review of Global, Regional and Country Level Coverage*, 375 LANCET 72-74 (2010); Compulsory Drug Detention in East and Southeast Asia, *supra* note 1 (reviewing estimates).

⁷ HRW, *The Rehab Archipelago: Forced Labor and Other Abuses in Drug Detention Centers in Southern Vietnam* [hereinafter *Rehab Archipelago*] (2011), available at <http://www.hrw.org/sites/default/files/reports/vietnam0911ToPost.pdf>.

⁸ J.E. Cohen & J.J. Amon, *Health and Human Rights Concerns of Drug Users in Detention in Guangxi Province, China*, 5 PLoS MED (2008), available at <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0050234>.

⁹ HRW, *Skin on the Cable: The Illegal Arrest, Arbitrary Detention and Torture of People Who Use Drugs in Cambodia* (2010), available at <http://www.hrw.org/reports/2010/01/25/skin-cable-0>.

¹⁰ R. Pearshouse, *Compulsory Drug Treatment in Thailand: Observations on the Narcotic Addict Rehabilitation Act B.E. 2545*, CANADIAN HIV/AIDS LEGAL NETWORK (2002), available at <http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=917>.

¹¹ See e.g., Campaign to Stop Torture in Health Care, *Treated With Cruelty: Abuses in the Name of Drug Rehabilitation*, OPEN SOC. FOUND. (Roxanne Saucier et al. eds., 2011), available at <http://www.opensocietyfoundations.org/sites/default/files/treatedwithcruelty.pdf>.

¹² *Id.*

¹³ *Id.*; Rebecca Schleifer, *The Disaster at Christ is Love*, HUFFINGTON POST, 2012, available at <http://www.huffingtonpost.com/rebeccaschleifer/thedisasteratchristisb1265248.html>.

¹⁴ HRW, *Torture in the Name of Treatment: Human Rights Abuses in Vietnam, China, Cambodia, and Lao PDR* (2012), available at http://www.hrw.org/sites/default/files/reports/HHR%20Drug%20Detention%20Brochure_LOWRES.pdf.

Children are detained in drug detention centers in some countries, often together with adults, and subjected to the same “treatments”—including forced labor and military exercises—as well as physical and sexual abuse.¹⁵ Sexual abuse has been reported against both women and children in detention.¹⁶

Individuals in such centers can be held for periods of months to years without trial, any semblance of due process, or even any clinical assessments of whether they are, in fact, drug dependent.¹⁷ As a result, occasional drug users and others merely suspected of using drugs are also detained. In some settings, the duration of detention may be increased for infractions of detention center rules, including such offenses as drinking tea, or failure to obey the “teachers.” Street children, people with psychosocial disabilities, and sex workers are also held in drug detention centers.

In many countries, compulsory treatment facilities are staffed by military or public security departments. The “treatment” itself often consists of forced, unpaid labor, psychological and moral “reeducation,” military drills, and in some cases, being chained or caged. Detainees may also be held in isolation cells, and subjected to physical and sexual violence by staff. Poor conditions of detention (such as unsanitary or overcrowded cells and inadequate food) pose additional risks to the health and lives of detainees.

For those who are drug-dependent, detention centers rarely offer evidence-based or effective addiction treatment, which would include pharmacological and psychosocial interventions tailored to the patient and typically provided in community settings. Where records of relapse are available, return to drug use among detainees is estimated to be as high as 100 percent.¹⁸ The World Health Organization (WHO) and the U.N. Office on Drugs and Crime (UNODC) have said, “Neither detention nor forced labor have been recognized by science as treatment for drug use disorders.”¹⁹

Effective, evidence-based HIV prevention, care and treatment services are rarely provided, despite high rates of HIV among detainees. Involuntary HIV testing has been reported as common in China’s drug treatment centers, but test results were not always disclosed to patients. Instead, according to one guard, the guards used HIV testing data “to know which female inmates they could sleep with without using a condom.”²⁰ In 2010, the head of the UNODC office in China said that the Chinese government knew that the centers were ineffective, and that being detained in them increased risk of HIV infection: “Being detained in these centers not only does not help drug users to recover, but also increases the likelihood that an individual will become infected with HIV.”²¹ Unprotected sex and unsafe drug use occur in the treatment centers, but condoms and sterile injecting equipment are not available, contrary to international best practice recommendations.

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ World Health Organization: Western Pacific Regional Office, *Assessment of Compulsory Treatment of People Who Use Drugs in Cambodia, China, Malaysia and Viet Nam* (2009).

¹⁹ U.N. Office of Drugs & Crime [UNODC] & WHO, *Principles of Drug Dependence Treatment: Discussion Paper* [hereinafter *Principles of Drug Dependence*] 15 (March 2008).

²⁰ J.E. Cohen & J.J. Amon, *supra* note 8.

²¹ Associated Press, *Group Slams China’s Drug User Detention Centers*, JAKARTA POST, January 7, 2010, <http://www.thejakartapost.com/news/2010/01/07/group-slams-china039s-drug-user-detention-centers.html>.

Application of the Prohibition on Torture and Other International Legal Standards

A growing body of national and international law examines the applicability of legal prohibitions against torture or cruel, inhuman, or degrading treatment in the context of compulsory detention for “drug treatment.”²²

The U.N. Convention against Torture (“CAT”) defines torture as any act that:

1. Inflicts severe pain or suffering, whether mental or physical;
2. is intentionally inflicted on a person;
3. is inflicted for such purposes as obtaining information, punishing, intimidating or coercing someone, or for any reason based on discrimination of any kind; and
4. is inflicted by, at the instigation of, or with the consent or acquiescence of a public official or other person acting in an official capacity.

As the U.N. Special Rapporteur on Torture observed in his 2013 report to the U.N. Human Rights Council, the application of the first, second and fourth of these elements (severe pain or suffering; intent; and involvement of or nexus to a public official) to abuses in drug detention settings is relatively straightforward.²³

With respect to the first and second elements, the question of whether a given practice in the context of drug detention constitutes “torture” will require assessment, based on the facts of a particular case, of whether the pain or suffering can be said to be severe and whether the practice is intentional.

With respect to the fourth element, in the case of government-run compulsory drug detention facilities, establishing State involvement is obvious and this requirement is easily satisfied. The requisite nexus with public officials may also be established in private drug “treatment” settings where, for example, the State’s law or regulation permits a given practice or public authorities know of and acquiesce to the practice(s) in question. The U.N. Committee Against Torture has confirmed that States parties may be held in breach of CAT for conduct by private actors when public officials, who knew or should have known of such treatment, fail to “take any appropriate steps in order to protect the [victim].”²⁴ The Committee has more recently affirmed that:

*The Convention imposes obligations on States parties and not on individuals. States bear international responsibility for the acts and omissions of their officials and others, including agents, private contractors, and others acting in official capacity or acting on behalf of the State, in conjunction with the State, under its direction or control, or otherwise under colour of law. Accordingly, each State party should prohibit, prevent and redress torture and ill-treatment in all contexts of custody or control, for example, in prisons, hospitals, schools, institutions that engage in the care of children, the aged, the mentally ill or disabled, in military service, and other institutions as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm.*²⁵

²² See Richard Elliott et al., *supra* note 1.

²³ U.N. General Assembly (2013), *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, para. 19, A-HRC-22-53 (2013) (by Juan Mendéz).

²⁴ U.N. Comm. Against Torture, *Hajrizi Dzemajl et al. v. Yugoslavi: Communication No. 161/2000*, para. 9.2 (1999).

²⁵ U.N. Comm. Against Torture, *General Comment No. 2: Implementation of Article 2 by States Parties*, para. 15, U.N. Doc. CAT/C/GC/2 (2008).

It should be noted that the International Convention on Civil and Political Rights (“ICCPR”) is arguably broader than CAT in protecting against torture, as it does not explicitly require that ill-treatment involve, at a minimum, the acquiescence of public officials in order for that treatment to constitute torture prohibited under the Covenant. The U.N. Human Rights Committee has interpreted the prohibition against torture and other cruel, inhuman or degrading treatment or punishment in the ICCPR (Article 7) to encompass all forms of treatment, whether it is “inflicted by people acting in their official capacity, outside their official capacity or in a private capacity.”²⁶

In applying the definition of torture under CAT to drug detention centers, it is the third element—a specific and improper purpose for the ill-treatment—that requires further analysis in illustrating the applicability of this treaty provision. As noted, the ill-treatment must be imposed “for such purposes as obtaining information, punishing, intimidating or coercing someone, or for any reason based on discrimination of any kind.” The treatment meted out in drug detention centers frequently satisfies this requirement, and this may be established in several ways.

First, in many cases, methods of drug dependence treatment are imposed with an explicit or implicit punitive objective, or with the objective of intimidating a person into avoiding future drug use (even if these objectives sit alongside an ostensibly therapeutic one). Government campaigns against drugs and people who use them as “social evils,” offer a prime example of a context in which abuses in drug detention centers are part and parcel of punishment and intimidation aimed, futilely, at ending drug use and exorcising people who use drugs from society.

Second, conduct may qualify as torture if applied with an improper purpose other than one explicitly stated in CAT. In the context of drug treatment, assisting “patients” in managing or overcoming drug dependence is the sole proper purpose—hence any other purpose, whether explicitly stated or determinable from the circumstances, is automatically suspect. In systems where there is no, or inadequate, clinical assessment of those detained to establish if, in fact, they are drug-dependent, it seems that the State could not even plausibly claim the purpose of detention, and of the practices to which detainees are then subject, is treatment of a health condition.

Furthermore, whether or not any such clinical assessment is validly undertaken, the involuntariness of the “treatment” should itself call into question whether medical management of the condition of drug dependence is the real purpose. In addition, in States where methods of drug dependence “treatment” are particularly egregious in inflicting pain or suffering, and where the State plays a role in either administering (e.g., by funding or through operation of sites by state personnel) or dictating the elements of treatment (e.g., via legislation, directives, guidelines), such treatment clearly amounts to state policy. With respect to abuses in private settings, where state law or policy determines or influences treatment methods, or compels treatment in such settings, and thus the State shows its interest in such treatment, it can be argued that “treatment” is undertaken for a purpose “such as” those mentioned explicitly in CAT.²⁷

Finally, the third element of CAT’s definition of torture may also be satisfied where it can be said that the treatment is carried out for “any reason based on discrimination of any kind.” The Committee Against Torture has declared that, as is the case with human rights law generally, the

²⁶ Human Rights Comm., General Comment No. 20, at para. 2 (1992).

²⁷ The European Court of Human Rights has ruled that a violation of the parallel prohibition in Article 3 of the European Convention on Human Rights may occur even where the purpose or intention of the State’s action or inaction was not to degrade, humiliate or punish the victim, but where this nevertheless was the result. *See* *Peers v. Greece*, App. No. 28524/95 paras. 68, 74 (2001); *Groni v. Albania*, Application No. 25336/04 para. 125 (2009).

basic principle of nondiscrimination is “fundamental to the interpretation and application of the Convention,” and has emphasized “that the discriminatory use of mental or physical violence or abuse is an important factor in determining whether an act constitutes torture.”²⁸ In particular, the Committee has noted that:

*The protection of certain minority or marginalized individuals or populations especially at risk of torture is a part of the obligation to prevent torture or ill treatment. States parties must ensure that, insofar as the obligations arising under the Convention are concerned, their laws are in practice applied to all persons, regardless of...mental or other disability, health status...reason for which the person is detained...or any other status or adverse distinction.*²⁹

Perceived or actual drug dependence obviously amounts to an (ostensible) “reason for detention” in drug detention settings, and as indicated by the reports cited above, people so detained are especially at risk of torture. Inflicting or tolerating torture of those in drug detention centers, in whole or in part because of their status as detainees in such settings, then amounts to “discrimination of any kind,” meaning the “improper purpose” requirement under CAT’s definition of torture is satisfied.

In addition, the discriminatory ill-treatment of drug users could be seen as discrimination based on “health status” or “other status” or based on “disability.”³⁰ As the WHO and UNODC have affirmed:

*Drug dependence is considered a multifactorial health disorder that often follows the course of a relapsing and remitting chronic disease. Unfortunately in many societies drug dependence is still not recognized as a health problem and many people suffering from it are stigmatized and have no access to treatment and rehabilitation...“Nothing less” must be provided for the treatment of drug dependence than a qualified, systematic, science based approach such as that developed to treat other chronic diseases considered untreatable some decades ago.*³¹

Other experts have articulated the same requirement, in human rights terms, that public policy must not discriminate against people with drug dependence. The U.N. Special Rapporteur on Torture has observed that: “With regard to human rights and drug policies...drug dependence should be treated like any other health-care condition.”³² Yet in many cases, public officials tolerate (or themselves administer) “treatment” for drug dependence that deviates from the requirements of evidence that are essential in treating other health conditions. To the extent that this is so because it is people who use drugs who are the subjects of this treatment, when non-evidence-based approaches are unacceptable in the treatment of other health conditions, then this substandard treatment amounts to discrimination, thereby satisfying this third element of the definition of torture. As noted by the U.N. Special Rapporteur on the Right to Health: “In place of evidence-based medical management, Governments and enforcement authorities coerce or force drug-dependent

²⁸ U.N. Comm. Against Torture, *General Comment No. 2*, at para. 20.

²⁹ *Id.*, para. 21.

³⁰ Some jurisdictions recognize drug dependence as a “disability” in anti-discrimination law including in Canada, the United States, and Australia. For a non-exhaustive list of cases, see Canadian HIV/AIDS Legal Network, *Legislating for Health and Human Rights: Model Law on Drug Use and HIV/AIDS* at 14 (2006), www.aidslaw.ca/modellaw; see also F. Gibson, *Drugs, Discrimination And Disability*, 17 J. OF L. & MEDICINE 400–411 (2009).

³¹ *Principles of Drug Dependence Treatment*, *supra* note 19, at 1-2; see, UNODC: Comm. On Narcotic Drugs, 53rd Sess., *Drug Control, Crime Prevention and Criminal Justice: A Human Rights Perspective— Note by the Executive Director*, para. 40 U.N. Doc. E/CN.7/2010/CRP.6—E/CN.15/2010/CRP.1 (Mar. 3, 2010).

³² U.N. Human Rights Council, *Report of the Special Rapporteur on Torture and Cruel, Inhuman or Degrading Treatment or Punishment*, para. 71, A/HRC/10/44 (2009).

individuals into centres where they are subject to ill-treatment and forced labour. This approach discriminates against people who use drugs, denying them their right to access medically appropriate healthcare services and treatment.”³³

Finally, note that discrimination may also be relevant to the question of the intent required for a finding of torture (the second element of the definition in CAT). The U.N. Special Rapporteur on Torture, in considering the particular vulnerability of people with disabilities to ill-treatment, has observed:

*Furthermore, the requirement of intent in article 1 of the Convention against Torture can be effectively implied where a person has been discriminated against on the basis of disability. This is particularly relevant in the context of medical treatment of persons with disabilities, where serious violations and discrimination against persons with disabilities may be masked as “good intentions” on the part of health professionals.*³⁴

There should, therefore, be little doubt that the “treatment” meted out to those detained in drug detention centers often amounts to torture, as that concept is defined in the two leading international treaties that prohibit it absolutely.³⁵

Finally, lest there be some argument that the standards articulated above do not apply in the context of drug detention settings, we note that the U.N. Human Rights Committee has explicitly clarified that the right to humane treatment under ICCPR Article 10 is held not just by those in prison but also by:

*Anyone deprived of liberty under the laws and authority of the State who is held in prisons, hospitals—particularly psychiatric hospitals—detention camps or correctional institutions or elsewhere. States parties should ensure that the principle stipulated therein is observed in all institutions and establishments within their jurisdiction where persons are being held.*³⁶

As for the CAT, it is well settled that its scope extends to all contexts of custody and control where there is some nexus with the state.

Having established the basic applicability of the international prohibitions on torture and other ill-treatment to the context of drug detention centers, the remainder of this section examines how specific phenomena documented in such centers violate these and other related legal standards.

1. Involuntary Medical Procedures

The U.N. Special Rapporteur on Torture, commenting on the question of drug dependence treatment in 2009, reminded States that “subjecting persons to treatment or testing without their consent

³³ U.N. General Assembly, *Report Of The Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, para. 30, A/65/255 (2010).

³⁴ U.N. Human Rights Council, *Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment of 28 July 2008*, para. 49, U.N. Doc. A/63/175 (2008).

³⁵ Limitations of space mean we do not treat in detail here the question of when ill-treatment that may fall short of “torture” may nonetheless still fall under the category of “cruel, inhuman or degrading treatment,” also prohibited by international law. Nor do we examine here the potential applicability, in certain cases, of analogous provisions in regional human rights treaties. For some further discussion of these points, and some applicable jurisprudence, see Richard Elliott et al., *supra* note 1.

³⁶ U.N. Human Rights Comm., *Compilation of General Comments and General Recommendations: General Comment 21*, Art. 10 para. 2, U.N. Doc. HRI/GEN/1/Rev.7 (1992). As some governments claim that detention centers are providing “treatment” for drug dependence, it is also worth noting that the Human Rights Committee has explicitly noted that the prohibition on torture or other cruel, inhuman or degrading treatment or punishment in ICCPR Article 7 “protects, in particular...patients in teaching and medical institutions”: General Comment 20, para. 5.

may constitute a violation of the right to physical integrity.”³⁷ He also observed that involuntary treatment and involuntary confinement run counter to various provisions of the Convention on the Rights of Persons with Disabilities (“CRPD”).³⁸ Commenting on psychiatric interventions, the U.N. Special Rapporteur on Torture has noted that forced administration of neuroleptics and other mind-altering drugs are a form of torture,³⁹ and the Human Rights Committee has found psychiatric experiments and forced injection of tranquilizers against a person’s will to constitute inhuman treatment.⁴⁰

2. Denial of Medical Care

The U.N. Human Rights Committee has specifically observed that ICCPR Article 10:

*[I]mposes on States parties a positive obligation towards persons who are particularly vulnerable because of their status as persons deprived of liberty, and complements for them the ban on torture or other cruel, inhuman or degrading treatment or punishment contained in article 7 of the Covenant.*⁴¹

Consequently, it has observed that the State’s failure to protect the health of people in detention could, in some cases, amount to inhumane treatment,⁴² and has ruled that inadequate medical care in prisons can amount in some cases to torture contrary to ICCPR Article 7.⁴³

The U.N. Committee Against Torture⁴⁴ and the U.N. Special Rapporteur on Torture⁴⁵ have specifically raised concerns that the failure to provide adequate health services to detainees may contribute to conditions amounting to cruel, inhuman, and degrading treatment. National and regional mechanisms have agreed. The European Committee for the Prevention of Torture has observed that: “An inadequate level of health care can lead rapidly to situations falling within the scope of the term ‘inhuman and degrading treatment.’”⁴⁶ The European Court of Human Rights has found failure to provide medical treatment to detainees to constitute a violation of the prohibition on such treatment under Article 3 of the European Convention on Human Rights. According to the Court,

³⁷ U.N. Human Rights Council, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, paras. 54, 71, U.N. Doc. A/HRC/10/44 (2009)(by Manfred Nowak).

³⁸ U.N. General Assembly, 64th Session, *Interim Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, para. 44, U.N. Doc. A/63/175 (2008)(by Manfred Nowak)(referencing CRPD Articles 3, 12 and 25 in particular).

³⁹ *Id.* at 63.

⁴⁰ U.N. Human Rights Comm., *Viana Acosta v. Uruguay, Views on Communication No. 110/1981*, U.N. Doc. CCPR/C/21/D/110/1981 paras. 2.7, 14-15 (2008) (adopted 29 March 1984).

⁴¹ U.N. Human Rights Comm., *General Comment 21*, op. cit., at para. 3.

⁴² U.N. Human Rights Comm., *Cabal and Pasini v. Australia*, para. 7.7, U.N. Doc. CCPR/C/78/D/1020/2002 (2003).

⁴³ U.N. Human Rights Comm., *Womah Mukong v. Cameroon: Communication No. 458/1991*, U.N. Doc CCPR/C/51/D/458/ (1991).

⁴⁴ See U.N. Comm. against Torture, *Concluding Observations: New Zealand*, para. 175, U.N. Doc. A/53/44 19 (1998).

⁴⁵ U.N. General Assembly, 62nd Session, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak*, para. 9, U.N. Doc. No A/62/221 (Aug. 13, 2007); U.N. General Assembly, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Mission to Indonesia)*, paras 29, 36, 67, 87, U.N. Doc. No. A/HRC/7/3/Add.7 (2008) (by Manfred Nowak).

⁴⁶ European Comm. for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, *Third General Report on the CPT’s Activities Covering the Period 1 January to 31 December 1992*, CPT/Inf (93) 12 [EN] para. 30 (June 4, 1993); see, European Comm. for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), *CPT Standards, CPT/IN/E* at section 3 (2002).

“the authorities are under an obligation to protect the health of persons deprived of liberty and the lack of appropriate medical care may amount to treatment contrary to art. 3.”⁴⁷

3. Judicial Corporal Punishment

In some jurisdictions, people who use drugs are subject to corporal punishment. In Singapore, for example, the government reports that people who use drugs may not only be detained for lengthy periods of time, but caned if they relapse into drug use—even though relapse is not uncommon for those with drug dependence.⁴⁸ The state-sanctioned beating, caning, or whipping of a person for drug use, purchase, or possession that takes place in some drug detention centers has been condemned by the Special Rapporteur on Torture as cruel, inhuman and degrading treatment, and in some cases, torture.⁴⁹

4. Forced Labor

The U.N. Committee on the Rights of the Child has called for Vietnam to prevent and end forced child labor in drug detention centers.⁵⁰ The U.N. Special Rapporteur on Health has also raised concerns about forced labor in detention centers, including in Vietnam.⁵¹ These practices have also drawn the concern of the U.N.’s human rights mechanisms concerned with torture. At least twice the U.N. Committee Against Torture has expressed its concerns regarding “re-education through labour” camps in China, in which hundreds of thousands of people with real or perceived drug dependence have been detained.⁵² Hard labor as punishment has also been raised as a concern by the Committee Against Torture under CAT Article 16.⁵³ The U.N. Special Rapporteur on Torture concluded that China’s approach of “reeducation through labor” can “be considered a form of inhuman or degrading treatment or punishment, if not mental torture.”⁵⁴

⁴⁷ See Rick Lines, *From Equivalence of Standards to Equivalence of Objectives: The Entitlement of Prisoners to Health Care Standards Higher than Those Outside Prisons*, 2 INT’L J. OF PRISONER HEALTH (2006).

⁴⁸ *Treatment and Rehabilitation Regime and Long Term Imprisonment for Abusers of Cannabis*, SINGAPORE CENTRAL NARCOTICS BUREAU, http://www.prisons.gov.sg/content/sps/default/newsaboutus/in_the_news/news_release_6.html.

⁴⁹ U.N. Human Rights Council, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, para. 63, A/HRC/13/39 (2010); see also Harm Reduction International’s work on this subject, <http://www.ihra.net/contents/1129> (which covers judicial corporal punishment outside detention centers, but analyzes the practice in the context of international law).

⁵⁰ U.N. Comm. on the Rights of the Child, *Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Concluding Observations: Vietnam*, para. 69, CRC/C/VNM//CO/3-4 (2012).

⁵¹ U.N. General Assembly, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, para. 30, A/65/255 (2010)(by Anand Grover); U.N. Human Rights Council, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: Addendum: Mission to Vietnam*, para. 47, A/HRC/20/15/Add.2 (2012) (by Anand Grover).

⁵² U.N. Comm. Against Torture, *Conclusions and Recommendations of the Committee Against Torture: China*, paras. 400, 412, 413, 419, 420, U.N. Doc. No. A/48/44 (1993); U.N. Comm. Against Torture, *Conclusions and Recommendations of the Committee Against Torture: China*, para. 111, U.N. Doc. No. A/55/44 (2000).

⁵³ Manfred Nowak & Elizabeth McArthur, *The United Nations Convention Against Torture: A Commentary* 560 (2008).

⁵⁴ U.N. Comm’n on Human Rights, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment and Punishment: Mission to China*, paras. 64, 82, U.N. Doc. E/CN.4/2006/6/Add.6 (2006).

5. Detention of Minors with Adults

Children are detained in drug detention centers in some countries, often together with adults, and subjected to the same “treatments”—including forced labor and military exercises—as well as physical and sexual abuse.⁵⁵ The Special Rapporteur on Torture has noted the particular vulnerability of children deprived of liberty in a variety of settings other than those related to the criminal justice system, and the indeterminate length of such detentions:

*“[c]hildren are sometimes held in such institutions and subjected to cruel and inhuman or degrading treatment without time limits or periodic review or judicial oversight of the placement decision. Such indeterminate confinement, particularly in institutions that severely restrict their freedom of movement, can in itself constitute cruel or inhuman treatment.”*⁵⁶

Ongoing International Support for Drug Detention Centers

U.N. agencies and international donors have in the past decade provided millions of dollars of financial and technical assistance to support drug control efforts that facilitate or exacerbate abuses in compulsory drug detention centers. This support has included actual material support to construct and renovate drug detention centers, providing legal advice on drug laws and policies, training and capacity building of security staff, and supporting vocational and health centers.

1. Technical Assistance: Training, Capacity Building and Legislative Guidance

U.N. agencies and international donors have supported the training of drug detention security staff in Vietnam and Cambodia. For example, UNODC (with more than USD \$1 million from Australia, Luxembourg and Sweden) and the U.S. government (USAID/PEPFAR) have funded (separate) projects that trained drug detention center staff and included the principle that drug treatment does not need to be voluntary to be effective. The training manuals for these projects do not mention UNODC and WHO statements that, “only in exceptional crisis situations of high risk to self or others, compulsory treatment should be mandated for specific conditions and periods of time as specified by the law.”⁵⁷

In 2005 and 2006, the U.S. Bureau of International Narcotics and Law Enforcement Affairs (INL) funded Daytop International (a U.S.-based drug treatment organization) to train staff from 20 centers on counseling and therapeutic community processes. An evaluation of the INL/Daytop training recommended that the “therapeutic community” model be implemented in all Vietnamese drug detention centers, apparently ignoring the fact that certain defining characteristics of the therapeutic community model (e.g., voluntary entry to and exit from treatment, that people not be held in government centers) do not exist in the Vietnamese context, as well as ignoring other human rights abuses in Vietnam’s centers.⁵⁸

INL also funded a similar Daytop initiative in Cambodia, providing funds in 2007 for training in residential drug treatment techniques to government officials, NGO workers, monks, military

⁵⁵ Richard Elliott et al, *supra* note 1.

⁵⁶ U.N. General Assembly, *Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, para. 12, U.N. Doc. A/55/290 (2000).

⁵⁷ Compulsory Drug Detention in East and Southeast Asia, *supra* note 1.

⁵⁸ Rehab Archipelago, *supra* note 7.

and police officials.⁵⁹ INL representatives who visited a detention center where staff members had attended Daytop training acknowledged that there was no therapy, and that “most of the day is filled with agricultural labor, physical exercise, watching television, and free time.”⁶⁰ They also noted that “most of the 140 residents are homeless individuals who are brought to the center by the police, and their inclusion at the center seems to be driven more by an interest in cleaning up Phnom Penh’s streets than in improving the lives of individual drug users.”⁶¹

UNODC has also provided advice on legislation that entrenches abuses in drug detention centers. For example, between 2008 and 2011, UNODC provided technical assistance to the Cambodian government in drafting revisions to the country’s drug control law. The revised law increased criminal penalties for possession of drugs for personal use and lengthened periods of detention for compulsory treatment—a result consistent with UNODC’s project goal to “strengthen” penalties in the law.⁶²

2. Material Support: Building and Renovating Drug Detention Centers

U.N. agencies and international donors have funded construction and renovation projects in drug detention centers.

Between 2001 and 2012, a number of donors, including the U.S. State Department’s International Narcotics and Law Enforcement Agency, UNODC, the German Development Agency, the Singaporean Embassy and Singapore International Foundation, provided financial support to Somsanga drug detention center in Lao PDR, including for the construction of the center’s walls and fences. The support greatly expanded the number of people that Somsanga could detain, including allowing it to expand women’s facilities.⁶³

Donors offered various justifications for their support to Somsanga. For example, the German Embassy said that their funding of services helped “create access and transparency.” The U.S. INL stated that “our assistance is critical in helping to bring the [Somsanga] center more closely in line with internationally recognized treatment practices and international standards.”⁶⁴

U.S. support continued even in the face of detailed criticism of widespread abuses, including suicides, in Somsanga. In June 2012, the U.S. committed USD \$400,000 in aid to Somsanga and other drug detention centers in Lao PDR, announcing that “this year continues its support for the detoxification process and the rehabilitation of drug addicts.”⁶⁵

Bilateral and multilateral donors have also funded the construction of drug detention centers in Vietnam. For example, as part of a million-dollar project funded by Australia, Luxembourg and Sweden, UNODC provided equipment for counseling clinics located in drug detention centers and the community.⁶⁶ Grant descriptions expressed no concern about the punishment rooms main-

⁵⁹ BUREAU FOR INT’L NARCOTICS AND LAW ENFORCEMENT AFFAIRS, U.S. DEP’T OF STATE, INTERNATIONAL NARCOTICS CONTROL STRATEGY REPORT 290 (2008).

⁶⁰ U.S. Embassy Phnom Penh, *Cambodia: Effective Narcotics Control and Treatment Face Substantial Hurdles*, WIKILEAKS (June 2007), <http://wikileaks.org/cable/2007/06/07PHNOMPENH782.html>.

⁶¹ *Id.*

⁶² I. Loy & J. O’Toole, *Prime Minister Approves Drug Law*, PHNOM PENH POST, July 11, 2011.

⁶³ Compulsory Drug Detention in East and Southeast Asia, *supra* note 1.

⁶⁴ *Id.*

⁶⁵ *US Supports Lao Drug Control Efforts*, VIENTIANE TIMES (2012), http://www.youtube.com/watch?v=onIl8Vo0r_c.

⁶⁶ See, e.g., UNODC, *VIEH68—Technical Assistance To Treatment And Rehabilitation At Institutional And Community Level: 2010 Semiannual Project Progress Report* (2010); UNODC, *VIEH68—Technical Assistance To Treatment And Rehabilitation At Institutional And Community Level: 2009 Quarterly Project Progress Report* (2009) (on file with authors).

tained in these centers or the routine physical and emotional violence inflicted upon detainees by the staff.

Japan contributed to the infrastructure of Vietnam's drug detention centers, donating USD \$86,197 to the Ha Nam Drug Addict Treatment Center to construct "rehabilitation facilities for women addicts."⁶⁷ Another contribution by Japan (USD\$77,380) financed the construction of the "Dormitory and Treatment House for Drug Addicts in the Center of Education, Labour and Social Affairs of Quang Nam Province."⁶⁸

3. HIV-Related and Other Healthcare Interventions

U.N. agencies and international donors have provided HIV prevention and/or treatment and care in centers, or funded government authorities to do so.

In Vietnam, for example, USAID/PEPFAR, AusAID, the Netherlands Embassy, the World Bank, and the Global Fund to Fight AIDS, Tuberculosis and Malaria have provided or supported HIV services in drug detention centers.⁶⁹

International organizations and donors have cited humanitarian grounds to justify this support, noting their obligation to relieve the suffering of detainees and provide them with access to life-saving treatment. But these organizations and implementing agencies do not seem to have systems in place to monitor or report human rights abuses that project staff would likely witness in the centers.

This position also ignores the fact that under Vietnamese law, ill detainees may be released to receive treatment when the center is unable to provide adequate healthcare. In practice, this support may have the perverse impact of facilitating the continued detention of individuals who would otherwise be eligible for release from detention and transferred to a government hospital or returned home for treatment and care.

As Vietnamese drug detention centers require detainees to undertake forced labor by law, funding health care service provision also effectively subsidizes the cost of detention in such centers, with the effect that the centers can be more profitable, while detainees continue to labor under dangerous conditions that compromise their health and lives.

4. Donor Support as Justification for Compulsory Drug Detention Centers

Beyond the objectionable complicity of donors in human rights abuses by supporting such drug detention centers, materially and through technical assistance, their involvement has a further effect in buffering criticism of these abuses.

The Vietnamese government, for example, has cited the (U.S.) National Institute on Drug Abuse ("NIDA"), UNODC and WHO to legitimize its drug detention centers. In response to Human Rights Watch's 2011 report documenting human rights abuses in its compulsory drug detention centers, the government claimed that its system was "in line with one of the Principles of Effective Drug Addiction Treatment released by the National Institute on Drug Abuse (NIDA) under the

⁶⁷ EUR. CONSULT.: AUSTRALIAN/JAPANESE REGIONAL CHAIR FOR SOUTH EAST ASIA AND CHINA, *Regional report [to the Dublin Group], on Southeast Asia and China* (2008).

⁶⁸ EUR. CONSULT.: JAPANESE REGIONAL CHAIR FOR SOUTH EAST ASIA AND CHINA, *Follow-up report [to the Dublin Group], on Southeast Asia and China for 2008* (2009).

⁶⁹ See Rehab Archipelago, *supra* note 7.

United States Department of Health and Human Services (USDHHS) and agreed by the United Nations Office on Drugs and Crime (UNODC)—World Health Organization (WHO).⁷⁰ While WHO and UNODC have stated elsewhere that, “neither detention nor forced labor have been recognized by science as treatment for drug use disorders,”⁷¹ that significant point is omitted from both training manuals.

Government officials in Cambodia have similarly claimed support by international organizations to defend against allegations of abuse. In 2010, Human Rights Watch published a report documenting abuses in drug detention facilities in Cambodia, including in Choam Chao detention center for children, which received funding from UNICEF. A spokesperson for the Cambodian Ministry of Social Affairs defended its operation of drug detention centers from allegations of abuse, in part by citing its receipt of UNICEF funding.⁷²

5. Donor and U.N. Responses

In recent years, there have been increasing calls to close drug detention centers, including by U.N. special mechanisms (e.g., each of the Special Rapporteurs on health and on torture), U.N. agencies, and health and human rights organizations. In March 2012, a dozen U.N. agencies (including UNODC and UNICEF) issued a joint statement condemning compulsory drug detention centers and calling for their immediate closure, emphasizing the health and human rights risks to detainees. According to the joint statement:

*The deprivation of liberty without due process is an unacceptable violation of internationally recognized human rights standards. Furthermore, detention in these centres has been reported to involve physical and sexual violence, forced labour, substandard conditions, denial of health care, and other measures that violate human rights.*⁷³

This is a welcome development. But it remains to be seen how these agencies will translate their words into country level action. Indeed, in March 2012, the same month the U.N. statement was released, UNODC co-sponsored a fashion show to raise funds for the Somsanga drug detention center in Lao PDR.⁷⁴

In May 2012, UNODC issued a policy guidance addressing human rights risks of engagement in drug detention centers (as part of guidance on the organization's human rights responsibilities in the context of counter-narcotics aid). UNODC's policy guidance recommends action to be taken when UNODC's work may conflict with human rights norms:

⁷⁰ Letter to J. Amon, Director, Health and Human Rights Division, Human Rights Watch from Do Thi Ninh Xuan Deputy Director Department of Social Evils Prevention, Ministry of Labour-Invalids and Social Affairs, Vietnam, September 5, 2011 (copy on file with authors).

⁷¹ *Principles of Drug Dependence Treatment*, *supra* note 18, at 14.

⁷² Joseph Amon, *How Not to Protect Children*, PHNOM PENH POST, March 8, 2010.

⁷³ *Joint Statement: Compulsory Drug Detention and Rehabilitation Centres*, UNITED NATIONS (2012), http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/JC2310_Joint%20Statement6March12FINAL_en.pdf.

⁷⁴ *Charity Fashion Parade to Help Somsanga Centre, 2012*, KPLLAO NEWS AGENCY, (2012), <http://www.kpl.net.la/english/news/newsrecord/2012/March/09.3.2012/edn5.htm>; <http://www.facebook.com/events/250057538418833/>.

*Direct UNODC support to any institution in which the above violations [lack of due process, lack of evidence based treatment, lack of harm reduction, mistreatment] are present places UNODC at an unacceptably high risk of providing aid or assistance to human rights abuses. UNODC must in such cases either work with these institutions to improve the human rights situation or consider withdrawal of support.*⁷⁵

Other international organizations and national agencies have made similar commitments to ensure human rights through their international assistance/development aid/drug policies. For example, the UK's "Human Rights Guidance for its Overseas Security and Justice Assistance," which includes support for drug control efforts, requires personnel to assess risks associated with certain types of assistance in advance of providing aid and then take steps to mitigate that risk. Specifically identified risks, among many others, include the death penalty; arbitrary detention; torture or cruel, inhuman and degrading treatment; unlawful killing; and unfair trials or denial of justice.⁷⁶ Similar concerns have been expressed at the EU level, in both its drugs strategy⁷⁷ and a European Parliament resolution.⁷⁸

Meanwhile, despite increased criticism of drug detention centers, some international organizations continue to support them. In 2012, the International Narcotics Control Board praised Vietnam for "the steps taken to improve the treatment and rehabilitation of drug abusers," and called on Vietnam to "reinforce and support existing facilities," making no mention of widespread human rights violations occurring in drug detention centers.⁷⁹

6. Human Rights Obligations of Donor States and International Organizations

U.N. bodies (including U.N. specialized agencies, such as the World Bank) and U.N. member states are all bound by their overarching obligations under the Charter of the United Nations to respect and promote "universal respect for, and observance of, human rights and fundamental freedoms" for all without distinction as to race, sex, language, or religion.⁸⁰ Article 103 of the Charter explicitly indicates that in the event of any conflict between states' obligations under the Charter and their obligations under any other international agreement, their Charter obligations shall prevail.⁸¹ The International Bill of Rights (including the ICCPR) is the key source used to interpret the human rights provisions in the U.N. Charter.⁸²

The scope of Article 103 relating to the primacy of the Charter over other international agreements also extends to decisions of the Principal Organs of the United Nations.⁸³ In other words, it extends to the governance systems and hierarchies created by the Charter.

⁷⁵ UNODC, *UNODC and the Promotion and Protection of Human Rights: Position Paper 13* (2012), http://www.unodc.org/documents/justice-and-prison-reform/UNODC_Human_rights_position_paper_2012.pdf.

⁷⁶ *Overseas Security and Justice Assistance*, HUMAN RIGHTS GUIDANCE (2011), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/35447/osja-guidance-151211.pdf.

⁷⁷ Eur. Consult., *EU Drugs Strategy* (2005–2012), 15074/04 (Nov. 22, 2004).

⁷⁸ EUROPEAN PARL., *Resolution On The Annual Report On Human Rights In The World 2009 And The European Union's Policy On The Matter* (2010/2202(INI)), P7_TA-PROV(2010)0489, para. 65 (2010).

⁷⁹ *2011 Annual Report*, INTERNATIONAL NARCOTICS CONTROL BOARD, <http://www.incb.org/incb/en/publications/annual-reports/annual-report-2011.html>.

⁸⁰ U.N. Charter of the United Nations, June 26, 1945, 59 Stat.1031, T.S. 993, 3 Bevans 1153, entered into force Oct. 24, 1945, arts. 1, 55, 56.

⁸¹ *Id.*, at Art. 103.

⁸² OLIVIER DE SCHUTTER, *INTERNATIONAL HUMAN RIGHTS LAW: CASES, MATERIALS, COMMENTARY* 50 (2010).

⁸³ See Int'l L. Comm. [ILC], *Fragmentation of International Law: Difficulties Arising from the Diversification and Expansion of International Law: Report of the Study Group of the International Law Commission*, para. 35, U.N. Doc A/CN.4/L.702 (2006).

International organizations derive human rights obligations from general rules of international law; their constituting documents; and international agreements to which they are parties.⁸⁴ General rules of international law include customary human rights law, in particular *jus cogens* norms (i.e., peremptory norms superseding all other norms and from which no derogation is permitted).⁸⁵ International organizations' own rules do not supersede their human rights obligations.⁸⁶ The International Law Commission has made clear its support for this conclusion, stating that "it is apparent...that peremptory norms of international law apply to international organizations" and that "it can hardly be maintained that states can avoid compliance with peremptory norms by creating an organization."⁸⁷ The prohibition against torture and cruel, inhuman, or degrading treatment or punishment is *jus cogens*.⁸⁸ It therefore applies to international organizations and binds every state, regardless of whether they have ratified any particular treaty prohibiting such treatment.

Governments also have human rights obligations based on treaties to which they are a party, which they retain when they become members of international organizations.⁸⁹ In that capacity, they are obliged to exercise due diligence with respect to their human rights obligations.⁹⁰

In recent years, there has been growing attention to human rights obligations of international organizations and donors with respect to projects they support. The International Law Commission offers guidance in judging complicity in this context. Its draft articles on the responsibility of international organizations state:

*An international organization which aids or assists a State or another international organization in the commission of an internationally wrongful act by the State or the latter organization is internationally responsible for doing so if: (a) That organization does so with knowledge of the circumstances of the internationally wrongful act; and (b) The act would be internationally wrongful if committed by that organization.*⁹¹

In his 2005 report to the U.N. General Assembly, Professor Giorgio Gaja, the International Law Commission's Special Rapporteur on the Responsibility of International Organizations, provided this example:

⁸⁴ ILC, *Draft Articles on the Responsibilities of International Organizations with Commentaries, in the Report of the ILC's Sixty-Third session, UNGAOR 66th session, U.N. Doc. A/66/10 at 14 para. 2 (2011).*

⁸⁵ See Andrew Clapham, *Human Rights Obligations of Non-State Actors*, INT'L REV. OF THE RED CROSS, at 65-8, n. 24 (2006).

⁸⁶ ILC, *Draft Articles on the Responsibility of International Organizations with Commentaries*, Art. 32 (commentary to Art. 32, para. 1 states the principle that an international organization cannot invoke its rules in order to justify non-compliance with its obligations under international law entailed by the commission of an internationally wrongful act.).

⁸⁷ ILC, *Report Of The International Law Commission on the Work of its Thirty-Fourth Session*, U.N. Doc. A/37/10, at 56 (1982).

⁸⁸ M. Nowak & E. McArthur, *The United Nations Convention Against Torture: A Commentary*, p. 8; U.N. Comm. Against Torture, *General Comment No. 2*, para. 1, U.N. Doc. CAT/C/GC/2/CRP.1/Rev.4 (2007); Human Rights Comm., *General Comment No. 29*, paras. 7, 11, U.N. Doc. CCPR/C/21/Rev.1/Add.11 (2011).

⁸⁹ See, e.g., Maastricht Principles On Extra-Territorial Obligations Of States, Principle 15; ILC, *Draft Articles on the Responsibility of International Organizations*, Art. 61 (2011).

⁹⁰ ILC, *Final Report of the International Law Association Committee on Accountability of International Organizations*, p. 15 (2004).

⁹¹ ILC, *Draft articles on Responsibility of International Organizations with Commentaries*, Art. 14.

[A]n international organization could incur responsibility for assisting a State, through financial support or otherwise, in a project that would entail an infringement of human rights of certain affected individuals.⁹²

The corresponding article on State responsibility states:

A State which aids or assists another State in the commission of an internationally wrongful act by the latter is internationally responsible for doing so if: (a) that State does so with knowledge of the circumstances of the internationally wrongful act; and (b) the act would be internationally wrongful if committed by that State.⁹³

In other words, both U.N. agencies, as international organizations, and donor States themselves, may be complicit in violations of international law through their support of drug detention centers.

Recommendations

United Nations agencies and international donors should:

- Publicly call for: detainees in drug detention centers to be released; permanent closure of the centers; an investigation into allegations of human rights violations inside such centers; holding those responsible for such violations to account; and reasonable compensation for detainees and former detainees for harm to their physical and mental health suffered during detention.
- Adopt clear policy guidelines rooted in international standards for financial, technical, and other assistance provided for drug enforcement, demand reduction, or related projects (such as HIV-focused programming) in recipient states.
- Audit all current funding and programmatic activities directed to assisting drug detention centers for compliance with adopted policies to ensure that no funding or programs contribute to or exacerbate human rights violations.
- Take immediate action on problems identified in the audit, including freezing support until governments take action to ensure drug treatment laws and policies meet international standards.
- Implement a transparent system of human rights impact assessments initially and throughout the lifetime of projects to identify human rights impact of projects and avoid or mitigate adverse impacts.
- Support the expansion of voluntary, community-based drug dependence treatment that is evidence-based, meets clinical standards, and complies with human rights law.

Governments operating drug detention centers should:

- Release current detainees and permanently close such centers.
- Carry out prompt, independent, and thorough investigations into human rights abuses in drug detention centers, and sanction perpetrators of abuses.

⁹² Special Rapporteur on the Responsibility of International Organizations, *Third report on responsibility of international organizations*, para. 28, A/CN.4/553 (2005)(by Giorgio Gaja). Courts have also ruled on the obligations of international organizations to ensure that activities do not violate human rights. See, Waite and Kennedy v. Germany, App. No. 26083/94, Eur. Ct. H.R. para. 67 (1999).

⁹³ U.N. General Assembly, *Responsibility of States for Internationally Wrongful Acts: Resolution Adopted by the General Assembly*, A/RES/56/83 (2002).

- Expand access to voluntary, community-based drug dependence treatment and ensure that such treatment is medically appropriate and comports with international clinical and human rights standards.

U.N. human rights procedures and bodies should take action as follows:

- The U.N. Committee Against Torture and the Subcommittee on Prevention of Torture should exercise their respective powers to investigate drug detention centers, particularly in countries where serious human rights abuses have been reported.
- Other U.N. mechanisms with a mandate to address abuses in drug detention centers (e.g., the Working Group on Arbitrary Detention; the Committee on Economic, Social and Cultural Rights; the Committee on the Rights of the Child; the Special Rapporteur on Torture; and the Special Rapporteur on Health) should also address human rights abuses in drug detention centers, including during country visits, periodic reports and concluding observations.

Privatizing Cruelty—Torture, Inhumane and Degrading Treatment in Non-Governmental Drug Rehabilitation Centers

ROXANNE SAUCIER & DANIEL WOLFE*

Abstract

Human rights protectors have increasingly called attention to abuses visited upon people in the name of rehabilitation from illicit drug use. Reports from East and Southeast Asia, in particular, have moved the UN Committee Against Torture, the Committee on the Rights of the Child, the Special Rapporteur on Torture, the Special Rapporteur on Health, the International Labor Organization, and numerous United Nations agencies to call for closure of government-run drug detention centers where people are detained en masse ostensibly for drug treatment, forced to work, and severely punished for failing to meet work quotas or for minor infractions of rules. Less documented—and less scrutinized—are so-called drug treatment or rehabilitation centers run by non-State actors. While conditions in these centers are often as dire as in larger government-run centers, they generally operate outside of public or government oversight. Often, these facilities are run by religious groups or private charities that offer their services at minimal cost to families and in places where government itself offers few or no treatment options, a fact that further insulates private centers from scrutiny or criticism. The Committee Against Torture has made clear that States that know about acts of torture or cruel, inhumane or degrading treatment by non-State actors have an obligation to prevent, investigate, prosecute and punish such abuses. Urgent and sustained action is needed to address abuses in these facilities, including those run by religious institutions and by private, not-for-profit, or for-profit organizations.

Introduction

Human rights protectors have increasingly called attention to abuses visited upon people in the name of rehabilitation from illicit drug use. Reports from East and Southeast Asia, in particular, have moved the U.N. Committee Against Torture,¹ the Committee on the Rights of the Child,² the Special

* Roxanne Saucier is an independent consultant working on health and human rights of people who use drugs. Daniel Wolfe is the director of the International Harm Reduction Development Program of the Open Society Foundations. Correspondence to: Daniel Wolfe, Daniel.wolfe@opensocietyfoundations.org

¹ U.N. Comm. Against Torture [CAT], 45th Sess., Concluding Observations of the Committee Against Torture: Cambodia (2010).

² U.N. Comm. on the Rights of the Child 60th Sess., *Concluding Observations: Viet Nam* (2012).

Rapporteur on Torture,³ the Special Rapporteur on Health,⁴ the International Labor Organization,⁵ and numerous United Nations agencies⁶ to call for closure of government-run drug detention centers where people are detained en masse ostensibly for drug treatment, forced to work, and severely punished for failing to meet work quotas or for minor infractions of rules.⁷ Less documented—and less scrutinized—are so-called drug treatment or rehabilitation centers run by non-state actors. While conditions in these centers are often as dire as in larger government-run centers, they generally operate outside of public or government oversight. Abuses in private centers have been reported in locations as varied as Brazil, Guatemala, India, Mexico, Peru, Russia, Serbia, South Africa, and the United States. Often, these facilities are run by religious groups, or private charities, that offer their services at minimal cost to families and in places where government itself offers few, or no treatment options—a fact that further insulates private centers from scrutiny or criticism.

The Committee Against Torture has made clear that states that know about acts of torture or cruel, inhumane or degrading treatment by non-state actors have an obligation to prevent, investigate, prosecute and punish such abuses.⁸ Urgent and sustained action is needed to address abuses in these facilities, including those run by religious institutions and by private, not-for-profit, or for-profit organizations.

Coerced Entry into Treatment

“We took him there with the hope of rehabilitation, and that he would stop using drugs. We didn’t send him to get beaten up, that was never our aim.”⁹

³ U.N. Special Rapporteur on Torture, Report of Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez, A/HRC/22/53 (2013)(by Juan E. Mendez).

⁴ U.N. Special Rapporteur on Health, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover: Mission to Viet Nam (2012)(by Anand Grover); U.N. Special Rapporteur on Health, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, A/65/255 (2010), <http://www2.ohchr.org/english/issues/health/right/annual.htm>.

⁵ Int’l Labor Org. [ILO], Report on the Committee of Experts on the Application of Conventions and Recommendations (2013).

⁶ ILO, OHCHR, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UN Women, WFP, WHO, UNAIDS, Joint statement: Compulsory Drug Detention and Rehabilitation Centres: United Nations Entities Call on States to Close Compulsory Drug Detention and Dehabilitation Centres and Implement Voluntary, Evidence-informed and Rights-based Health and Social Services in the Community (2012), www.unaids.org/en/media/unaids/contentassets/documents/document/2012/JC2310_Joint%20Statement6March12FINAL_en.pdf.

⁷ See e.g., Human Rights Watch, *Torture in the Name of Treatment: Human Rights Abuses in Vietnam, China, Cambodia and Lao PDR* (2012), <http://www.hrw.org/fr/node/109048>; P Gallahue et al., *Partners in Crime: International Funding for Drug Control and Gross Violations of Human Rights* (Harm Reduction Int’l 2012), http://www.ihra.net/files/2012/06/22/Partners_in_Crime_web1.pdf; Campaign to Stop Torture in Health Care, *Treated with Cruelty: Abuses in the Name of Drug Rehabilitation*, OPEN SOCIETY FOUNDATIONS (2011), <http://www.opensocietyfoundations.org/sites/default/files/treatedwithcruelty.pdf>; D WOLFE & R SAUCIER, IN REHABILITATION’S NAME? ENDING INSTITUTIONALIZED CRUELTY AND DEGRADING TREATMENT OF PEOPLE WHO USE DRUGS, 21 INT’L J. OF DRUG POLICY 145—148 (2010); N THOMSON, DETENTION AS TREATMENT: DETENTION OF METHAMPHETAMINE USERS IN CAMBODIA, LAOS, AND THAILAND, OPEN SOCIETY FOUNDATIONS (2010), http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/detention-as-treatment-20100301; INT’L HARM REDUCTION DEVELOPMENT PROGRAM, AT WHAT COST? HIV AND HUMAN RIGHTS CONSEQUENCES OF THE GLOBAL “WAR ON DRUGS.” OPEN SOCIETY FOUNDATIONS (2009), http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/atwhatcost_20090302; WORLD HEALTH ORGANIZATION-WESTERN PACIFIC REGION, ASSESSMENT OF COMPULSORY TREATMENT OF PEOPLE WHO USE DRUGS IN CAMBODIA, CHINA, MALAYSIA AND VIET NAM: AN APPLICATION OF SELECTED HUMAN RIGHTS PRINCIPLES (2009), http://www.who.int/hiv/topics/idu/drug_dependence/compulsory_treatment_wpro.pdf.

⁸ U.N. Comm. Against Torture, *General Comment No. 2: Implementation of Article 2 by States Parties*, CAT/C/GC/2 (2008), <http://www.refworld.org/docid/47ac78ce2.html>.

⁹ Campaign to Stop Torture in Health Care, Mexico: Left With No Other Option in Treated with Cruelty: Abuses in the Name of Drug Rehabilitation [hereinafter Mexico: Left With No Other Option], OPEN SOCIETY FOUNDATIONS (2011).

International and national law has increasingly recognized the importance of participation, consultation, and active involvement of disabled persons in decision-making about their health and social arrangements.¹⁰ For people who use drugs, however, the fact that they use of illicit substances is often used as a pretext for removal of autonomy and coercion into “treatment.” Family members who involuntarily commit drug users to treatment may do so with good intentions: the quote above, from Mexico, captures a reality common to many countries, where families with little idea of the conditions inside centers receive reassurances from management that the facilities are safe. A Russian ex-detainee explained how the system worked:

*What they say to the parents was like “He is a drug user.... Let us reform him for you, you have suffered enough”.... And the parents sign a paper. Technically, on what grounds can they hold me there? I am of legal age, why am I deprived of my freedom?...And then the staff would come and tell you to write that you are staying there voluntarily. How can you say otherwise? They would force you to comply anyway.”*¹¹

Another drug user in Russia spoke of her internment in another center run by the same group, “City without Drugs”, dubbed the “Foundation”:

*While I was at home one day my mom secretly phoned the Foundation. There was a ring at the door. I ran and opened it...They came in. “Come on, get ready to go.” And they took me away with them... They think of themselves as a sort of local police. Like they don’t have to follow any rules.”*¹²

As they took her to the center, they drove around her neighborhood and pressured her to identify other drug users.

Coercion without legal review is also enacted by strangers, or by police. In Russia, family members can arrange for people using drugs to be kidnapped and brought to centers against their will. In Guatemala, internment is effected by police, who take people from the street and deliver them to be locked inside religious centers. As one policeman told a researcher: “[These centers] help us a lot because they keep [people] inside, even though sometimes their methods are not the greatest, even though the patients complain that they get hit and insulted and tied down.”¹³

In Guatemala, people may also be rounded up by *grupos de cazadores* (so-called “hunting parties”). These groups are usually constituted of men who are themselves in the rehabilitation centers. Participation in a hunting party offers a chance to get out of the center, even for a brief time, and “hunters” typically target people too high or drunk to resist, and those whose families they deem able to pay for rehabilitation. As one detainee described:

*“[T]hey go out hunting for people who are really high or running the streets. And then they just get out of the car [when they see someone]. The guy always tries to [run]...But then they hit him...They then take them to the rehab.”*¹⁴

¹⁰ U.N. General Assembly, Final report of the Ad Hoc Committee on a *Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, 61st Sess., Item 67 (b), (Dec. 6, 2006), <http://daccess-dds-ny.un.org/doc/UNDOC/LTD/N06/645/30/PDF/N0664530.pdf?OpenElement>.

¹¹ Campaign to Stop Torture in Health Care, Russia: When Vigilantes Step In in Treated with Cruelty: Abuses in the Name of Drug Rehabilitation [hereinafter Russia: When Vigilantes Step In], OPEN SOCIETY FOUNDATIONS (2011).

¹² Nastia’s story, (2010)(on file with Open Society Foundations).

¹³ K O’Neill, *Guatemala’s Compulsory Rehabilitation Centers*, UNIVERSITY OF TORONTO (2013), http://www2.ohchr.org/English/bodies/cat/docs/ngos/UniversityToronto1_Guatemala_CAT50.pdf.

¹⁴ Id.

Even when approved on the basis of physician opinion or court process, involuntary commitment into drug treatment is frequently based on poorly defined or arbitrary standards. In Peru, a single doctor's opinion can be used by families to declare an addict "incapable," and to initiate involuntary internment. As of this writing, the Brazilian Congress is debating a law permitting compulsory treatment based on the recommendation of any public official. The states of Rio de Janeiro and São Paulo have already approved forced treatment,¹⁵ with at least 85 boys and girls hospitalized against their will.¹⁶ In São Paulo, the campaign is called, tellingly, "Pain and Suffering." Advocates report that medical professionals operating in these areas feel pressured by politicians to take all children rounded up to psychiatric treatment, even when medically unnecessary and inappropriate, in what they interpret as a method to "clean up the streets," rather than a real commitment to help drug users.¹⁷ United Nations Special Rapporteurs have expressed their concern about this campaign,¹⁸ and about arbitrary detention of drug users in Brazil more generally.¹⁹ In "therapeutic communities" in Brazil, patients report overcrowding, squalid conditions, beatings, unmedicated withdrawal, lack of medication for conditions like HIV, forced manual labor, and locked wards.²⁰

Detention Without Review or Appeal

*"[The security wall] doesn't keep people out; it keeps us in."*²¹

Forced to enter private drug treatment centers, people also cannot leave voluntarily. In Peru, two fires in religious rehabilitation centers claimed the lives of those placed there for "rehabilitation"—detainees struggled against locked doors as they burned to death.²² Detainees in a Russian center described being handcuffed to their beds; if brought outside to work, guards supervised them. In Guatemala, where centers are run by Pentecostal groups who collect fees from family members, centers are often windowless spaces with steel bars, razor wire, and reinforced concrete topped with shards of broken glass.

Even medical care may be restricted due to worries about escape. A Russian woman told of a fellow inmate who had a severe infection: "Her leg got all swollen. It got huge and turned a strange color. They only took her to the doctor when she could hardly walk; she was in so much pain. They

¹⁵ J Bateman, *Public Health Approach Takes Back Seat to Law Enforcement as Brazil Cracks Down on Drug Use*, WASHINGTON OFFICE ON LATIN AMERICA (2013), http://www.wola.org/commentary/public_health_approach_takes_back_seat_to_law_enforcement_as_brazil_cracks_down_on_drug_u.

¹⁶ G Moncau, *A internação compulsória é sistema de isolamento social, não de tratamento* (2013), <http://oesquema.com.br/penselivre/2013/01/29/a-internacao-compulsoria-e-sistema-de-isolamento-social-nao-de-tratamento.htm>.

¹⁷ Bateman, *supra* note 15.

¹⁸ U.N. Special Rapporteur on Adequate Housing, U.N. Rapporteur on Extreme Poverty and Human Rights, & U.N. Special Rapporteur on the Right to the Highest Attainable Standard of Physical and Mental Health, *Letter to the government of Brazil* (2012), https://spdb.ohchr.org/hrdb/21st/public_-_AL_Br%C3%A9sil_11.04.12_%283.2012%29.pdf.

¹⁹ Office of the High Commissioner on Human Rights [OHCHR], *Working Group on Arbitration (sic) Detention Statement Upon Conclusion of its Visit to Brazil* (2013), <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13197&LangID=E>.

²⁰ G Moncau, *Nem comunidades, nem terapeuticas—reportagem na Revista Caros Amigos* (2012), <http://coletivodar.org/2012/04/nem-comunidades-nem-terapeuticas-reportagem-na-revista-caros-amigos/>.

²¹ O'Neill, *supra* note 13.

²² D Wolfe, *Drug Users Burned by the System in Peru*, OPEN SOCIETY FOUNDATIONS (2012), <http://www.opensocietyfoundations.org/voices/drug-users-burned-system-peru>.

took her to the doctor for surgery and brought her back after one day; they refused to let her stay in the hospital because they were afraid she would escape."²³

Family visits are usually monitored, and when people do complain to their family members about conditions in the center, or plead for help to get out, their complaints are frequently dismissed because they are regarded as unreliable. A sister in Mexico described the pleas from her brother after he was released from a treatment center: "'Please don't put me in there [ever again], you'll regret it for the rest of your life.' But because they are addicts, sometimes you don't believe what they say."²⁴

Just as there are no clear criteria articulated for entry into private centers, there are often none for exit. Length of confinement can be changed at any time. One detainee in Guatemala complained: "My family brought me here. And, from what I know, the pastor has to tell my family that I'm ready to go. I don't know, like, they will find a reason to keep me here, and every time I think I am ready, they change the game."²⁵

"Treatment" Through Punishment

*"Their system is based on the whip; they condition you through pain, isolation, and continuous humiliation."*²⁶

Detainees in private centers often find themselves subjected to punishments if they complain about the conditions. In a Guatemalan center, for example, those who say, "I don't like it" are punished with 1,000 squats, as are those who fail to love the Bible. Those who "grumble" about the authorities are required to perform 2,000 squats. Swearing is punished with 1,000 squats per letter, including "the spaces." Escape attempts are punished with 5,000 squats a day for eight days.²⁷

Physical abuse is also a part of the regimen in other religious centers. This physical scourging has a religious nature, and some drug users are told that they will be confined until they are deemed freed from their "demons." In one drug treatment center in Serbia, run by orthodox priests, beating was a mainstay of "rehabilitation." "In the yard, they gather the addicts in a circle to watch the 'bad one' get beaten. They hit him with clubs, shovels, fists, bars, belts, whatever they can get their hands on," a former patient reported.²⁸ The center was exposed after a video was posted on YouTube of center staff paddling and punching a patient in front of a religious icon.²⁹

Many secular centers also use harsh methods like beating, flogging, or survival challenges. A former detainee in Russia told of the "treatment" in the center where he was held,

*"When you are new, just brought in, they take you to a separate room; there is a couch there, you lie down, take off your pants, so you are in your underpants, and two or three members of the...staff stand beside you. I was whipped by three people at a time. And they would whip you until your butt is completely black. You are not allowed to cover yourself with your hands, with anything...They do it to teach drug users a lesson."*³⁰

²³ Nastia's story (2010) (on file with Open Society Foundations).

²⁴ Mexico: Left with No Better Option, *supra* note 9.

²⁵ O'Neill, *supra* note 13.

²⁶ Russia: When Vigilantes Step In, *supra* note 11.

²⁷ O'Neill, *supra* note 13.

²⁸ NGO Veza, Report on Human Rights Violence in Spiritual Drug-Rehabilitation Centers. (2013)(on file with the authors).

²⁹ Mračna tajna Crne Reke Ubijanje Boga lopatom—in Serbian Orthodox Church (Crna Reka). Available online at <http://www.youtube.com/watch?v=-IL1dPdOxK4>.

³⁰ Russia: When Vigilantes Step In, *supra* note 11.

Programs for “troubled teens” in the US have faced allegations of sexual abuse; moreover dozens of children have died in such programs, due to causes like dehydration and heatstroke.³¹ Psychologists in Siberia defend their use of “flogging therapy”, noting that, “caning counteracts a lack of enthusiasm for life which is often behind addictions, suicidal tendencies and psychosomatic disorders.”³²

In Guatemala, a detainee described the routine in the center where he was being held, “The head guy would put shoes on, tell us to lie down, and then run on top of us. Back and forth. Back and forth. After he would beat us, he would make us sleep on the stairs, in boxers. We would sleep there. He called it discipline.”³³

Substandard and Abusive Living Conditions

“We almost always heard screams at night, but then they calm down.”³⁴

Beyond the abuses associated with supposed treatment, many drug treatment centers are not safe places. Staff may not intervene when they see physical abuse between detainees. Furthermore, living conditions are sometimes unhygienic, smelling of urine, feces, mildew, and rotting vegetables.³⁵

A man who’d been held in a center in Yekaterinburg, Russia, told of the squalid conditions there:

Everyone in the “cold room” was going through withdrawal. Well, just imagine, there were 21 of us, all in withdrawal. There was a bottle to pee in—it was the toilet. We were given only water and bread to eat. Stuff literally oozed from the walls, and the stench was horrible. Everyone was sweating, all that odor and ooze.³⁶

Deaths in Drug Treatment Centers

“I do not approve of beating, but unfortunately it is sometimes necessary to beat up beneficiaries for their own good.”³⁷

It is appalling, though perhaps not surprising, that there are reports of deaths in these centers. One woman in Mexico reported on her brother’s death following physical abuse at the hands of center management:

We are certain he was beaten from August 5, when he was admitted, until August 8—approximately four days. According to the other guys [in the center] every day there were several padrinos [those in charge of “treatment” at the center] “visiting” him to beat him...The other guys even said that on the days that the padrinos were beating him, they bathed him with powder soap, with a hose, they scratched him with a broom...When I visited him in the hospital, he had a heavy blow on his eye...

³¹ M Szalavitz, *New Efforts to Crack Down on Residential Programs for Troubled Teens*, TIME (2011), <http://healthland.time.com/2011/10/07/new-efforts-to-crack-down-on-residential-programs-for-troubled-teens/>.

³² W Stewart, *How to Beat Your Demons, Literally: Siberian Psychologists Thrash Patients with Sticks to Help Them Kick Their Addictions* (2013) <http://www.dailymail.co.uk/news/article-2258395/How-beat-addictions-literally-Siberian-psychologists-thrash-patients-sticks-help-kick-habits.html#ixzz2IEecFDkr>.

³³ O’Neill, *supra* note 13.

³⁴ Roberto Cortijo (AFP), *Firekills14inPerudrugrehabcenter:Firefighters* (2012), http://www.google.com/hostednews/afp/article/ALeqM5i8RIZSiClgViWDOonnDpU3yK_rBQ?docId=CNG.0737c640174ca721d68b08076948e78f.a01 (neighbor commenting about a nearby drug rehabilitation in Peru).

³⁵ O’Neill, *supra* note 13.

³⁶ Russia: When Vigilantes Step In, *supra* note 11.

³⁷ A Serbian Archbishop defending his practice of beating detainees in a drug rehabilitation center in NGO Veza, *Report on Human Rights Violence in Spiritual Drug-Rehabilitation Centers*. (2013) (on file with the authors).

*We learned afterward that the padrinos did this with a small baseball bat...he also had a punctured lung and six broken ribs; the medical certificate determined that they were broken with a blunt object.*³⁸

Similarly, in Serbia, the head of a drug rehabilitation center was arrested for murdering a patient treated there. Autopsy findings showed that the victim suffocated from vomiting that was caused by repeated blows to the head with a blunt object.³⁹ In South Africa, the death of a teenager in a private drug treatment center led to an investigation that found that the boy had been chained to the iron gate of a cell in a way that prevented him from sitting or sleeping, because “this is a method used by the Centre to break difficult or troublesome patients.” Though he couldn’t have hanged himself, there were bruises all over his body because “it was not unusual for patients to be assaulted if they did not follow the instructions of the monitors during such a punishment program.”⁴⁰

Responsibilities of State Actors

*“In a large number of countries, state and non-state actors are resorting to antiquated methods of treatment, including starvation, torture, etc. to force drug users to give up the consumption of drugs. There are even some reports alleging that such non-scientific methods lead to the death of drug users. This has to be actively discouraged.”*⁴¹

The fact that these drug treatment and rehabilitation centers are privately run does not exempt the state from preventing, investigating and offering redress for harms caused by abuses committed there. State “consent and acquiescence” described in the Convention against Torture is particularly clear when police deliver people who use drugs to centers without due process, or when the state compels entry into private, unregulated facilities. As the Committee Against Torture has noted, states are also accountable through failure of “due diligence”: that is, state officials bear responsibility when they know, or have reasonable grounds to believe, that torture or ill-treatment are being perpetrated by private actors, and they do nothing to stop, sanction, or provide remedies to victims of such abuses.⁴² The Committee has applied this principle to failure to prevent and protect victims from rape, female genital mutilation, and human trafficking.⁴³ Abuses in drug treatment and rehabilitation in private facilities—which can include rape and human trafficking, but also multiple other forms of ill-treatment—require similar intervention.

Additional legal and ethical questions are raised by the relations between state failure to provide or regulate community and evidence-based drug treatment, and the proliferation of abusive private centers operating with impunity. Indeed, families often report that they commit people who use drugs to private facilities because there are no other viable options available. These dynam-

³⁸ Mexico: Left with No Better Option, *supra* note 9.

³⁹ NGO Veza, Report on Human Rights Violence in Spiritual Drug-Rehabilitation Centers (2013) (on file with the authors)

⁴⁰ South African Gov’t Information, Report on Findings of the Investigation into Circumstances Related to the Death of a Child at the Noupooort Christian Care Centre (2001), <http://www.info.gov.za/otherdocs/2001/noupooort.htm>.

⁴¹ U.N. Special Rapporteur on the Question of Torture & U.N. Special Rapporteur on the Right to the Highest Attainable Standard of Physical and Mental Health, *Letter to the Commission on Narcotic Drugs* (2008), <http://www.humanrightsanddrugs.org/wp-content/uploads/2009/12/SpecialRapporteursLettertoCND012009.pdf>.

⁴² UNCAT, *General Comment No. 2: Implementation of Article 2 by States Parties*, CAT/C/GC/2 (2008), <http://www.refworld.org/docid/47ac78ce2.html>.

⁴³ Redress & Amnesty Int’l, *Gender and Torture Conference Report* (2012), <http://www.redress.org/downloads/publications/GenderandTortureConferenceReport-191011.pdf>.

ics highlight the intersection of concerns about torture and ill-treatment and other international human rights violations in private centers, including rights to due process, to health, and to protection of those with disabilities.

Unfortunately, countries do not seem to be taking proactive steps to meet their obligations to prevent ill-treatment in private drug treatment centers, to sanction the facilities, or to punish those responsible. Indeed, many such centers are not even officially registered with government entities. For example the Peruvian agency responsible for drug prevention and treatment—the Comisión Nacional para el Desarrollo y Vida Sin Drogas, or DEVIDA—notes that of 222 “rehabilitation” facilities in the country, only 20 percent have all the necessary licenses and required medical staff. There are an estimated 700 “treatment” slots in registered facilities for an estimated 100,000 people in need.⁴⁴ Similarly, in Guatemala, there is reportedly one government worker responsible for visiting the hundreds of drug rehabilitation centers and accrediting them. When a researcher pressed him about how incomplete his list of centers was, the official admitted that many centers are in dangerous neighborhoods that he does not wish to visit. Because of this, he knowingly keeps these centers off his list.⁴⁵

Conclusion

Not everyone who uses drugs needs drug treatment. The majority of people who use drugs are not clinically dependent, and their drug use will resolve itself over time. However, people who do have a problematic addiction, for which they want help, should be able to access voluntary treatment that is tailored to their individual needs and is based on evidence of effectiveness.⁴⁶ Such treatment is often best offered in the community, rather than in closed settings. Multiple studies have suggested outpatient counseling, contingency management, and other psychosocial approaches for those experiencing problems related to stimulant dependence.⁴⁷ For those dependent on heroin or other opioids, methadone and buprenorphine are proven treatments that can be provided on an outpatient basis, allowing participants to work and otherwise remain involved in community and family life.⁴⁸ Some people prefer a period in a residential treatment setting; because closed institutions where people are kept out of the public eye are prone to abuse, these settings should allow family visits and outside contact as much as possible.

Recommendations

To Governments: Governments have a responsibility to accredit and regularly monitor private drug treatment centers in their territory. Outside monitors (such as human rights groups and others like the International Committee of the Red Cross) should also be allowed entry. Among the conditions that should be investigated are: locked wards, evidence of physical and mental abuse, and involuntary detention. States should ensure that police and other state actors are not delivering

⁴⁴ Wolfe, *supra* note 22.

⁴⁵ O'Neill, *supra* note 13.

⁴⁶ U.N. Office on Drugs and Crime & World Health Organization, *Principles of Drug Dependence Treatment* (2008), <https://www.unodc.org/documents/drug-treatment/UNODC-WHO-Principles-of-Drug-Dependence-Treatment-March08.pdf>.

⁴⁷ *Therapeutic Interventions for Users of Amphetamine-Type Stimulants*, WORLD HEALTH ORGANIZATION, WESTERN PACIFIC REGION (2011), http://www.wpro.who.int/hiv/documents/docs/Brief4forweb_7DF1.pdf.

⁴⁸ World Health Organization, *Guidelines for Psychosocially Assisted Pharmacological Treatment of Opioid Dependence* (2009), http://whqlibdoc.who.int/publications/2009/9789241547543_eng.pdf.

people to drug treatment centers against their will. Furthermore, there should be clear mechanisms for people to report abuses; when abuses are reported, such allegations should be taken seriously and investigated by the government. Victims should be offered protection and means of redress. Perpetrators should be held accountable in the legal system, and centers that harbor human rights violations should be sanctioned or closed.

To U.N. treaty bodies and special procedures: Several U.N. mechanisms have a mandate to call attention to abuses in private drug treatment centers. The Committee Against Torture, the Subcommittee for the Prevention of Torture, the Working Group on Arbitrary Detention, the Committee on Economic, Social, and Cultural Rights, the Committee on the Rights of the Child, the Special Rapporteur on Torture, and the Special Rapporteur on Health should all investigate rights violations in private drug treatment centers during their country visits.

To U.N. agencies: U.N. agencies, particularly the U.N. Office on Drugs and Crime and the World Health Organization, should help countries establish evidence-based, community alternatives to abusive centers.

To nongovernmental organizations: Organizations like the World Federation of Therapeutic Communities and religious orders should speak out against abuses in drug treatment centers. Human rights groups should also work to shine light on abuses happening in the name of drug treatment in their countries.

Denial of Pain Treatment and the Prohibition Against Torture and Ill-Treatment

DIEDERIK LOHMAN* & TAMAR EZER**

CONTRIBUTORS: LILIANA DE LIMA***, EVA DUARTE****, M R RAJAGOPAL***** & WILLEM SCHOLTEN*****

Abstract

Cancer pain, as well as pain due to other illnesses, causes tremendous suffering for patients and their families alike. Millions of people worldwide suffer from severe pain without access to adequate treatment each year. Although morphine and most other strong pain medications are off-patent, inexpensive, safe and highly effective, they are virtually unavailable in more than 150 countries around the world. Furthermore, the regional disparity in treatment availability is enormous. Low and middle income countries account for just 6% of morphine use worldwide, despite having half of all cancer patients and 95% of all new HIV infections. Lack of access to pain treatment is mainly due to overly-restrictive regulations, government neglect, and inadequate training of health professionals.

Given the scale and extent of suffering, the failure of governments in many countries to ensure the adequate availability of pain treatment services not only raises questions of whether these countries live up to their obligations under the right to health, but also the obligation to ensure freedom from torture and ill treatment. The Special Rapporteur on Torture explains that the prohibition against torture and ill treatment is indeed triggered in these cases when suffering is severe, the state is or should be aware of the suffering, no appropriate treatment is offered, and the government fails to take reasonable steps to address this. His recent landmark report on torture in health settings thus instructs states to deal with policy gaps and regulatory, educational, and attitudinal obstacles to full access to palliative care.

*Senior Researcher, Health and Human Rights Division, Human Rights Watch, New York City, New York 10018, USA, lohmand@hrw.org.

**Senior Program Officer, Law and Health Initiative, Public Health Program, Open Society Foundations, 224 West 57th St., New York, New York 10019, USA, tamar.ezer@opensocietyfoundations.org.

***Executive Director, International Association for Hospice and Palliative Care, 5535 Memorial Dr. Suite F-PMB 509, Houston, Texas 77007, USA, ldelima@iahpc.com.

****Director, Palliative Care Department, Instituto de Cancerología ICAN Guatemala, 6a Avenida 6-58, Zona 11, Guatemala City, Guatemala 01011, evarossina@gmail.com.

*****Director, Trivandrum Institute of Palliative Sciences (WHO Collaborating Center for Training and Policy of Access to Pain Relief), S-10, Vrindavan Gardens, Pattom, Trivandrum 695004, Kerala, India, mrraj47@gmail.com.

*****Consultant—Medicines and Controlled Substances, chemin du Lignolet 18A, 1260 Nyon, Switzerland, wk.scholten@bluewin.ch.

The former and current Special Rapporteurs on Torture firmly establish denial of pain treatment as a violation of torture and CIDT in certain cases. The use of this lens has important implications, clarifying that state obligation to remedy this violation is immediate, non-derogable, and not contingent on available resources. It also raises critical attention to what has been a silent violation.

Introduction

Cancer pain, as well as pain due to other illnesses and conditions, causes tremendous suffering for patients and their families alike. A cancer patient from Ukraine described his pain as follows: “The pain was so bad that my whole body seemed to break. We would call the ambulance every 2 to 3 hours because I could not stand the pain. It was intolerable to live like that.”¹ In fact, patients with severe pain express sentiments similar to victims of police torture. While victims of police torture may sign a confession to make the pain stop, these patients need care and a system that allows for pain treatment. Unfortunately, this is not available to many patients around the world, and frequently they see death as the only way to stop the suffering.² The mother of a Ukrainian cancer patient, for example, told Human Rights Watch that her son had tried to jump head-first from his hospital room because he couldn’t bear the pain anymore.³ A doctor in India recalled a cancer patient who had swallowed agricultural poison in an attempt to kill herself and escape her untreated pain, failing to do so but causing extensive damage to her internal organs. The mother of a patient in Colombia with cervical cancer placed an ad in a local paper pleading with the secretary of health to help her because “the pain is killing us.”⁴ Experts estimate that on average 80% of patients with cancer or 50% with HIV develop moderate to severe pain during the last three months before death.⁵

Like these patients from Ukraine, India and Colombia, millions of people worldwide suffer from severe pain without access to adequate treatment each year. Although morphine and most other strong pain medications are off-patent, inexpensive, safe and highly effective, they are virtually unavailable in more than 150 countries around the world.⁶ The World Health Organization (WHO) estimates that 80% of the world population lives in countries with no or almost no access to medications like morphine and that tens of millions of people worldwide suffer from moderate to severe pain without access to treatment every year, including 5.5 million people with terminal cancer.⁷

¹ Open Society Foundations, *Palliative Care as a Human Right: A Fact Sheet* (2011), available at <http://www.opensocietyfoundations.org/sites/default/files/palliative-care-human-right-20110524.pdf>, p. 2.

² Human Rights Watch, “*Please Do Not Make Us Suffer Any More...: Access to Pain Treatment as a Human Right*” (March 2009) <http://www.hrw.org/reports/2009/03/02/please-do-not-make-us-suffer-any-more> [hereinafter “*Please Do Not Make Us Suffer*.”] Human Rights Watch, *Unbearable Pain: India’s Obligation to Ensure Palliative Care*, (Oct. 2009), available at <http://www.hrw.org/reports/2009/10/28/unbearable-pain-0>. Human Rights Watch, *Uncontrolled Pain: Ukraine’s Obligation to Ensure Evidence-Based Palliative Care* (May 2011), <http://www.hrw.org/reports/2011/05/12/uncontrolled-pain-0> [hereinafter *Uncontrolled Pain*]; Human Rights Watch, *Global State of Pain Treatment: Access to Medicines and Palliative Care* (Jun. 2011), available at <http://www.hrw.org/reports/2011/06/02/global-state-pain-treatment-0>.

³ Human Rights Watch, *Uncontrolled Pain*, *supra* note 2.

⁴ Human Rights Watch, “*Please Do Not Make Us Suffer*,” *supra* note 2.

⁵ Kathleen M. Foley et al., “Pain Control for People with Cancer and AIDS,” in *Disease Control Priorities in Developing Countries*, 2nd ed., (New York: Oxford University Press, 2003), pp. 981-994.

⁶ Statement by Professor Sevil Atasoy, President of the International Narcotics Control Board, at the Economic and Social Council Substantive Session for 2009 (Jul. 30, 2009), available at: http://www.incb.org/documents/President_statements_09/2009_ECOSOC_Substantive_Session_published.pdf.

⁷ “Briefing Note: Access to Controlled Medicines Program,” *World Health Organization Briefing Note* (Feb. 2009), available at: http://www.who.int/medicines/areas/quality_safety/ACMP_BrNoteGenrl_EN_Feb09.pdf.

The regional disparity in treatment availability is also enormous. Low and middle income countries account for just 6% of morphine use worldwide⁸, despite having half of all cancer patients⁹ and 95% of all new HIV infections.¹⁰ A study by a WHO team showed that in Africa access to opioid analgesics is nowhere higher than 3% of what is considered adequate and in many African countries, it is close to zero. The team further found a high correlation between the adequacy of access to opioid analgesics and the Human Development Index.¹¹

Research by palliative care and human rights groups has found three common policy failings that allow this situation to persist:

1. In their efforts to crack down on illicit drug use, many governments have adopted regulations that are so restrictive that they directly and needlessly interfere with medical access to morphine and other essential but controlled medications. For example, many Indian states hospitals need to obtain five different licenses that must all be valid at the same time in order to be able to buy morphine; in Mexico, doctors must request special bar coded stickers to prescribe opioid medications, which can only be obtained in state capitals and in limited quantities. While these regulations aim to prevent misuse and diversion of these medications, they result in hospitals, pharmacies and doctors refusing to stock or prescribe them, thus condemning patients and their families to severe and unnecessary suffering.
2. Government health policies frequently neglect the health needs of patients with chronic and incurable illnesses. Although in most low and middle income countries 60-70% of cancer patients are diagnosed when they already have advanced disease and can derive little benefit from curative treatment, cancer control programs often focus almost exclusively on curative care and do not allocate budget resources to palliative care or pain treatment services.¹² The failure to assess pain treatment need and plan accordingly leads to inadequate availability and often unnecessarily high cost of controlled medicines in many countries.
3. Public medical and nursing schools in many countries fail to train healthcare workers even in basic pain management and palliative care skills. As a result, healthcare workers often simply do not know how to treat severe pain and other symptoms and have irrational fears about using morphine. In India, for example, doctors routinely tell cancer patients that they should expect to suffer from pain because they have a serious illness, even though WHO confirms that the vast majority of cancer pains can be treated effectively.¹³

⁸ International Narcotics Control Board, *2004 Report*. New York, United Nations (2005), available at: http://www.incb.org/pdf/e/ar/2005/incb_report_2005_full.pdf.

⁹ WHO, *National Cancer Control Programmes: Policies and Managerial Guidelines* (2002) p. 17, <http://www.who.int/cancer/media/en/408.pdf>.

¹⁰ National Institute of Allergy and Infectious Diseases, "HIV Infection in Infants and Children" (Jul. 2004), available at: <http://www.niaid.nih.gov/factsheets/hivchildren.htm>. Fauci A.S., "AIDS epidemic: Considerations for the 21st century," *New England Journal of Medicine*, vol. 341, no. 1414, (1999) pp. 1046-1050.

¹¹ Seya MJ, Gelders SFAM, Achara UA, Milani B, Scholten WK, "A First Comparison between the Consumption of and the Need for Opioid Analgesics at Country, Regional and Global Level," *J Pain and Palliative Care Pharmacotherapy* (2011) 25: 6-18, available at: <http://apps.who.int/medicinedocs/documents/s17976en/s17976en.pdf>.

¹² Human Rights Watch, "Please Do Not Make Us Suffer," *supra* note 2.

¹³ Vitorrio Ventrafrida et al, "A Validation Study of the WHO Method of Cancer Pain Relief" *Cancer* 59:850-856 (1987).

Discussion

1. Application of Torture and Ill-treatment Standards

Given the scale and extent of suffering, the failure of governments in many countries to ensure the adequate availability of pain treatment services not only raises questions of whether these countries live up to their obligations under the right to health,¹⁴ but also of state obligation to ensure freedom from torture and cruel, inhuman and degrading treatment (CIDT or ill treatment). In his recent landmark report on torture and ill treatment in health settings, Professor Juan E. Méndez, the UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment (Special Rapporteur on Torture), highlighted denial of pain treatment as a key instance of abuse in health settings.¹⁵ He explained, “When the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment.”¹⁶ This echoes findings by the former Special Rapporteur on Torture, Professor Manfred Nowak, that “the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.”¹⁷

However, not every case where a person suffers from severe pain but has no access to appropriate treatment will constitute torture or CIDT. In his recent report, the Special Rapporteur against Torture articulates the following test:

- “the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment”;
- “the State is, or should be, aware of the suffering, including when no appropriate treatment was offered”; and
- “the Government failed to take all reasonable steps to protect individuals’ physical and mental integrity.”¹⁸

a. Severity and Extent of the Suffering

Most international human rights mechanisms use a minimum level of severity for any suffering to qualify as torture or ill treatment. Suffering related to severe pain that should be treated is unnecessary and seems to achieve the minimum level of severity:

Physical suffering: Pain due to cancer or other illnesses can be very severe, it often extends to many parts of the body, may be constant and without reprieve, and can last over long periods of time. Experts estimate that, on average, a person dying of cancer or AIDS will suffer from moder-

¹⁴ UN Committee on Economic, Social and Cultural Rights, “*Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights*,” General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (2000), [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument), paras 12 and 34.

¹⁵ Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan Méndez, “Applying the torture and ill-treatment protection framework in health settings,” A/HRC/22/53 [hereinafter Méndez Report].

¹⁶ *Id.* at para. 55.

¹⁷ Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, January 14, 2009. <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf>, para. 72.

¹⁸ Méndez Report, para. 54.

ate to severe pain for a period of three months.¹⁹ As mentioned above, patients without access to treatment often develop suicidal ideation and sometimes attempt suicide.

Mental suffering: Patients in severe pain often experience a profound sense of loss of control, fear, anxiety, depression and isolation, become bedridden and incapable of being active or even making basic decisions about their own lives.²⁰ Pain frequently causes acute sleep deprivation that builds over time and has a profound impact on patients' mental state.²¹

Long-term consequences: According to WHO, the physical effect of pain can influence the course of the diseases and even result in death.²² Pain frequently causes immobility, which can result in permanent loss of function in patients.²³

b. Lack of Reasonable Justification

The prevalence of severe pain in patients with cancer, HIV and various other conditions and its impact on patients and families are well-established in medical and public health literature. WHO has issued treatment protocols for pain in cancer and that offer low-cost options.²⁴ Therefore, states cannot claim a lack of awareness as a justification for allowing severe suffering of large numbers of patients from untreated pain to persist.

Indeed, research has found that serious policy failings are a core reason for much of the suffering from untreated pain in the world today. We discuss two examples that are particularly relevant:

Access to controlled medications. Because medications like morphine are internationally controlled substances, governments need to take action to enable their manufacture, distribution and prescription under the Single Convention of Narcotic Drugs. If governments do not take steps to ensure their availability, patients will not be able to legally obtain them. In other words: Patients are at the mercy of the government for access to these medications.

The UN drug conventions, however, oblige states to make adequate provision to ensure the availability of controlled substances for medical purposes and the UN Commission on Narcotic Drugs reminded countries of this in resolutions adopted in 2010 and 2011.²⁵ Yet, compliance remains deeply problematic. Many countries fail to make adequate arrangements for the supply of these medications. For example, in 2009 Burkina Faso requested a quantity of morphine that was sufficient to treat just eight terminal cancer or HIV patients for pain, whereas the need exceeded 25,000 people.²⁶

¹⁹ Kathleen M. Foley, et al., "Pain Control for People with Cancer and AIDS."

²⁰ Gureje O, Von Korff M, Simon GE, Gater R., "Persistent pain and well-being: a World Health Organization study in primary care," *JAMA*, vol. 80 (1998) pp. 147-51. See also: B. Rosenfeld, et al., "Pain in Ambulatory AIDS Patients. II: Impact of Pain on Psychological Functioning and Quality of Life," *Pain*, vol. 68 (1996) pp. 2-3, 323—28.

²¹ Brennan F, Carr DB, Cousins MJ, "Pain Management: A Fundamental Human Right," *Anesthesia & Analgesia*, vol. 105, No. 1 (Jul. 2007). pp. 205-221.

²² WHO, "National Cancer Control Programme: Policies and Managerial Guidelines" (2002) p. 83.

²³ Brennan F, Carr DB, Cousins MJ, "Pain Management: A Fundamental Human Right," *Anesthesia & Analgesia*, vol. 105, No. 1 (Jul. 2007)_ pp. 205-221.

²⁴ WHO, *Cancer Pain Relief, Second Edition, With a Guide to Opioid Availability*, (Geneva: World Health Organization, 1996).

²⁵ The Commission on Narcotic Drugs, Resolution on availability of internationally controlled substances, Resolutions 53/4 and 54/6.

²⁶ Human Rights Watch, "Please Do Not Make Us Suffer Any More..." *supra* note 2.

Additionally, many governments maintain drug regulations that directly and arbitrarily interfere with proper medical practice. Until recently, for example, Ukrainian drug control policies allowed only licensed nurses or physicians to administer every dose of morphine, condemning thousands of patients to die at home in pain. This kind of requirement is unnecessary from both a medical and drug control perspective. After morphine has been legitimately prescribed and dispensed to patients who are at home, it is recognized good practice for them or their families to administer the medication themselves. (In May 2013, the Ukrainian government adopted new drug regulations that permit patients to administer morphine themselves at home). In Guatemala, regulations require that every prescription for a controlled medication such as morphine be validated at a government office in Guatemala City before a pharmacy can dispense it.²⁷ This requirement, unnecessary from a drug control or medical perspective, makes morphine practically inaccessible for many patients, particularly those in rural areas.

Failure to address health needs without discrimination. In many countries, government health policies neglect the needs of people with incurable or terminal illnesses. For example, in Guatemala, there is no availability in any public health facility to oral or parenteral opioid analgesics for out-hospital patients with severe pain due to cancer, HIV, or other advanced/terminal illnesses. These patients are abandoned by the public health system. Private services and lucrative drug distributors are their only source of pain relief and come at a considerable cost, which most cannot afford. In India, Human Rights Watch found that more than half of the country's regional cancer centers, which see tens of thousands of cancer patients per year, do not offer adequate pain treatment as they do not have morphine or doctors trained in using it. This is despite the fact that 70% or more of their patients have advanced cancer and are likely to require pain treatment. Although the Indian government bestows the prestigious designation of regional cancer center on hospitals and provides some financial support, it has not used its leverage with these hospitals to ensure that they offer pain treatment services. As a result, tens of thousands of patients in these cancer centers suffer unnecessarily from severe pain every year.²⁸

This kind of gross neglect of the needs of large numbers of patients, who as a result face severe suffering, violates the prohibition against torture and ill treatment, and states should be held accountable accordingly.

2. Government Obligations

In his report, the Special Rapporteur on Torture provides explicit guidance to states on their obligations:

- "Ensure that narcotic drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering; review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical purposes."

²⁷ Price, J. Pain Relievers. *On Wisconsin* 2010; Winter: 39-45. See also Dirección General de Regulación, Vigilancia y Control de la Salud, Departamento de Regulación y Control de Productos Farmacéuticos y Afines, Guatemala, *Normativa 17-2002* (May 16, 2002), available at: http://webcache.googleusercontent.com/search?q=cache:c5KkE_nyuSAJ:www.medicamentos.com.gt/index.php/legislacion-vigente/normas-tecnicas%3Fdownload%3D76%253Ano-17-2002+Ministerio+de+salud+de+guatemala+normativa+17-2002&cd=1&hl=en&ct=clnk&client=safari; http://www.medicamentos.com.gt/index.php/legislacion-vigente/normas-tecnicas?download=76%3Ano-17-2002.

²⁸ Human Rights Watch, *Unbearable Pain*, *supra* note 2.

- “[O]vercome current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine.”
- “Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programmes and developing the necessary standards, guidelines and clinical protocols.”²⁹

This guidance significantly addresses policy gaps and regulatory, educational, and attitudinal obstacles to full access to palliative care.

Conclusion

The former and current Special Rapporteurs on Torture firmly establish denial of pain treatment as a violation of torture and CIDT in certain cases. The use of this lens has important implications, clarifying that state obligation to remedy this violation is immediate, non-derogable, and not contingent on available resources. This provides local advocates with a new tool to engage governments and challenge problematic policies, while drawing increased international attention to this issue. This attention is critical. Currently, not only do staggering numbers of patients live and die in excruciating, untreated pain, but their suffering is invisible. People dying in their homes and villages do not have the ability to go into the streets and cry out. It is time to give a voice to their suffering and stop the needless pain.

²⁹ Mendez Report, para. 86.

American Psychiatric Association**World Psychiatric Association**

Remigiusz Achilles Henczel, President, United Nations Human Rights Council
 Juan E. Mendez, Special Rapporteur on Torture
 Office of the High Commissioner for Human Rights
 United Nations Office at Geneva
 CH-1211 Geneva 10
 Switzerland

December 9, 2013

Dear Mr. Henczel and Mr. Mendez,

The **American Psychiatric Association (APA)** and the **World Psychiatric Association (WPA)** are providing a joint statement in response to the report of Special Rapporteur on Torture (A/HRC/22/53), Juan E. Mendez, submitted to the 22nd Session of the United Nations' Human Rights Council (UNHRC). Mr. Mendez's report focused on "certain forms of abuses in health-care settings" that may constitute forms of torture or cruel, inhuman or degrading treatment or punishment. The APA and WPA wish to express great concern regarding the possibility of the definition of "torture" encompassing a range of practices employed by psychiatrists, including (1) the use of involuntary civil commitment, (2) the provision of treatment delivered under the auspices of guardianship and other currently accepted legal processes, and (3) the use of restraint. The APA and WPA are greatly concerned that the adoption of these perspectives and recommendations may be detrimental to the interests of individuals with serious mental disorders, and likely to cause serious harm to the very groups it intends to protect.

Please find attached the following items for consideration: Attachment 1, a paragraph-by-paragraph response to the report of the Special Rapporteur; Attachment 2, a list of recommendations for consideration by the UNHRC; and Attachment 3, a list of official APA position statements relevant to the issue at hand. The APA and WPA greatly welcome the opportunity for further discussion to facilitate a greater understanding of the issue. Please feel free to contact us at internationaloffice@psych.org for any follow-up. Thank you for your consideration.

Respectfully,

Jeffrey Lieberman, M.D.
 President, American Psychiatric Association

Pedro Ruiz, M.D.
 President, World Psychiatric Association

Saul Levin, M.D., M.P.A.
 CEO/Medical Director, American Psychiatric Association

cc
 Ambassador Samantha Power, U.S. Representative to the United Nations
 Ambassador Elizabeth M. Cousens, U.S. Representative on the United Nations Economic and Social Council



ATTACHMENT 1: Paragraph-by-Paragraph Response to A/HRC/22/53

Below are excerpts from the report of the Special Rapporteur followed by responses for each cited statements. Statements have been provided for paragraphs 32, 35, 63-66, 68, 69, 85(e), and 89(b), (d).

Paragraph 32. The mandate has recognized that medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose, may constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned (ibid., paras. 40, 47). This is particularly the case when intrusive and irreversible, non-consensual treatments are performed on patients from marginalized groups, such as persons with disabilities, notwithstanding claims of good intentions or medical necessity. For example, the mandate has held that the discriminatory character of forced psychiatric interventions, when committed against persons with psychosocial disabilities, satisfies both intent and purpose required under the article 1 of the Convention against Torture, notwithstanding claims of “good intentions” by medical professionals (ibid., paras. 47, 48). In other examples, the administration of non-consensual medication or involuntary sterilization is often claimed as being a necessary treatment for the so-called best interest of the person concerned.

There is agreement to the first sentence of paragraph 32 that any treatment without a therapeutic purpose constitutes, at a minimum, ill-treatment. However, the paragraph subsequently asserts that “the *discriminatory character of forced psychiatric interventions* [emphasis added], when committed against persons with psychosocial disabilities, satisfies both intent and purpose required under the article 1 of the Convention against Torture, notwithstanding claims of “good intentions” by medical professionals.” Having begun by condemning treatment with no therapeutic purpose, the Special Rapporteur links such treatment to all involuntary psychiatric intervention when, in fact, involuntary treatment used in appropriate circumstances and when medically indicated, can restore the functional and decisional capacity of persons with severe psychiatric disorders, and can protect them and others from the behavioral consequences of their conditions.

Paragraph 35. The doctrine of medical necessity continues to be an obstacle to protection from arbitrary abuses in health-care settings. It is therefore important to clarify that treatment provided in violation of the terms of the Convention on the Rights of Persons with Disabilities – either through coercion or discrimination – cannot be legitimate or justified under the medical necessity doctrine.

There is disagreement with the conclusion in paragraph 35 that it is “important to clarify the treatment provided in violation of terms of the Convention on the Rights of Persons with Disabilities – either through coercion or discrimination – cannot be legitimate or justified under the medical necessity doctrine.” Although not sufficient by itself to justify involuntary treatment of capable persons, “medical necessity” is a cornerstone of insuring that involuntary treatment is used only when appropriate and when other interventions are not likely to be successful.

Paragraph 63. The mandate has previously declared that there can be no therapeutic justification for the use of solitary confinement and prolonged restraint of persons with disabilities in psychiatric institutions; both prolonged seclusion and restraint may constitute torture and ill-treatment (A/63/175, paras. 55-56). The Special Rapporteur has addressed the issue of solitary confinement and stated that its imposition, of any duration, on persons with mental disabilities is cruel, inhuman or degrading treatment (A/66/268, paras. 67-68, 78). Moreover, any restraint on people with mental disabilities for even a short period of time may constitute torture and ill-treatment.⁷⁸ It is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions. The environment of patient

powerlessness and abusive treatment of persons with disabilities in which restraint and seclusion is used can lead to other non-consensual treatment, such as forced medication and electroshock procedures.

There is agreement that solitary confinement and prolonged restraint are problematic practices and can constitute abuse. However, there is disagreement that “restraint on people with mental disabilities...constitute torture and ill-treatment.” For psychotic patients attempting to severely injure themselves or others, restraint may be the only way to prevent severe injury to the patient and essential to the protection of other patients and staff. It should be noted that patients in restraint must be monitored carefully and such restraints must only be used for the shortest amount of time possible. Short-term restraint, when applied humanely, can be life-saving.

Paragraph 64. The mandate continues to receive reports of the systematic use of forced interventions worldwide. Both this mandate and United Nations treaty bodies have established that involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.⁷⁹ Forced interventions, often wrongfully justified by theories of incapacity and therapeutic necessity inconsistent with the Convention on the Rights of Persons with Disabilities, are legitimized under national laws, and may enjoy wide public support as being in the alleged “best interest” of the person concerned. Nevertheless, to the extent that they inflict severe pain and suffering, they violate the absolute prohibition of torture and cruel, inhuman and degrading treatment (A/63/175, paras. 38, 40, 41). Concern for the autonomy and dignity of persons with disabilities leads the Special Rapporteur to urge revision of domestic legislation allowing for forced interventions.

There is agreement that when “involuntary treatment” is used to inflict severe pain and suffering, rather than for the patient’s benefit, it may constitute cruel inhuman and degrading treatment. However, there is disagreement with the statement that “involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.” It should be recognized that involuntary treatment, when used appropriately, is not a form of torture or ill-treatment.

Paragraph 65. Millions of people with disabilities are stripped of their legal capacity worldwide, due to stigma and discrimination, through judicial declaration of incompetency or merely by a doctor’s decision that the person “lacks capacity” to make a decision. Deprived of legal capacity, people are assigned a guardian or other substitute decision maker, whose consent will be deemed sufficient to justify forced treatment (E/CN.4/2005/51, para. 79).

There is disagreement with the statement that circumstances, in which illegitimate motives that may underlie interventions, ostensibly intended to protect persons with psychiatric disorders, are present in all such interventions. An appropriate decision that a person lacks the ability to make decisions for himself or herself (e.g. an elderly person with severe dementia), and reached by means protecting the rights of such a person, should be commended and not condemned.

Paragraph 66. As earlier stated by the mandate, criteria that determine the grounds upon which treatment can be administered in the absence of free and informed consent should be clarified in the law, and no distinction between persons with or without disabilities should be made.⁸⁰ Only in a life-threatening emergency in which there is no disagreement regarding absence of legal capacity may a health-care provider proceed without informed consent to perform a life-saving procedure.⁸¹ From this perspective, several of the 1991 Principles may require reconsideration as running counter to the provisions of the Convention on the Rights of Persons with Disabilities (A/63/175, para. 44).

There is disagreement with the second sentence of paragraph 66 as it suggests that the disagreement of a single individual, regarding a person in need of an emergency procedure not capable of consent, is sufficient to block

the procedure. In an emergency, reasonable professional judgment should be relied upon to determine whether a person is competent to make a treatment decision. The mere presence of a dissenting opinion that goes against the consensus of medical professionals involved in the case should not be permitted to halt life-saving procedures.

Paragraph 68. Involuntary commitment to psychiatric institutions has been well documented.⁸³ There are well-documented examples of people living their whole lives in such psychiatric or social care institutions.⁸⁴ The Committee on the Rights of Persons with Disabilities has been very explicit in calling for the prohibition of disability-based detention, i.e. civil commitment and compulsory institutionalization or confinement based on disability.⁸⁵ It establishes that community living, with support, is no longer a favourable policy development but an internationally recognized right.⁸⁶ The Convention radically departs from this approach by forbidding deprivation of liberty based on the existence of any disability, including mental or intellectual, as discriminatory. Article 14, paragraph 1 (b), of the Convention unambiguously states that “the existence of a disability shall in no case justify a deprivation of liberty”. Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished. This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness (A/HRC/10/48, paras. 48, 49).

There is disagreement with the conclusion of the last two sentences of paragraph 68 regarding the abolishment of institutionalization legislation. The hospitalization of persons with psychiatric disorders can be life-saving, and result in restoring a person with the ability to direct his or her own life.

Paragraph 69. Deprivation of liberty on grounds of mental illness is unjustified if its basis is discrimination or prejudice against persons with disabilities. Under the European Convention on Human Rights, mental disorder must be of a certain severity in order to justify detention.⁸⁷ The Special Rapporteur believes that the severity of the mental illness is not by itself sufficient to justify detention; the State must also show that detention is necessary to protect the safety of the person or of others. Except in emergency cases, the individual concerned should not be deprived of his liberty unless he has been reliably shown to be of “unsound mind”.⁸⁸ As detention in a psychiatric context may lead to non-consensual psychiatric treatment,⁸⁹ the mandate has stated that deprivation of liberty that is based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture (A/63/175, para. 65). In making such an assessment, factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.⁹⁰

There is disagreement with the statement that the “severity of...mental illness is not by itself sufficient to justify detention.” It should be noted that the severe impairment and suffering as a result of mental illness can be an appropriate basis for involuntary hospitalization. There also seems to be some inconsistency with the statement in paragraph 68 calling for the “repeal of provisions authorizing institutionalization” and paragraph 69 which states that institutionalization is unacceptable “if its basis is discrimination or prejudice against persons with disabilities.” This may leave the door open to the use of involuntary hospitalization when “necessary to protect the safety of the person or others” after this notion was apparently rejected in the previous paragraph.

Paragraph 85 (e). Safeguard free and informed consent on an equal basis for all individuals without any exception, through legal framework and judicial and administrative mechanisms, including through policies and practices to protect against abuses. Any legal provisions to the contrary, such as provisions allowing confinement or compulsory treatment in mental health settings, including through guardianship and other substituted decision-making, must be revised. Adopt policies and protocols that uphold autonomy, self-determination and human dignity. Ensure that information on health is fully available, acceptable, accessible and of good quality; and that it is imparted and comprehended by means of supportive and protective measures such as a wide range of community-based services and supports (A/64/272, para. 93). Instances of treatment without informed consent should be investigated; redress to victims of such treatment should be provided;

There is disagreement with the recommendation of paragraph 85, section e. Clarification and alternate recommendations are provided in Attachment 2: APA and WPA Recommendations for Consideration by the UNHRC.

Paragraph 89 (b). Impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as neuroleptics, the use of restraint and solitary confinement, for both long- and short-term application. The obligation to end forced psychiatric interventions based solely on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation;127

There is disagreement with the recommendation of paragraph 89, section b. Clarification and alternate recommendations are provided in Attachment 2: APA and WPA Recommendations for Consideration by the UNHRC.

Paragraph 89 (d). Revise the legal provisions that allow detention on mental health grounds or in mental health facilities, and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned. Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished.

There is disagreement with the recommendation of paragraph 89, section d. Clarification and alternate recommendations are provided in Attachment 2: APA and WPA Recommendations for Consideration by the UNHRC.



ATTACHMENT 2: APA/WPA Recommendations for Consideration

Psychiatric disorders, such as schizophrenia, bipolar disorder, and major depressive disorder, along with neurodegenerative disorders such as Alzheimer disease, can impair attention, memory, information processing, emotional regulation, and other brain functions. Persons suffering from psychotic disorders may experience delusional ideation (e.g., believing that other people are controlling their minds) or hallucinatory perceptions (e.g., hearing voices telling them that they are evil and deserve to die). During a major depressive episode, persons may suffer psychic pain so severe that they see no recourse but to end their lives. Although most people with psychiatric disorders retain the capacity to make decisions for themselves—including medical treatment decisions—others lose such capacity, especially during the most acute phases of their illnesses. At such times, they may lack the ability to recognize that they are suffering from an illness or to identify treatments that are likely to be in their interests. Moreover, their illnesses may lead them to behave in ways that are likely to cause serious harm to themselves or other people.

From APA Clinical Practice Guidelines:

The decision to hospitalize a patient involuntarily will depend on multiple factors, including the estimated level of risk to the patient and others, the patient's level of insight and willingness to seek care, and the legal criteria in that jurisdiction. In general others will satisfy the criteria for involuntary admission; however, the specific requirements vary from state to state, and in some states, willingness to enter a hospital voluntarily may preclude involuntary admission. To that end, psychiatrists need to be familiar with their specific state statutes regarding involuntary hospitalization.

Advance directives are attempts to ensure that individuals' wishes about treatment will be honored. Such directives may relate to wishes about treatment at the end of life but may also relate to wishes about psychiatric treatment or assignment of a durable power of attorney or health care proxy to make decisions in the event that the individual lacks capacity to do so. Although the specifics of advance directive regulations vary by jurisdiction, psychiatrists should include in their evaluation whether the patient has executed an advance directive and, if so, the nature of the advance directive should be determined.

In response to the need to protect and treat persons with psychiatric disorders who cannot make capable decisions and/or present a serious risk of harm to themselves or to other people, most countries have developed law and procedures permitting involuntary hospitalization and treatment. The standards and procedures for such interventions differ across jurisdictions. However, when properly implemented, involuntary hospitalization and treatment are reserved for persons who are incapable of making decisions for themselves and/or who as a result of their psychiatric disorders pose a serious risk of harm to themselves or to other people. In addition, except in emergencies, prior to the implementation of involuntary interventions, persons with psychiatric disorders should be afforded appropriate procedural protections intended to protect their rights, encompassed by the term “due process.”

Most persons with psychiatric disorders, of course, are not and should not be subject to involuntary interventions. They retain the capacity to make treatment decisions and pose no serious risk to themselves or to other people. However, for the minority of persons who are sufficiently disabled by their disorders to be unable to protect their own interests and/or who endanger themselves or others, the existence of involuntary interventions may be life-saving and may hold the prospect of restoring them to a fully functional, independent life. For this reason, the characterization of involuntary interventions for people with psychiatric disorders in the report is inaccurate and that the related recommendations are harmful and should be reconsidered.

In contrast to the approach recommended by the Special Rapporteur, the APA and the WPA recommend the following:

1) that involuntary interventions for psychiatric disorders be recognized as appropriate when persons are incapable of making decisions about their treatment and/or present a serious risk of harm to themselves or other people, and when no less intrusive means are likely to be effective; and

2) the rights of people with psychiatric disorders be protected by encouraging every country to develop

- (a) clear criteria for the use of involuntary interventions, consistent with the criteria in (1),
- (b) procedures designed to protect the rights of persons with psychiatric disorders, including impartial judicial or administrative review of decisions regarding findings of incapacity, and requests for involuntary hospitalization and involuntary treatment, and
- (c) mechanisms to investigate improprieties and abuses in the use of involuntary interventions, with appropriate penalties.



ATTACHMENT 3: Relevant Official APA Position Statements

"Policy documents are approved by the APA Assembly and Board of Trustees... These are... position statements that define APA official policy on specific subjects..." – *APA Operations Manual*.

Joint Resolution Against Torture of the American Psychiatric Association and the American Psychological Association

Whereas, American psychiatrists are bound by their *Principles of Medical Ethics with Annotations Especially Applicable to Psychiatry* to "provide competent medical service with compassion and respect for human dignity," and Whereas, American psychologists are bound by their *Ethical Principles* to "respect the dignity and worth of the individual and strive for the preservation and protection of fundamental human rights," and Whereas, the existence of state-sponsored torture and other cruel, inhuman, or degrading treatment has been documented in many nations around the world, and Whereas, psychological knowledge and techniques may be used to design and carry out torture, and Whereas, torture victims often suffer from multiple, longterm psychological and physical problems, Be it resolved, that the American Psychiatric Association and the American Psychological Association condemn torture wherever it occurs, and Be it further resolved, that the American Psychiatric Association and the American Psychological Association support the *UN Declaration and Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment*; and the *UN Principles of Medical Ethics*, as well as the joint Congressional Resolution opposing torture that was signed into law by President Reagan on October 4, 1984.

Approved by the Board of Trustees, December 1985

Position Statement on Abuse and Misuse of Psychiatry

The American Psychiatric Association supports the use of psychiatric knowledge, practice, and institutions only for purposes consistent with ethical evaluation and treatment, research, consultation, and education. Abuse and misuse of psychiatry occur when psychiatric knowledge, assessment, or practice is used to further illegitimate organizational, social, or political objectives. *Developed by the Council on National Affairs, Committee on Abuse and Misuse of Psychiatry in the U.S.*

Approved by the Board of Trustees, March 1 1994
Approved by the Assembly, May 1 1994.

Position Statement on Identification of Abuse and Misuse of Psychiatry

Background: In May, 1994 the APA approved the following position statement developed by the Committee on Abuse and Misuse in Psychiatry in the U.S.: "The American Psychiatric Association supports the use of psychiatric knowledge, practice and institutions only for purposes consistent with ethical evaluation and treatment, research, consultation, and education. Abuse and misuse of psychiatry occur when psychiatric knowledge, assessment, or practice is used to further illegitimate organizational, social, or political objectives." (*Amer J Psych* 151:1399 (1994)) Abuse and misuse of psychiatry may occur when psychiatry is used to advance organizational purposes or the purposes of a system and not for the benefit of the patient. There may be overlap between abuse and misuse of psychiatry and ethical considerations, but there are broader concerns as well. Psychiatrists function in their work with patients within a social, cultural and political milieu. Situations will inevitably arise in which there is tension among the interests of the individual patient, the interests of the psychiatrist, and the interest of the systems in which psychiatrists do their work. Sensitivity to what is in the best interests of the patient and how the patient's interests are affected by these forces must be understood and considered. Also, we need to be aware of how the psychiatrist and psychiatry are influenced by these external forces. The Committee on Abuse and Misuse of Psychiatry in the U.S. and the Committee on International Abuse of Psychiatry and Psychiatrists are charged with reviewing allegations of abuse and misuse and fulfilling an educational function. In an attempt to develop guidelines by which the Committees will pursue allegations, and to develop a better consensus within the APA as to what constitutes abuse and misuse of psychiatry, the following principles are presented in keeping with medical ethics (*The Principles of Medical Ethics with Annotations Especially Applicable to Psychiatry*):

The Principles

1. The use of psychiatric knowledge, practice and institutions is only for purposes consistent with ethical evaluation and treatment, research, consultation, and education. Abuse and misuse of psychiatry occur when psychiatric knowledge, assessment, or practice is used to further morally illegitimate organizational, social, or political objectives.
2. It is psychiatrists' primary responsibility to use their clinical skills and knowledge for the benefit of their patients. External social, political, management and economic forces should not be the primary consideration.
3. Psychiatrists shall not allow their professional opinions to be inappropriately influenced by illegitimate outside factors. It is essential for psychiatrists to consider biopsychosocial factors in their assessment of patients.
4. In certain situations (e.g. forensic evaluations, disability evaluations) the primary responsibility of a psychiatrist may not be for the benefit of the evaluatee per se. The evaluatee must be informed of the purpose of the evaluation or service, and any lack of confidentiality, as well as the reality that the psychiatrist may not know how the information will be used. This information may require repetition. The responsibility to provide clinically sound and scientifically based consultation is still the case.
5. Psychiatrists shall always be mindful of patients' rights. In their role of treating psychiatrist, they should resist and attempt to counteract forces interfering with patient-focused, humane treatment. A psychiatrist should not be a participant in a legally authorized execution. Psychiatrists shall not detain or incarcerate persons for political reasons, use medical knowledge for interrogation, persuasion or torture, or provide unsubstantiated diagnoses for use against political dissidents, whistleblowers or others.
6. It is the psychiatrist's responsibility when working in the context of an organization or social or political environment to advocate for the mental health needs of the community or population in which he/she is working.
7. Since confidentiality is critical to patient care, psychiatrists must be sure the information and/or records they provide are sensitive to the mental health interests of the persons and/or populations with whom they are working. It is important to release the least amount of information possible to accomplish the desired function.
8. All psychiatrists are encouraged to speak to egregious issues which adversely affect them and/or the mentally ill, and to bring forward perceived misuses of their function or role as psychiatrist for review by the Committee on Abuse and Misuse of Psychiatry in the U.S. and the Committee on International Abuse of Psychiatry and Psychiatrists.

Approved by the Board of Trustees, December 1998

Endorsement of Declaration of Professional Responsibility: Medicine's Social Contract with Humanity

Preamble

Never in the history of human civilization has the wellbeing of each individual been so inextricably linked to that of every other. Plagues and pandemics respect no national borders in a world of global commerce and travel. Wars and acts of terrorism enlist innocents as combatants and mark civilians as targets. Advances in medical science and genetics, while promising great good, may also be harnessed as agents of evil. The unprecedented scope and immediacy of these universal challenges demand concerted action and response by all. As physicians, we are bound in our response by a common heritage of caring for the sick and the suffering. Through the centuries, individual physicians have fulfilled this obligation by applying their skills and knowledge competently, selflessly and at times heroically. Today, our profession must reaffirm its historical commitment to combat natural and man-made assaults on the health and wellbeing of humankind. Only by acting together across geographic and ideological divides can we overcome such powerful threats. Humanity is our patient.

Declaration

We, the members of the world community of physicians, solemnly commit ourselves to:

- I. Respect human life and the dignity of every individual.
- II. Refrain from supporting or committing crimes against humanity and condemn all such acts.
- III. Treat the sick and injured with competence and compassion and without prejudice.
- IV. Apply our knowledge and skills when needed, though doing so may put us at risk.
- V. Protect the privacy and confidentiality of those for whom we care and breach that confidence only when keeping it would seriously threaten their health and safety or that of others.
- VI. Work freely with colleagues to discover, develop, and promote advances in medicine and public health that ameliorate suffering and contribute to human wellbeing.
- VII. Educate the public and polity about present and future threats to the health of humanity.
- VIII. Advocate for social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being.
- IX. Teach and mentor those who follow us for they are the future of our caring profession. We make these promises solemnly, freely, and upon our personal and professional honor.

Approved by the Board of Trustees, June 2002

Approved by the Assembly, May 2002

Position Statement on Human Rights

The American Psychiatric Association is concerned about the psychiatric consequences of human rights violations – violations such as unjust incarceration and cruel or unusual punishment, including terror and torture. The World Psychiatric Association goals include: to educate psychiatrists and other professionals about human rights abuses and the persecution of physicians who speak out against their governments; to encourage psychiatrists to use all their efforts against the use of torture and for the rehabilitation of torture victims; to promote research on the effects of human rights violations; and to prevent human rights violations.

Position Statement on Denial of Human Rights Abuses

When well documented human rights abuses are denied or covered up by governments and other institutions, such denial is a further violation of human rights of the victims and is antithetical

Approved by the Board of Trustees, December 1993

Approved by the Assembly, November 1993

Position Statement on Prevention of Violence

Psychiatry has a public health role related to the prevention of violence. The prevention/reduction of abuse, trauma and violence and sophisticated approaches to intervention are part of the mission of the profession. The psychiatrist must take a leadership role in the prevention, diagnosis, and treatment of victims and perpetrators of violence. The APA should support primary, secondary and tertiary approaches to the prevention of violence and should advocate for the education of trainees and practicing psychiatrists about violence prevention.

Approved by the Board of Trustees, December 2001

Position Statement: Resolution Condemning the Role of Psychiatrist Radovan Karadzic in Human Rights Abuses in the Former Yugoslavia

The American Psychiatric Association deplores and condemns Dr. Karadzic for his brutal and inhumane actions as the Bosnian Serb leader. Those actions deserve condemnation by all civilized persons, but psychiatrists issue that condemnation with particular offense, urgency and horror because, by education and training, Dr. Karadzic claims membership in our profession. In fact, his actions as a political leader constitute a profound betrayal of the deeply humane values of medicine and psychiatry. In condemning him, we affirm those values and join all persons of good will in defending the right to life and to freedom from oppression of all human beings anywhere in the world regardless of race, religion, national origin and ethnicity. *Prepared by the Council on International Affairs, Committee on Human Rights.*

Approved by the Board of Trustees, March 1993



HAUT-COMMISSARIAT AUX DROITS DE L'HOMME • OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS
PALAIS DES NATIONS • 1211 GENEVA 10, SWITZERLAND
www.ohchr.org • TEL: +41 22 917 9000 • FAX: +41 22 917 9008 • E-MAIL: registry@ohchr.org

Mandate of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment

January 22, 2014

Dr. Jeffrey Lieberman, President
American Psychiatric Association
Dr. Pedro Ruiz, President
World Psychiatric Association
Dr. Saul Levin, CEO/Medical Director
American Psychiatric Association

Dear Drs. Lieberman, Ruiz and Levin:

I have received the letter dated December 9, 2013 that you have sent to me (in my capacity as UN Special Rapporteur on Torture) and to the President of the Human Rights Council. Speaking only for myself, I wish to acknowledge the effort you have made to engage my rapporteurship in a detailed conversation about the report I presented to the Council in March 2013, on torture and cruel, inhuman and degrading treatment in some health care settings.

I will of course let President Henczel respond as to what the Human Rights Council proposes to do about my report of last year. That report was in the agenda of the Council in its session of March 2013. Several States and accredited non-governmental organizations chose to speak on the subject, some voicing criticism at some of my findings. As far as I know, there are no plans to continue the conversation or to “adopt” the report. In fact, reports from mandate-holders like me are not submitted for adoption by the Council but only for a free and open discussion. It would be up to a member State to propose a resolution to the Council on the basis of my report but I have no knowledge that any member State has such intention.

The nature of these thematic reports is of a vehicle to generate a discussion among States and interested civil society on standards that the mandate believes are necessary to cover issues and practices for which the existing normative framework is ambiguous or unclear. My thematic reports are not meant to be read as the ultimate word on the international law governing the issues I choose to deal with, but rather to initiate a discussion about what international law should provide for regarding those matters. They are also a recognition that the normative framework changes, as it must, to reflect evolving social standards and scientific advances. Precisely because that is the purpose of my report, I am encouraged by the detailed attention you have given to it and by your very substantial and authoritative contribution to the discussion I wished to generate.



With respect to the content of the report, I regret that some inartful wording has given rise to misunderstanding of some statements included in it; some passages can be legitimately read as contradictory with other passages. One example is my paragraph 32. For the record, I did not mean to propose an absolute ban on non-consensual interventions (including institutionalization and restraints) under any and all circumstances. I meant to restrict my condemnation to non-consensual treatment based exclusively on discrimination against persons with disabilities. In other words, the fact that a person is diagnosed as having a psychosocial disability should not by itself be enough to justify non-consensual treatment. Unfortunately, in many countries that is standard practice, often validated by domestic courts and even by international tribunals (in some decisions that my report criticizes). As you point out, elsewhere in my report (paragraphs 68 and 69) I do mention that involuntary detention and treatment is legitimate if its purpose is to prevent the patient harming him or herself or causing serious harm to others, and then for the limited time and scope necessary to prevent such harm. I firmly believe, however, that legislation should be revised to place the burden on the State to justify each decision to apply non-consensual treatment under such narrow grounds.

I do not doubt that my proposal coincides – in large part, at least – with the highest professional standards of your profession as reflected in the policy statements relevant to this topic that you have attached. My concern is with the many parts of the world where those professional standards are not applied. More specifically, I am concerned that domestic legislation generally allows for a very loose understanding of disability, of legal capacity, of guardianship and even of medical necessity. I believe very strongly that in many countries these provisions are the enabling legal environment where abuses take place. It is important to encourage all States to take another look at domestic legislation and to overhaul antiquated norms that effectively make free and informed consent meaningless. It seems to me that, in general at least, your associations are comfortable with the existing normative framework; if so, yes there is a disagreement between us. I hope, however, that this letter helps to narrow the scope of that disagreement.

My report was difficult to write because I believe the legal landscape on these issues is changing rapidly. In particular, the Convention on the Rights of Persons with Disabilities has altered that landscape in a significant way. Beyond what the Convention provides for in its text, the authoritative interpretation of it by the treaty body it created, the Committee on the Rights of Persons with Disabilities, may be moving that normative framework even further. Whether one agrees with the Committee's interpretations or not, there is no doubt that pronouncements of treaty bodies entrusted with a specific area of law must be taken into account. It is part of my task as Special Rapporteur to encourage States to align their domestic legislation with binding international standards. More important than the legal reasons, however, is my conviction that there is plenty of abuse of psychiatry in our world today. My report was an attempt to call attention to such abuse; not by any means to impugn the profession and the science of psychiatry, for which I hold great respect and admiration.

Let me thank you again, sincerely, for your comments and criticism. They help me understand the problem in all its dimensions. As part of my work on this issue I plan to publish a volume with contributions from many individuals and entities interested in the matter. It will include divergent views, including of course



disagreements with my report. I would very much appreciate your permission to publish your letter in full in that volume. Needless to say, I intend to include this letter as well.

Sincerely,

A handwritten signature in black ink, appearing to read 'J. Méndez'.

Juan E. Méndez

Special Rapporteur on the question of torture and other cruel,
inhuman or degrading treatment or punishment

Cc Baudelaire Ndong Ella, President, UN Human Rights Council

An International Comparison of Mechanisms in Mental Health Monitoring

JUDY LAING & RACHEL MURRAY*

Abstract

Based on a study conducted for the UK's Care Quality Commission, the paper stresses the importance of regular monitoring of health-care settings in order to prevent torture and other forms of abuse. The significance of applying a human rights framework to issues related to health is emphasized. The paper argues that the international treaties provide useful benchmarks and frameworks with which to address these issues holistically, whether this is through providing the necessary independent mechanisms to monitor places where individuals may be deprived of their liberty in a healthcare setting or with the specific rights relevant to individuals in such situations. The authors discuss the number of diverse approaches to monitoring mental health, as well as variability in how states discharged this function. Specifically, they evaluate three main areas of these inspections and monitoring systems, relating to the visiting body and its methodology, the relationship between monitoring and complaints, and the processes for evaluating impact and following-up recommendations. The paper concludes that although the language in OPCAT may suggest a particular type of national institution, the approach advocated by OPCAT should be taken as the minimum to monitoring and prevention. It is unlikely, and in some cases undesirable that the broad range of monitoring functions will be carried out by a single institution. A holistic approach to these functions ought to be in existence in any one jurisdiction.

Introduction

There is a presumption that regular, unannounced visits by independent bodies to places of detention, defined broadly, will prevent torture and other forms of abuse.¹ Many states have institutions which monitor and visit places where individuals are deprived of their liberty in healthcare settings, whether these be psychiatric institutions, rehabilitation centers, social care institutions, boarding schools, residential centers, and public and private hospitals, among others.² The visiting mechanisms are diverse and include chief psychiatrists, independent monitoring bodies such as healthcare inspectorates, commissions, patient advocates and advisers, and others. Benchmarks

*Senior Lecturer in Law and Professor of International Human Rights Law and Director HRIC, respectively, Human Rights Implementation Centre, University of Bristol, BS8 1RJ, UK. The authors can be contacted via email J.M.Laing@bristol.ac.uk, Rachel.Murray@bristol.ac.uk.

¹ 'The Approach of the Subcommittee to the Concept of prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment under the Optional Protocol', Doc.CAT/OP/12/6; Mental Disability Advocacy Centre (MDAC), Inspect! Inspectorates of Mental Health and Social Care Institutions in the European Union (Budapest, MDAC 2006).

² See Report of the Special Rapporteur.

to enhance the effectiveness of such bodies and outline their minimum powers are perhaps best illustrated in the Optional Protocol to the UN Convention Against Torture (OPCAT).³ Besides an international committee with a remit to visit places of detention (the Subcommittee on Prevention of Torture (SPT)⁴) perhaps OPCAT's most important contribution is through the requirement that State parties "maintain, designate or establish...one or several independent national mechanisms for the prevention of torture at the domestic level."⁵ Such national preventive mechanisms (NPMs), have typically been ombudspersons,⁶ national human rights commissions,⁷ single or a group of bodies,⁸ or in some cases specifically created bodies,⁹ with the powers to regularly examine the treatment of those deprived of their liberty, make necessary recommendations, access all information relating to those detained, all places of detention, and the opportunity to interview individuals in private. By encouraging the provision of NPMs, OPCAT provides a detailed and useful benchmark against which the effectiveness of national visiting bodies can be measured. Although preventive visits may traditionally have been associated with prisons and police settings, Article 4 of the Protocol makes it clear that its scope extends further, encompassing "any place under [the state party's] jurisdiction and control where persons are or may be deprived of their liberty,"¹⁰ and "any form of detention or imprisonment or the placement of a person in a public or private custodial setting which that person is not permitted to leave at will by order of any judicial, administrative or other authority."¹¹ In so doing, it provides protection for healthcare settings, including mental health institutions.¹²

Although OPCAT is not specifically mentioned in the Special Rapporteur's (SR) Report, the Report does note the obligation of states to "regulate, control and supervise healthcare practices with a view to preventing mistreatment" and the need to "strengthen accountability and redress mechanisms."¹³ Moreover, the Report recommends that States should "enable national preventive mechanisms to systematically monitor, receive complaints and initiate prosecutions"¹⁴ and calls upon States to "conduct prompt, impartial and thorough investigations into all allegations of torture and ill-treatment in healthcare settings."¹⁵ The research that we have conducted and

³ GA Res.57/199, adopted on 18th December 2003; came into force 26th June 2006.

⁴ Art.2(1) OPCAT.

⁵ Art.17 OPCAT.

⁶ For example in Denmark, which ratified OPCAT in 2004. It designated the Danish Parliamentary Commissioner for Civil and Military Administration (Ombudsman) as its NPM in 2007. Four ombudsman staff are involved in the NPM tasks and nine members participate in the performance of NPM functions. The Ombudsman is assisted by a NGO, Dignity, the Danish Institute Against Torture (previously known as the Danish Institute for Human Rights and the Rehabilitation & Research Centre for Torture Victims) to provide appropriate medical and human rights law expertise/ advice.

⁷ For example in New Zealand, which ratified OPCAT in 2007. Five different bodies are designated as the NPM, co-ordinated by the Human Rights Commission, including the Office of Ombudsmen, Office of Children's Commissioner, Independent Police Conduct Authority, and the Inspector of Service Penal Establishments of the Office of the Judge Advocate General of the Armed Forces.

⁸ As found in the UK, which ratified OPCAT in 2007 and designated 18 bodies as the NPM, including healthcare regulators such as the Care Quality Commission in England, the Healthcare Inspectorate in Wales and the Regulation and Quality Improvement Authority in Northern Ireland.

⁹ As found in Switzerland which established the National Commission for the Prevention of Torture, <http://www.nkvf.admin.ch/content/nkvf/en/home.html>.

¹⁰ Art.4(1) OPCAT.

¹¹ Art.4(2) OPCAT.

¹² See E Steinerte, R Murray and J Laing, 'Monitoring those deprived of their liberty in psychiatric and social care institutions and national practice in the UK', (2012) 16(6) *International Journal of Human Rights* 865-882.

¹³ *Report of the Special Rapporteur*, para 12.

¹⁴ *Report of the Special Rapporteur*, para. 85(b).

¹⁵ *Report of the Special Rapporteur*, para. 85(c).

which is presented in this chapter endorses the SR's view that the work of NPMs is essential, and OPCAT provides a useful framework on the regularity and preventive aspects of visits to health-care settings.

The SR Report recognizes that there are "unique challenges to stopping torture and ill-treatment in health-care settings" and that "there is a need to highlight the specific dimension and intensity of the problem, which often goes undetected."¹⁶ Patients in healthcare settings rely on healthcare workers to provide them with appropriate care and treatment and the "structural inequalities, such as the power imbalance between doctors and patients" can lead to increased powerlessness, vulnerability and discrimination.¹⁷ It is increasingly recognized that forced medical treatments, which are intrusive and irreversible, may amount to torture and ill-treatment when they are administered without the free and informed consent of the person concerned. Moreover, the SR Report cites further examples, such as the use of restraint, seclusion¹⁸ and concepts such as medical necessity and capacity, and the potential for stigma and discrimination as "obstacles to protection from arbitrary abuses in health-care settings."¹⁹ It is therefore crucial to ensure that patients in healthcare settings are being protected from such abuses, and regular preventive visits from an independent monitoring body, such as the NPM, are a vital tool to achieve this. Independent monitoring is only one component, however. It is also incumbent on those working in the healthcare sector to embrace a rights-based approach to the delivery of care and treatment. As recommended by the SR in his Report, there is an important obligation on State Parties to provide appropriate human rights education and information to healthcare personnel on the prohibition of torture and "to promote a culture of respect for human integrity and dignity" in delivering healthcare and treatment.²⁰ In that respect, due consideration should be given by relevant states to the Convention on the Rights of Persons with Disabilities (CRPD) and its potential reach in promoting a paradigm shift to bolster the rights of patients with disabilities, including patients with long-term mental and physical impairments in healthcare settings.²¹ As noted by Bartlett, "the CRPD expects governments to promote and protect the rights of persons with disability in society at large...and making social integration an overarching objective of the Convention."²² And countries such as Canada, which have not yet ratified OPCAT, are indeed focusing on the CRPD to provide some impetus to establish a national monitoring mechanism and promote awareness of and protection for the rights of patients with disabilities in society. Canada ratified the CRPD in March 2011, and there is now a strong focus in the Canadian Mental Health Commission on developing and embedding a human rights framework to implement and monitor the CRPD. The Commission established a Human Rights Evaluation Project to focus on implementation of the CRPD, which produced a

¹⁶ *Report of the Special Rapporteur*, para. 12

¹⁷ *Report of the Special Rapporteur*, para. 29.

¹⁸ Any restraint on people with mental disabilities, for even a short period of time, may constitute torture and ill-treatment—See CAT/C/CAN/CO/6, para. 19(d); ECHR *Bures v. Czech Republic*, Application No. 37679/08 (2012) para. 132.

¹⁹ *Report of the Special Rapporteur*, para. 35.

²⁰ *Report of the Special Rapporteur*, para. 85(d).

²¹ See further B McSherry & P Weller (Eds), *Rethinking Rights-Based Mental Health Laws* (Hart Publishing 2010); P Weller, 'The Convention on the Rights of Persons with Disabilities and the social model of health: new perspectives', [2011] (Spring) *Journal of Mental Health Law* 74 and P Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law', (2012) 75(5) *Modern Law Review* 752-778 for further discussion of the paradigm shift and potential impact of the CRPD on mental health law and compulsory psychiatric treatment.

²² Bartlett *op cit* p. 757.

final report in 2011.²³ It recommended, inter alia, that a national plan to implement and monitor the principles and rights contained in the CRPD should be established, and emphasis placed on the need for collaboration with national non-government disability organizations and human rights organizations. Clearly, designation as part of the independent national framework under Article 33(2) of the CRPD may be important here in terms of monitoring. There is an overlap and potential duplication of roles with respect to OPCAT, and there are few bodies, which have been designated as the national body both under OPCAT and the CRPD, particularly with respect to visiting psychiatric institutions.²⁴

The Research Study

This chapter draws upon the findings of research that the authors carried out for the Care Quality Commission (CQC), the independent regulator of health and social care services in England.²⁵ The CQC is tasked with monitoring the operation of the domestic mental health legislation in England, under which patients with a mental disorder may be deprived of their liberty and subjected to compulsory admission and treatment, both in hospital and in the community. Mental Health Act (MHA) Commissioners at the CQC are responsible for inspecting psychiatric units, interviewing patients and ensuring that their rights are respected. Allied to this is the fact that the CQC is designated as one of the 18 institutions, which form part of the UK's NPM under OPCAT to monitor deprivations of liberty in healthcare settings, so it performs a number of important regulatory and inspection functions.

We were commissioned to undertake an initial desktop review followed by a small number of in-depth semi-structured interviews with a sample of senior representatives²⁶ from the inspection visiting bodies from other comparable liberal democratic jurisdictions, including Wales, Ireland, Scotland, Northern Ireland, Denmark, Sweden, Netherlands, New Zealand, Canada and three Australian states. The interviewees in the study were senior representatives from a diverse range of organizations who each have a mental health monitoring function. Some of the bodies in the study were generic and largely responsive in nature, such as the Ombudsmen in Sweden, Denmark and some Canadian provinces. Their mental health monitoring was simply one aspect of a generic monitoring and complaints role; whilst others were more preventive and focused exclusively on visiting mental health places of detention, for example the specialist Inspector of Mental Health Services in Ireland. The Australian mental health monitoring and visiting bodies, such as the Visitor Schemes and Chief Psychiatrists have specific functions to respectively visit mental health places of detention and respond to patient complaints. And other organisations in the study,

²³ Mental Health Commission Human Rights Evaluation Project, *Minds that matter: Report on the Consultation on human rights, mental health and addictions* located at www.ohrc.on.ca/en/book/export/html/8404.

²⁴ For example, the New Zealand Ombudsman has been designated as one of the independent mechanisms to monitor implementation of the CRPD (shared with the Human Rights Commission & NZ Convention Coalition) and they are drafting a joint framework to align and strengthen the monitoring process in New Zealand.

²⁵ www.cqc.org.uk. The Healthcare Inspectorate covers this function for Wales. In Scotland it is the Mental Welfare Commission for Scotland (MWC), and in Northern Ireland the Regulation and Quality Improvement Authority (RQIA) carries out similar functions.

²⁶ Note that the comments made by the interviewees are anecdotal and should be treated with caution, as we were unable to verify the accuracy (or otherwise) of all the comments. Where interviewees have provided consent to be attributed, reference is made in this paper to the source of the quotation. In cases where interviewees did not wish to be attributed we have simply provided the quotation. The report of the findings of the research is available via the CQC's website: <http://www.cqc.org.uk/public/publications/reports/mental-health-act-annual-report-2011/12/comparative-review-international>.

such as the Healthcare Inspectorate in the Netherlands, Healthcare Inspection for Wales and the Northern Ireland Regulation and Quality Improvement Authority share a similar dual function to the CQC in England, in terms of monitoring mental health detentions and regulating standards of mental health care. Most, though not all, of the bodies in the study were also discharged with carrying out OPCAT-related NPM functions. In fact, the New Zealand body was tasked solely with this function. Very few of the bodies however were tasked with a specific legislative duty to monitor domestic mental health legislation.

The purpose of the review was to examine monitoring methodology and practices in mental health settings in a number of different jurisdictions, which would then be used by the CQC to help inform its own strategic direction for its work.²⁷ For the study, we identified information on the mental health legislative frameworks and monitoring systems, focusing both on inspections and visiting bodies, NPMs and complaint mechanisms. However, the available data was limited in some jurisdictions and other researchers have noted the difficulties in making comparisons between jurisdictions, particularly in Europe, as data on mental health and compulsory detention rates are not routinely documented or published using comparable definitions in all EU member states.²⁸ Moreover, there was considerable variability in some of the mechanisms adopted by the jurisdictions in the study.

The research identified some key findings from across these jurisdictions, which we will outline further below. Although it focused on mental health settings, we believe it also has some relevance for other healthcare settings, as the potential abuses and issues around stigma, discrimination, capacity and enforced treatment can apply to other vulnerable and marginalized groups, as identified in the SR Report.²⁹

Caveats should be stressed here though: our research did not attempt to be comprehensive in its approach to all aspects of the monitoring function, however that may be defined, nor in its geographical coverage. It was premised on the needs of the CQC. Therefore, the choice of states and the questions posed to those whom we interviewed reflect the interests of the CQC. Nevertheless, the research findings indicate a number of pertinent issues that were common across the sample of jurisdictions that we examined and a number of key themes emerged from our analysis of the data in the study.

Indeed, the findings from our research (although the study was not specifically focused on this) stress the utility and importance of a human rights framework in dealing with these issues. Whether this is through providing the necessary independent mechanisms to monitor places where individuals may be deprived of their liberty in a healthcare setting (OPCAT) or with the specific rights relevant to individuals in such situations (CRPD), it is apparent that the international treaties jointly and severally provide useful benchmarks and frameworks with which to address these issues holistically.

²⁷ The CQC launched a public consultation to review its monitoring and regulatory functions in September 2012. As part of its review, the CQC commissioned this comparative research study and the report is available on the CQC's website: located at www.cqc.org.uk. We are grateful to the CQC for funding the research and for granting permission to us to publish findings from the study.

²⁸ M Zinkler et al, 'Detention of the Mentally Ill in Europe—a review', (2002) 106 *Acta Psychiatr Scand* 3-8.

²⁹ *Report of the Special Rapporteur*, para. 26.

1. An Overview of Monitoring and Inspection Methods

We found a number of diverse approaches to monitoring mental health legislation, as well as variability in how states discharged their OPCAT NPM duties. Some countries, such as England, Wales, Ireland and the Netherlands have a more streamlined approach as they have a specific specialist body with dual mental health law monitoring and regulatory functions. This body also performs the NPM function to monitor deprivations of liberty in health and adult social care, though there are differences in the mental health legislative frameworks, responsibilities and visiting methodologies. New Zealand, Australia, and Canada do not appear to have a statutory mental health monitoring body as such, but instead have a multi-faceted approach with a variety of different independent and generic monitoring bodies, some of which are statutory and perform OPCAT related functions, where relevant. Additionally, in a healthcare context in Canada, there is a formal Charter of Patient Rights, which gives patients enforceable rights, as well as a system of patient advisers or advocacy embedded in the mental health legislation. The advocacy role is purely advisory in terms of informing patients of their rights and assisting with complaints, and they tend to be conduits of complaints rather than arbiters of them. However, they do visit on a much more frequent basis and will meet with patients, inspect facilities and access documentation and medical records. There are also significant differences in the Danish and Swedish approach, as they both have a generic Parliamentary Ombudsman or Commissioner with responsibility under OPCAT to monitor places of detention, including psychiatric facilities, as well as a reactive role to investigate complaints. But there does not seem to be a body with a specific duty to monitor mental health detentions in either jurisdiction.

Specifically, our research focused on three key areas of these inspection and monitoring systems, relating to the visiting body and its methodology, the relationship between monitoring and complaints, and the processes for evaluating impact and following-up recommendations. These aspects are explored in more detail below.

2. Lack of Consensus/Agreement About Definition of Monitoring and Approaches

As the SR Report notes, one element in ensuring that individuals are not subject to torture and other forms of abuse in healthcare settings is the obligation of the state to regulate healthcare practices in order to prevent ill treatment, and this requires NPMs and other bodies to monitor such institutions.³⁰ What monitoring entails in this context, however, is not always clear. This was apparent in our research study. First, and perhaps most obvious, monitoring can encompass a visiting element, as illustrated most clearly by OPCAT, whether that be by national or international bodies. Secondly, it can also encompass more strategic analysis, not only through visits, but also through “national overviews”—namely to report on the state of mental health nationally; and to data collection (e.g. on deaths, restraint, seclusion, ECT) through a variety of mechanisms. As some of the interviewees explained, this information may come from “gossip” and “informal information,” “attendance at events such as academic events,” which are perceived by some interviewees as “an informal, soft way of gathering information.” Indeed, several of the bodies we spoke to identified their “monitoring” role as extending well beyond visiting and relying on data collected from a range of sources and discussions with a range of external bodies and individuals to help them to fulfill their role. Thirdly, monitoring can include a more reactive approach, responding to com-

³⁰ *Report of the Special Rapporteur*, para. 85(b).

plaints from individuals and others alleging abuses and, as the Special Rapporteur notes in his report, initiating prosecutions.³¹

In theory, one might imagine an effective monitoring mechanism would include all three elements, although not necessarily present in the same body. This is born out by our research where we saw that these different strands are often kept quite distinct: monitoring and visits, monitoring and strategic direction; and complaints. Often, the same body or indeed the same person[s] does not carry out all three functions and there is considerable variation in how complaints will prompt visits, what happens with information picked up during visits and whether individual complaints will then follow. For example, the Crimes of Torture Act (COTA) division, part of the NPM in New Zealand:

“will just pass the information onto the other side of the Ombudsman’s office and let them deal with it...as part of their ordinary complaints service...we quite often get the Human Rights Commission ring us with issues that have gone to them, we frequently point people in the right direction of the Health and Disability Commissioner. No complaint sort of just falls on the floor.”³²

Some visiting bodies do, however, keep the individual’s concern in the file on the institution, so that when they visit again at a later stage, this is picked up. Some of this appears to depend on whether the body carrying out the visits is doing so on a reactive or proactive or preventive basis.

The relationship between the three strands is dealt with further below. However, a consequence of this in a particular jurisdiction is that this diversity of mechanisms and institutions covering the range of monitoring functions can cause considerable confusion for those individuals who may wish to make a complaint and approach an organization for assistance or guidance. So, in some jurisdictions, the legislative framework does not impose a statutory duty on a specific body to monitor compliance with the mental health compulsory detention legislation. In addition, in some jurisdictions, there is a lack of agreed national mental health standards (for example in Canada and Australia). In these countries, there may be complaints mechanisms of various forms, but no one that regularly monitors mental health legislation, policy, or standards on a consistent basis. The complaints mechanisms tend to be responsive, generic, and can be complex. For example, in Australia, each state has a diverse and complex range of oversight and regulatory mechanisms, which may overlap and are confusing for patients and consumers. Critics argue that there is a need in Australia for a more “streamlined” independent commission, which has expertise and a dedicated complaint arm, as well as investigatory functions.³³

3. A Generic Body or One Focused on Healthcare Settings?

If one examines the visiting element of the monitoring function specifically, again, OPCAT provides a useful framework. However, it is also clear in this context that greater attention needs to be paid to a more nuanced approach to visiting. Where specialist bodies do exist, there is often a breadth of professional or personal experience and background relevant to the settings of those undertaking the visits. Where the body is more generic, such as a single national ombudsperson, the possibility of this breadth of experience is significantly diminished, prompting the body to look to external organizations to provide this expertise. As OPCAT has gained some years’ experience,

³¹ *Report of the Special Rapporteur*, para. 85(b).

³² Interviewee from New Zealand COTA division.

³³ B McSherry, ‘Who do I turn to? Resolving complaints by mental health consumers and carers’, (2011) 18 *Journal of Law & Medicine* 669.

greater insights have developed into the key components of an effective monitoring process. This has included examining who should carry out visits in terms of the expertise and background required depending on the type of institution being visited. Thus, it is now recognized that having appropriate medical expertise among the visiting personnel is crucial. As the SPT have stated “members of the NPM should collectively have the expertise and experience necessary for its effective functioning”³⁴ and it is recommended that this should be a multidisciplinary team including “healthcare experts,” former service users as well as those with a background in human rights.³⁵

This has been particularly relevant in the mental health context. The CQC in the UK is perhaps unusual in that, as a member of the UK NPM, and due to the fact that it inherited its mental health inspectors from the previous Mental Health Act Commission, it has an extensive array of expertise on mental health issues encompassing those from psychiatry, law, mental health, and social care.³⁶

In addition, in those jurisdictions we examined which had a statutory monitoring function, such as Wales, Ireland, Scotland, and the Netherlands, most inspectors were qualified and experienced professionals drawn from mental health nursing, social work, psychiatry, psychology and law. The visits are often carried out by groups of two or more multi-disciplinary teams as one interviewee explained: “[the visiting teams] represent all of the disciplines normally found in a multi-disciplinary mental health team.”³⁷

In other jurisdictions, however, the expertise and experience of other types of visiting and inspection bodies vary considerably. For example, some of the Visitors’ Schemes in one jurisdiction have been fortunate “to recruit an exceptional community visitor team, people who have got many, many years of experience” such as lawyers, social workers, teachers, former service users and caregivers, and relatives of people who have suffered from mental illness and disability. In New Zealand, the NPM arm of the Ombudsman employs a full-time inspector with a mental health nursing background and co-opts a psychiatrist to help with the visits to mental health and learning disability units. Similarly, in Denmark, the NPM involves members of a specialist body, such as the Danish Institute Against Torture³⁸ to provide appropriate medical and psychiatric expertise to accompany ombudsmen on visits to mental health places of detention. The Ombudsman has indicated that he will attach decisive weight to the expert contributions he receives from the organization.³⁹ Undoubtedly, there is evidence here that designation under OPCAT has increased the number of visits to healthcare and psychiatric facilities and given a more rights-based focus to the work of the monitoring body, which is important, particularly from a disability perspective. Designation under OPCAT can also make it more visible to patients to whom they can direct complaints and concerns. Other generic ombudsmen, for example in Nova Scotia, recognize the importance of ensuring that staff with a social work background will visit individuals who may be considered to have psychiatric or mental health issues. Some jurisdictions, such as New Zealand,

³⁴ SPT, *Guidelines on National Preventive Mechanisms*, (9 December 2010) CAT/OP/12/5, para. 17.

³⁵ *The ITHACA Toolkit for Monitoring Human Rights and General Health Care in Mental Health and Social Care Institutions* (ITHACA Project Group, London, 2010,) para. 26.

³⁶ J McHale, ‘Standards, Quality and Accountability—The NHS and mental health: A case for joined-up thinking?’, (2003) 25(4) *The Journal of Social Welfare and Family Law* 369-382.

³⁷ Ordinarily this would include clinicians/psychiatrists and mental health nurses as well as social work, clinical psychology, occupational health and pharmacy input where appropriate.

³⁸ Previously known as the Danish Institute for Human Rights and the Rehabilitation & Research Centre for Torture Victims.

³⁹ See Danish Parliamentary Ombudsman, *OPCAT Annual Report 2010* (Copenhagen, 2010) p.17, <http://en.ombudsmanden.dk/publikationer/summary/pdf/>.

find it helpful to use a roster of experts from which they can draw to conduct visits to specialized units, such as mental health and learning disability units.

It then becomes crucial to consider the amount and type of training provided to inspectors and hospital visitors and, in this context, we found the approach was extremely variable. In some jurisdictions, where qualified professionals are employed to perform the monitoring function, their professional knowledge and expertise is perceived as sufficient to help them to fulfill their inspection role: “usually by their background they would have had a lot of experience working in the services.” “They tend to be quite senior people and are paid at a senior level.” Some organizations provide inspectors with tailored in-house training, which is ongoing, though there is often a lot of “on the job training.” In other jurisdictions, training has varied from two-day intensive workshops focusing on interviewing and communication skills and then ongoing regular support, training by psychiatrists and lawyers, and carrying out joint shadowing visits with experienced visitors.

The risks of no experience in mental health, or lack of specific training on mental health issues, for example, are greater where the body undertaking the visits is one which has a broader remit than beyond healthcare or mental health settings, such as a generic ombudsman.

4. The Methodology of the Visits

The preventive aspect of visits is the *raison d'être* of OPCAT and the importance of this is born out by the research we conducted. One interviewee felt that the preventive element was achieved by “the mere act of having an inspector coming in and staff knowing that they will be inspected and all our inspections are unannounced as well.” Although factors such as the independence of the monitoring body are crucial to ensure legitimacy and credibility,⁴⁰ there are a variety of different approaches in terms of the methodology of undertaking visits, and the effectiveness of such may depend on the specific context. Therefore, we saw that the manner in which visits are carried out by different national bodies varies considerably, whether this was in terms of the length of the visit (between half a day to 2-3 days and in some cases a total of 5 days in duration); the frequency and regularity of the visit (once a year; determined by risk: “we trust the institution because of previous experiences or information we have we tend to visit them less than if we have some doubts about what’s going on;” every few weeks or once a month); the type of visit (routine annual inspections, “quality regular visits, themed visits”⁴¹ and visits which responded to specific incidents or concerns). Similarly, visits can be carried out in accordance with more prescriptive reporting templates, checklists and proformas,⁴² or be more flexible in their format:

*“We don’t have any hard and fast rules. I think it’s a lot of custom and practice was developed over the last 200 years. [I]t’s patient driven so there could be a lot of time spent with patients or a lot of patients want to speak to the inspectors. The key is to get an atmosphere of how well the place is run from talking to staff, asking staff to point out aspects of the regulations that are being looked for in documentation and generally just having a discussion, but a lot of it is documentation”.*⁴³

⁴⁰ Article 18 OPCAT; Article 33(2) CRPD; SPT *Guidelines on National Preventive Mechanisms*, para 16.

⁴¹ E.g. in Northern Ireland the RQIA carried out themed reviews in 2011-12 based on human rights issues and the Healthcare Inspectorate in the Netherlands also conducts similar themed visits.

⁴² E.g. Some of the Visitor Schemes in Australia issue detailed pro-formas to the visitors and the NPM in New Zealand has published a detailed inspection manual and check-list for inspectors.

⁴³ Anonymous Interviewee.

Indeed, the more generic the body was, in terms of its broader focus beyond mental healthcare settings, the less likely it was that the policy manual or visiting methodology was tailored to the specifics of mental health institutions or to mental health issues.

It is now recognized that a combined approach of announced and unannounced inspections may prove to be the most effective from a preventive point of view⁴⁴ and, indeed, many jurisdictions do provide both, with a general recognition of the need to move towards a greater proportion of unannounced inspections: “if you know that the Ombudsman can turn up at any time of the day or night to carry out an inspection of your site I’m sure that that’s a bit like knowing that the boss might have a hidden camera on you so that you’re not going to do some of the silly things that you might have done not being aware of that.”⁴⁵

Whilst OPCAT focuses on providing guidance for the statutory or official monitoring body, it is also worth stressing the role of less formal and less visible actors in the process. In many jurisdictions, patient advisors, advocacy services and officials, and community visitors,⁴⁶ many of whom are volunteers, visit mental health institutions frequently (sometimes on a weekly basis), meet patients, inspect facilities and assess records. In one jurisdiction we were informed that concerns raised by patient advocates with the monitoring body led the latter to conduct a visit to the relevant institution. These type of visitors provide an informality, flexibility and regularity, which may not be possible through the statutory body, and thus compliment the more formal structures. As one person told us: “we’ve used advocates who will be on the ward when we’re there, who will maybe jointly interview with patients.” They can be perceived as independent, responsive, accessible—“frank and fearless” visitors⁴⁷—who may provide a different perspective on the institution or the issues: “it sort of fills out and gives us a rounder more national view.” Inevitably, though, there are limitations to these visitors: they are often advisory, they may not have the appropriate training,⁴⁸ they are there to inform patients of their rights but not having the mandate to arbitrate on patient complaints, or enforce major change.⁴⁹ Therefore, such advocacy and visitor services should not be seen as a replacement for the independent statutory bodies, but rather as a compliment to the more formal structures that may exist.

It is perhaps this capturing of patients’ voices and experiences that is an important contribution of advocacy and visitor services that many of the formal statutory visiting bodies attempt to achieve through other means. For example, it can include direct meetings with individual patients or discussions that take place at some stage during the visit to the ward or unit, perhaps during meal times for example “we will lunch on the ward with the patients to see how the atmosphere is;” regular meetings with consumers and users; conducting patient experience reviews prior to an announced inspection;⁵⁰ as well as finding ways of obtaining the view of relatives, caregivers and other family members.⁵¹

⁴⁴ See Articles 19 and 20 OPCAT; SPT *Guidelines on National Preventive Mechanisms*, para. 25.

⁴⁵ Anonymous interviewee.

⁴⁶ E.g. In Victoria, Australia, the Mental Health Act 1986 provides for Community Visitors to conduct visits to detained patients in mental health units,

⁴⁷ *Council of Official Visitors Annual Report 2010-11* (October 2011) located at www.cooov.org.

⁴⁸ MHC Human Rights Evaluation Project, *Minds that matter: Report on the Consultation on human rights, mental health and addictions* para. 54 located at www.ohrc.on.ca/en/book/export/html/8404.

⁴⁹ *Council of Official Visitors Annual Report 2010-11* (October 2011) located at www.cooov.org.

⁵⁰ E.g. in one jurisdiction patients are sent a template of questions, to assist Inspectors to identify areas of concern in advance of the inspection: ‘there are informal discussions with patients before we did the inspection. A lot of the time patients would have directed us to areas where we’ve really needed to drill down more which was helpful... but we also did questionnaires to patients, to relatives, to carers and staff on the ward’.

⁵¹ E.g. through interviewing family members, placing posters on the ward, and meeting with family members separately.

5. Difficulty of Integrating Visits with Complaints

The relationship between the visiting strand of monitoring and the more reactive strand of responding to complaints is, as noted above, not always clear and it depends on the type of institution carrying out the visit and its specific mandate and role. In most jurisdictions it would appear that the system of complaints is kept relatively distinct from the visit mechanisms. The Ombudsman in New Zealand, as part of the NPM for example, writes up a report after a visit, and this report can include concerns arising from the visit.⁵² However, the complaints mandate and NPM visiting mandate are separate. The information from visits will be passed on to the complaints team, but the two are distinct. In part, this is due to the fact that many complaints mechanisms need to be initiated by the individual rather than the monitoring body.

This causes a number of tensions. First, the need to preserve confidentiality means that passing on an individual case that has been picked up on a visit may not be possible. Secondly, sharing information between different bodies may depend on their respective legislative mandates or memorandum of understanding. Thirdly, as many complaints systems require the complaint to be initiated by the individual victim, those undertaking the visits can only provide information to the individual on accessing such mechanisms. But these are often individuals who are already vulnerable and powerless, particularly in the mental health setting, and may be not in a position to submit that complaint themselves. Although there are clear attempts to ensure that nothing falls between the gaps in many of the jurisdictions we examined, the system is not always conducive to ensure a smooth transition from a visit to a complaint and vice versa. As another person said to us, there is a need for “somehow embedded in the monitoring process, a better way of collecting that information from the individuals that are using the services so that it’s not incumbent upon the individual to have to come forward but there is some kind of a survey, some kind of information gathering process as part of the monitoring from the actual individuals.”

It also depends on the extent to which the body undertaking the visit is doing it in response to a complaint (as would be the approach of an ombudsman, for example), or is carrying out the visit as part of a broader preventive or proactive mandate. The relationship between complaints and visits in the former scenario may be clearer. Here, the person undertaking the investigation of a complaint may decide that a visit for that individual is necessary. In addition, if a number of complaints are received from a particular unit, an ombudsman or inspector may use this as evidence of the need to initiate an investigation or inspection of their own volition.

With respect to the latter type of visit, a preventive visit, not premised on responding to a particular complaint, the challenge is then to identify a procedure whereby concerns picked up during the course of a visit are then fed back into a complaints mechanism. In some jurisdictions, such concerns are referred back to the ombudsman office, for example, or those who would investigate individual complaints:

“[we] will just pass the information onto the other side of the Ombudsman’s office and let them deal with it...as part of their ordinary complaints service...we quite often get the Human Rights Commission ring us with issues that have gone to them, we frequently point people in the right direction of the Health and Disability Commissioner. No complaint sort of just falls on the floor.”

⁵² *New Zealand Office of the Ombudsman Annual Report for 2011-2012* (2012), http://www.ombudsman.parliament.nz/system/paperclip/document_files/document_files/466/original/annual_report_2011_-_2012.pdf.

Some visiting bodies do however keep the individual's concern in the file on the institution, so that when they visit again at a later stage, this is picked up. And one interviewee highlighted the significance of the complaints process in terms of alerting the inspection body to particular areas of concern and systemic failures: "if we find that there are a number of complaints coming out of somewhere about the same sort of things which indicates some sort of systemic breakdown then we'll go in and look at it from a[n OPCAT] perspective."

6. Challenges in Evaluation of Effectiveness

It is ironic that, despite OPCAT and visits to such healthcare settings being premised on the idea that this will prevent abuse and ill treatment from occurring, it was apparent from the study that there is very little evaluation of whether visits and monitoring actually have a positive impact. Nevertheless, the importance of evaluating the impact and effectiveness of monitoring and inspections was recognized by all the respondents that we spoke to:

"That's the key question isn't it, the organisation is doing the monitoring but it's how are they doing the monitoring and it's not just for monitoring sake. And is really the intention to change practice or is it just to report on the violations if there are any? That's where it becomes so important that there is that loop in the process, that feedback loop, and there's a mechanism to actually change that process."

Indeed, many bodies have enforcement powers and sanctions to impose on failing units and institutions.⁵³ Yet, it was the perception among many we spoke to that it was often the more collaborative, softer approach, which would yield results.⁵⁴ So building strong relationships with and respect from providers, through ensuring continuity of visiting personnel, as well as other informal methods of persuasion, were felt to be more effective in influencing practices. This "softer" approach is also regarded as particularly useful in bringing about changes to culture, as one interviewee stated: "even when you've got a stick you still have to work collaboratively these days." For example: "We have powers to direct but I've used those powers once, nearly all the time we can persuade or cajole or add a bit of money here and a bit of love there and try to get things through...It was all done through relationships really... culture was what had to change and that's sort of how we did it by that sort of talking and watching and persuading." This would appear to be the hallmark of a preventive approach: "I've always found informally is the best. It's all about prevention, it's all about fixing stuff....it's not about catching people out and thinking we're getting brownie points for all the stuff that we find wrong. I'd rather say at the end of the year no it's been a really good year and the agencies have worked well with us and things that needed to be done have been addressed." This softer approach will also go some way towards influencing cultural shifts and promoting greater "respect for human rights and dignity," as recommended by the Special Rapporteur in his Report.⁵⁵ Some generic ombudsmen bodies also recognized the value of "informal resolution of a complaint" unless "the issue is significant and has an impact on a great number of people, it would then automatically go up to the Ombudsman's level." Although this "informal" resolution approach seems to be preferred by many of the bodies that we spoke to, it does make it even more difficult to evaluate the precise impact and effectiveness of their inspection and monitoring work.

⁵³ E.g. Both the CQC in England and the Healthcare Inspectorate in the Netherlands are able to impose a variety of sanctions, such as suspending or withdrawing registration or attaching conditions to the registration of a particular unit/institution.

⁵⁴ See also F A G Hout *et al*, 'Supervision by the Dutch Healthcare Inspectorate', (2010) 17 *European Journal of Health Law* 347-360, at 357-358.

⁵⁵ *Report of the Special Rapporteur*, para. 85(d).

Whilst many such visiting and monitoring bodies recognize the importance of evaluating their work, we found few examples in our research of formal evaluation mechanisms. Just as the approach is collaborative and softer, so too are the methods of evaluating effectiveness, relying, for example, on perceptions of impact (examining media attention on the issue, and the extent to which they perceived the relevant authorities to take their recommendations seriously and the political or community response) and anecdotal evidence, rather than a systematic approach based on hard data: “if we didn’t have a body like this there would be a lot more breaches of [rights] I’m sure of it.”

Where methods of evaluation have been employed, these have included some form of self-evaluation through distribution of anonymous questionnaires to patients and staff following an inspection: “they report on it anonymously as to whether they were treated with respect, were they happy with the way they were inspected and so on... so that’s one sort of measure.” Other bodies collect views from patients;⁵⁶ or track the extent to which recommendations made by the visiting body had been followed, whether that is through follow up visits,⁵⁷ maintaining a database of information,⁵⁸ or engaging directly with staff at the institutions themselves. Much may depend on the type of recommendation being made: some may be more conducive to an immediate response, while others may require a longer period of time to implement.

In such economically challenged times, many regulators and visiting bodies are increasingly being called upon to justify their work and its impact. A greater degree of formality in assessing that impact may provide some protection for their work and, in turn, achieve greater credibility, leverage and influence. Yet, it is equally apparent that there is not necessarily one particular type of evaluation that will determine effectiveness in its entirety and it may be a combination of these different methods that should be employed to best effect.

Conclusion

The importance of regular monitoring of healthcare settings in order to prevent torture and other forms of abuse is central to the recommendations of the Report of the Special Rapporteur. OPCAT and the CRPD underscore the obligations of states in this regard by requiring them to establish formal independent structures at the national level to monitor implementation of the rights to be free from torture, as set out in CAT and the rights of persons with disabilities as provided for in the CRPD. Although the powers listed in OPCAT may suggest a particular type of national institution, the approach advocated by OPCAT should be taken as the minimum to monitoring and prevention. It is unlikely, and in some cases undesirable that the broad range of monitoring functions: visits, strategy and complaints, will be carried out by a single institution. Yet a holistic approach to these functions needs to be in existence in any one jurisdiction. This system needs to encompass: an appropriately staffed independent body or bodies, as well as more informal visitors; a preventive

⁵⁶ The Community Visitors Scheme in South Australia has recently introduced a system to collect follow-up information from patients to find out how useful the visit/meeting was for them. This approach focuses very much on the inspection *process*, rather than the actual outcomes/impact of the inspection, Community Visitors Annual Report 2011-2012, <http://www.sa.gov.au/upload/franchise/Community%20support/Disability/community-visitor/pvc-annual-report-2011-12.pdf>.

⁵⁷ ‘Every year we pull out the recommendations and look at the ones where something had to be done....And I’ll be going to a site specifically to see whether they fixed something that they said they would’.

⁵⁸ Although it is recognised that some systems may not have the capacity to do this: e.g. one of the Chief Psychiatrist Reports in Australia has noted that its ‘current database has limited capacity to document or track the outcome of complaints’, Department of Health Victoria, *Chief Psychiatrists Annual Report 2010-11*, (2012) p. 9.

and reactive approach; the ability to capture patients' experiences; and a regular, respected and established presence on the ground. It will need to be premised on trust, collaboration, and informality and have strong enforcement powers to back up any recommendations made, and communication and collaboration between the variety of different actors which make up the system. Both the CRPD and OPCAT provide crucial guidance, as recommended in the Special Rapporteur's Report, to which states should have particular regard, to ensure that effective systems are put in place to prevent abuses against patients in healthcare settings.

Implementing A Paradigm Shift: Implementing the Convention on the Rights of Persons with Disabilities, in the Context of Mental Disability Law

PETER BARTLETT*

Abstract

The passage of the CRPD in 2006 promises a paradigm shift in the rights of people with disabilities. Implementing this paradigm shift is a major undertaking requiring the involvement of a wide range of stakeholders. The required reforms extend across the legal landscape, and attainment of any consensus on many reforms may take many years in some areas. In the interim, people with disabilities remain subject to situations that are indefensible in human rights terms, whether that is understood in the pre- or post-CRPD paradigm. This creates a set of dilemmas: how do human rights advocates argue for the amelioration of manifest abuses in the short to mid-term without undermining the underlying transformative promise of the CRPD's new paradigm; and how is the pressure on states parties to be maintained in the long process of finding ways fully to implement the CRPD? These difficulties are discussed in the context of laws relating to mental disability, both in general and with particular reference to the revisions to the Standard Minimum Rules for the Treatment of Prisoners (SMR) now under consideration.

Introduction

[F]or 650 million persons around the world living with disabilities, today promises to be the dawn of a new era—an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long.¹

We all rejoiced when the CRPD was passed in 2006, with its promise of a paradigm shift in the human rights of people with disability. People with disabilities are to be full and participating members of society, able to make their own choices and live their own lives—heady promises indeed. Non-discrimination, the order of the day, is buttressed with expectations of meaningful reasonable accommodation to allow the aspirations of people with disabilities to be made real in all aspects of life. The problems related to disability were articulated as flowing from social responses, not as intrinsic to the people with disabilities themselves.

*Nottinghamshire Healthcare NHS Trust Professor of Mental Health Law, School of Law and Institute of Mental Health, University of Nottingham, United Kingdom

¹ U.N. Secretary-General, Secretary-General Hails Adoption of Landmark Convention on Rights of People with Disabilities, U.N. Doc. SG/SM/10797 (Dec. 13, 2006), available at <http://www.un.org/News/Press/docs//2006/sgsm10797.doc.htm>.

After the party, we now face the morning after—the bleary hangover of implementation, a process that will take many years. This is, of course, a problem with any new treaty, but the CRPD is meant to be not merely a new treaty but a new paradigm. Where the traditional view of treaties is that they consolidate previous developments in international law, a considerable aspect of the CRPD's importance is its break with previous international law. For example, far from being a guide to the interpretation of the CRPD, the UN High Commissioner for Human Rights and the UN Special Rapporteur on Torture expressly identified the UN Mental Illness Principles² as no longer reliable statements of international law because of their inconsistencies with the CRPD.³ The impetus for the CRPD was not that the existing law required consolidation; it was that existing law was not working for people with disabilities, and that something new was required.

The CRPD thus opens up a new range of possibilities, but at the same time, this creates particular difficulties for implementation. Consistent with its role as a convention, the CRPD provides the human rights standards and values of this brave new world into which we are venturing; but also quite properly for a convention, it does not generally provide specific requirements as to how those values are to be implemented. Individual States Parties must determine this consistently with their own legal and political cultures. This paper will argue below that conceptualisation of specific forms of legal regulation to implement the values in the CRPD are in their infancy. New forms of law require development and testing in the contexts in which they will be implemented. All that takes time.

Further, while the community of people with disabilities may have taken up the new paradigms contained in the CRPD, many people in the remainder of the population have not. Meaningful change on the ground cannot be introduced by administrative fiat: the new approaches must be 'owned' by the people who administer them on the ground if they are to be successful. For matters such as reasonable accommodation in housing, employment, and social inclusion, that means ownership by the bulk of the population. That is primarily a political process rather than a legal one, and that, too, will take time.

In this period of transition, what should our advocacy look like? We cannot simply say that we will force the new ideas onto domestic governments and the body politic of the States Parties. First, we do not always yet know what specific laws we would demand, and second, without the support of the governed, laws cannot succeed. It is equally unacceptable however to say that we will leave things as they are until the relevant legal interpretations are agreed upon. People with disabilities have been told for decades that they are next year's priority. Under any standards, people with disabilities face unacceptable human rights violations in many countries of the world. Allowing the CRPD to become an excuse to delay improvements while we wait for the perfect, near-perfect, or consensus legal models of implementation to arise would be reprehensible.

The result leaves us in a practical dilemma. Following the old paradigms of human rights law to improve the human rights of people with disabilities may be more attainable in the short to mid-

² G.A. Res. 46/119, U.N. Doc. A/RES/46/119 (Dec. 17, 1991).

³ Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities, Human Rights Council, 10th Sess., ¶ 48, U.N. Doc. A/HRC/10/48 (Jan. 26, 2009) [hereinafter UNHCR Study on Enhancing Awareness of CRPD]; Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, Human Rights Council, ¶ 66, U.N. Doc. A/HRC/22/53 (Feb. 1, 2013) (by Juan E. Méndez) [hereinafter Special Rapporteur on Torture, Report on Feb. 1, 2013]; Special Rapporteur on Torture, *Interim report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 32, U.N. Doc. A/68/295 (Aug. 9, 2013) (by Juan E. Méndez) [Special Rapporteur on Torture, Interim Report].

term because those paradigms enjoy greater acceptance among a wider range of stakeholders in many countries. This may make real improvements in the lives of people with disabilities in those countries. Reliance on these old paradigms however provides them with a credibility and status that may undercut the ongoing political efforts to implement the new paradigm. At the same time, waiting for a consensus on how to proceed under the new CRPD paradigms is reached may take years if not decades, leaving people with disabilities in indefensible conditions in the interim.

There are multiple questions that result from this situation:

- How do we keep the heat on governments and other actors to ensure that the developmental work occurs and that the paradigm shift promised by the CRPD does actually occur? The CRPD is likely to be a once-in-a-lifetime opportunity to make significant changes in the way people with disabilities are dealt with in law and policy and in the community; it is too important to let slip.
- How do we work to prepare the political ground so that the legislative developments to implement the CRPD are 'owned' not only by the communities of people with disabilities but also by lawmakers, the people who will be administering the new law, and the public at large?
- Pending those changes, how do we work to improve the lives of people with disabilities without undercutting the larger project of social and legal change called for by the CRPD?
- A volume of papers compiled by the United Nations Special Rapporteur on Torture establishes that it is appropriate to ask what sorts of steps that office and other international bodies like it ought to be taking to further the above points.

This paper examines these tensions in the context of mental disability law. It does not purport to provide definitive answers or a doctrinaire way forward. It is intended instead to open discussion on the subject.

Mental Disability Law as a Case Study

Mental disability law provides a particularly good case study on this problem. There can be little doubt that implementation of the CRPD requires fundamental changes to most states' mental disability law.

First, the CRPD requires social integration of people with disabilities through, for example, the provision of community living (Art 19), education (Art 24), and employment opportunities (Art 27). Express rights are provided to social and political integration (Arts 29, 30). While their inclusion in a formal convention relating to disability is, of course, significant, these Articles can be seen as a development of previous international instruments and good practice and should not, therefore, be controversial. They do not, however, reflect the current reality in which people with mental disabilities (be they developmental or psychosocial disabilities) live; in much of the world, large closed institutions remain the main mode of care. Often, those institutions often lack adequate conditions regarding, for example, the physical state of the institutions; healthcare provision; the availability of adequate food, clothing, and warmth; social contacts with the outside world; educational and other rehabilitation facilities and programmes; and assuring the safety of inhabitants.⁴

⁴ Regarding the conditions in such institutions, see, for example, the reports of the U.N. Subcomm. for the Prevention of Torture, available at http://www2.ohchr.org/english/bodies/cat/opcat/spt_visits.htm, and, for Council of Europe countries, see the reports of the Council of Europe Comm. for the Prevention of Torture, available at <http://www.cpt.coe.int/en/visits.htm>.

The implementation of these 'uncontroversial' aspects of the CRPD will, therefore, be a significant change in the way mental disability is considered in many countries. The experience of countries with systems of community living is, however, that such systems take time to develop. This includes both obtaining the physical community housing for previously institutionalised people to move into and also developing the social services structures to provide the systems of support that will make such moves practical. Even if the political will exists to implement community living, and often it does not, there will be a significant period of transition in which many people will be living in the institutions.

On the above issues, the CRPD is relatively clear in its terms and requirements (although even regarding deinstitutionalisation, the nature of the social services that are required for the people now living in the community is not entirely clear). On other key issues relevant to mental disability law, however, the CRPD is ambiguous. Based on the drafting history, Article 17's right to integrity appears to be intended at least in part to address the use of medication under compulsion. The actual wording of Article 17 can be viewed as the result of failed negotiations; the drafting committee debated detailed wordings but did not agree upon any of them.⁵ The wording in the Convention therefore merely provides a right to 'integrity'. This right does not exist per se in other international law, so there is no established canon of interpretation. The result is unsatisfactory. Freedom from enforced medication is a vital human rights issue for people with mental disabilities (particularly, but not exclusively, psychosocial disabilities), but it may well be many years before a settled view as to what this article means is reached. Further, the degree to which the article extends into matters beyond medication remains entirely unclear.

While this is a particularly clear example of interpretive ambiguity, it is by no means the only one. The right to equality before the law (Art 12) addresses issues of incapacity—issues that are of tremendous importance to people with mental disabilities—but it is not entirely clear what it requires. At times, it seems to preclude any form of decision-making on behalf of others (Art 12(2)), but at other points, it is more ambiguous (Art 12(4)). Additionally, there is the broad interpretive question of the extent to which the CRPD provides new rights (clearly sometimes yes—eg., Art 17), and how far it instead is intended to ensure the equal application of existing rights to people with disabilities (and what, precisely, that means).

The early interpretations of the CRPD establish that it has a considerable impact on the traditional centre of mental health law. The UN High Commissioner for Human Rights has stated that CRPD compliance requires the demise of compulsory detention on the basis of mental disability: mental health acts as we know them have to go.⁶ Similarly, criminal defences based on mental disorders—long a staple of criminal law—are viewed as inconsistent with the CRPD.⁷ Legal regimes that base findings of incapacity on mental disability must change their laws,⁸ if indeed capacity can be used as a legal concept at all. The Special Rapporteur on Torture has called into question the use of psychiatric medication without the consent of the patient.⁹ All of these would require

⁵ For the drafting history, see Anna Lawson, *The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?*, 34 SYRACUSE J. INT'L L. & COM. 563, 609 (2007); Rosemary Kayess & Phillip French, *Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities*, 8 HUM. RTS. L. REV. 1, 30 (2008).

⁶ UNHCR Study on Enhancing Awareness of CRPD, *supra* note 3, ¶ 49; see also Special Rapporteur on Torture, Report on Feb. 1, 2013, *supra* note 3, ¶ 69.

⁷ UNHCR Study on Enhancing Awareness of CRPD, *supra* note 3, ¶ 47.

⁸ *Id.* ¶ 45; Special Rapporteur on Torture, Report on Feb. 1, 2013, *supra* note 3, ¶¶ 65-66.

⁹ Special Rapporteur on Torture, Report on Feb. 1, 2013, *supra* note 3, ¶ 64.

fundamental changes in the legal provisions of virtually every country, and there is no suggestion that politicians, political and professional stakeholders, or the public are ready to countenance these changes.¹⁰

Notwithstanding the merits of such interpretations, sufficiently developed concepts and legislative models are not in place for legal reform to reflect the new paradigm. Which legal powers should be entirely abolished and which maintained in a fashion that makes them applicable to the population as a whole rather than just to people with mental disabilities? It does seem that current laws that allow intervention to stop people with mental disabilities from injuring themselves but do not permit such intervention for people without disabilities are discriminatory; but it may be the case that we would wish to amend the law not to abolish the power but, in some circumstances, to extend it to the population as a whole. No thought has been given to what those circumstances might be, how to define them, or indeed if such a way forward is desirable at all. Similarly, while it seems obvious that many laws relating to mental capacity must change radically, there is no consensus as to what a new law would look like. Certainly, any express reference to mental disability as a prerequisite to a finding of incapacity seems in violation of the CRPD, but can a capacity-based system of law that is disability-neutral on its face be developed in such a way as not to affect people with mental disabilities disproportionately, and therefore avoid indirect discrimination? Thinking in such areas is in its infancy, and even the systems that have been developed, such as that by Bach and Kerzner,¹¹ have not been subjected to field trials; we do not know what will happen if we implement them.

Indeed, the reports noted above contain their own difficulties in this regard. The UN High Commissioner makes a point of noting that the abolition of conventional mental health law should not be taken to preclude the possibility that people would be preventively detained; merely that it should not be done on the basis of disability. This is a surprising comment. Can it really be the High Commissioner's view that a statute allowing detention of people based on, for example, perceived dangerousness would be consistent with human rights? The difficulty of prediction in this area makes this a startling view; indeed, it is these difficulties of prediction that have made dangerousness a controversial detention criterion in mental health law for many years. For such a system to be credible for the general population, it would at the very least require immense forensic research and public debate.

This serves as a reminder that disability law does not exist in its own bubble. Changes to disability law raise issues in other legal contexts, including other human rights contexts. It is all very well to say that the insanity defence is discriminatory, for example, but criminal conviction of people who lack 'responsibility' is not merely a question of disability law but also of criminal theory more generally. Certainly, domestic law must comply with the CRPD, but the result must also make sense in the context of the theory of criminal law. If it is expected that the new structures will not merely be neutral on their face but also will lack a discriminatory effect based on disability, that is likely to be a fiercely complex undertaking.

At the same time, the human rights violations to which people with mental disabilities are subject are legion: enforced treatment with powerful drugs, detention based on prospective danger-

¹⁰ For a discussion of the CRPD requirements in the context of English and Welsh mental disability law, see Peter Bartlett, *The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law*, 75 MOD. L. REV. 752 (2012).

¹¹ MICHAEL BACH & LANA KERZNER, THE LAW COMMISSION OF ONTARIO, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY (2010), available at www.lco-cdo.org/disabilities/bach-kerzner.pdf.

ousness to self or others or 'in their own interests', and removal of decision-making authority through the use of guardianship legislation are three of the most obvious examples. Even with reference to the pre-CRPD paradigms, these often occur with inadequate legal oversight to ensure compliance with existing domestic law, which is itself often inadequate. These examples are before one even begins to consider social and economic rights such as rights to adequate healthcare, to employment, to social inclusion, and to proper community housing. All these issues are pressing and must be addressed as a matter of urgency. They cannot wait while the larger legal debates occur as to how to re-structure society in a non-discriminatory way despite how important those debates may be.

Implementation Possibilities

1. Preparing the Ground for Reform

The disability communities and others in the human rights community were first to interpret the CRPD, and a variety of strong interpretations have, therefore, entered the mainstream legal discourse. The reports of the UN High Commissioner for Human Rights and the Special Rapporteur on Torture noted above are particularly clear examples of these and have been particularly helpful in establishing an agenda for change.

Divergent interpretations, however, are now beginning to appear. Some place the CRPD in the context of the international law that came before, and are thus more conservative in their approach. Others are based on restrictive readings of the wording of the Convention itself. Some medical professionals, for example, view psychosocial disabilities as 'illnesses' rather than disabilities, and their viewpoints are, therefore, outside the scope of the Convention. This reading effectively slips through the back door the medical model of disability back into the discourse. Others take the view that the definition of disability in the CRPD is triggered only when social responses to impairments result in adverse impacts and, therefore, that the CRPD does not apply to the impairment absent the social element. If given credence, this too would significantly restrict the effect of the Convention.

Divergent interpretations were bound to arise, and we must engage with them. Sometimes, this will be by way of direct challenge to an interpretation that is not consistent with the text or is not supported by the standard canons of legal interpretation, and this is one place where official international officials and organisations, including but not limited to the Special Rapporteur on Torture, should use their influence to ensure that interpretations are supported by the Convention itself. It must however be acknowledged that the early articulations do not have a monopoly on the interpretation of the Convention: we are at a stage where we must accept the wording of the CRPD as it is and not as we wish it had been. Similarly, no individual or organisation has a monopoly on interpretation of the Convention apart from the CRPD Committee. New interpretations open up new meanings. Some of those will be viewed by human rights and disability activists as helpful and some not, but that is the nature of international human rights law.

Engagement with key stakeholders will be essential in any event. For the CRPD to have effect, the body politic as a whole, including all stakeholder groups, need to own it. Insofar as it is possible, there needs to be one integrated conversation regarding CRPD implementation, not a multitude of discussions in isolation from each other. Just talking to our friends is not sufficient. Certainly, service users and service user organisations must be central throughout the conversation, both because that is right and because it is required by the CRPD itself; but if change is going to be effective, it is necessary to both talk and listen to the diversity of stakeholders and the broader body politic.

2. Developing Reform Possibilities

As noted, the process of reforming domestic law has barely begun. Some work has been done on possible developments relating to legal capacity and Article 12, but it is still at a relatively early stage. Little if any work appears to have been done on other key issues relating to mental disability law, such as reform of criminal law and of mental health law. These involve major re-organisations of existing legal structures, and appropriate reforms will arise only after considerable effort. It is appropriate that the CRPD Committee recognise this. While it is realistic to expect that implementation of this sort of major reform may take considerable time, it is reasonable for the Committee to insist on evidence that the process is taking place. Absent such a process, reform never occurs.

While this is the case for legal reform, it is also the case for new policy. As noted above, countries that have moved to systems of care in the community have experienced that it takes time to get programmes right. While it is reasonable to expect some time to be taken, it is equally reasonable to insist that concrete steps be evidenced promptly and throughout the reform process that appropriate reforms are actually occurring.

Once again, this will involve discussions with stakeholders across a wide range of legal and policy fields. At the moment, it is questionable whether this is occurring. For example, for implementation of the right to community living, housing lawyers and academics must start to see the CRPD as integral to their work, and the developments in criminal law will require a similar commitment from criminal law practitioners and academics. It is not obvious that this cross-fertilisation is occurring to any significant degree, and that is a significant problem if the CRPD is to have actual effect. It would be appropriate for the CRPD Committee to require information on what national programmes are in place to drive these changes forward.

3. Developing Measures Toward Full Implementation

Some elements of the CRPD will take time to implement. The rights to community living, to education, to adequate standards of living, and to social integration, for example, will take time to reach full realisation. Too often, however, ‘progressive realisation’ becomes a justification for states to do nothing. In principle, developing measures to monitor the implementation of these rights is not difficult: how many people with disabilities are in community living (and how many in institutional environments); how many in what sort of education; how many in employment; what standard of living is provided for those without employment; how many are participating in broader society more generally?

Consistent with Article 31 of the CRPD, the CRPD Committee should insist on the collection of this information. It is not their sole responsibility, however. The issues in question overlap with the mandates of other international bodies. Those bodies should be expected to be active in pressing for implementation of the CRPD as relevant to their mandates.

This may, sometimes, involve a re-assessment of the mandates of these organisations. The United Nations Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (“SPT”), for example, has tended to view its mandate on inspections as focused on the conditions of detention. These are of tremendous importance for people with mental disabilities, as for anyone else. The provision of appropriate programmes for people with mental disabilities in prisons; the availability of appropriate physical health care for people with mental disabilities; the provision of appropriate standards of food, heat, and other necessities; and

the provision of reasonable accommodation within the meaning of Article 5 of the CRPD to people with mental (and other) disabilities really do matter. They are not, however, the only issues in these facilities. Too frequently, the life of a person with mental disabilities starts with early institutionalisation where inadequate education, care, and social integration are provided. Upon attaining adulthood, the individual is unable to be integrated into the community and is therefore moved to an institution for adults where they may remain for the rest of their life (or may, upon reaching old age, be again moved to yet another institution, this time for old people). This pattern of institutionalization is itself an example of inhuman or degrading treatment, and that violation is not dependent on the quality of the food or the other matters currently viewed as central to the mandate of the SPT and similar bodies. Bodies of this type need to understand their mandates as extending to the inappropriate institutionalisation of people with disabilities. They need to be asking questions about the provision of community alternatives to institutional care. The damaging effects of inadequate care, particularly for children, are well-known; this is not a case where there is much by way of dispute. Certainly, the development of alternative models of care takes time, but the failure of international bodies to probe into the development of those alternatives amounts to collusion in the human rights violation itself.

4. The Contextual Complexity of Reform in the Here and Now

As noted, there are situations where reform cannot wait for the grand projects envisaged by the CRPD. Sometimes this occurs in particularly serious cases involving people with disabilities—the provision of particularly intrusive forms of medical treatment without consent, for example—and sometimes it involves broader human rights reforms where the rights of persons with disabilities are significant but not the only relevant issue.

Further, reform does not occur in the abstract, but on the ground, in the context of existing environments and institutions. As with the issues of legal reform noted above, the issues that arise are not merely geographically and socially specific, but they may also raise issues in fields beyond disability. Like the legal issues discussed above, they may involve human rights situations that are pressing and immediate, where precise requirements of the CRPD may yet be unclear, and where those charged with reform may have little experience in international law of disability, and may not intuitively support its objectives. The precise direction of reform in such situations may be unclear, and even if clear, may not be politically achievable. Even if politically achievable, such reforms may not be implemented on the ground, through intransigence or hostile incomprehension of people in the system. Approach to reform in these situations is, therefore, complex. How does one provide reforms that address the immediate needs of people with disabilities without undermining the greater reforming vision of the CRPD?

A concrete example of the difficulties can be seen in the current reform processes relating to the United Nations Standard Minimum Rules for the Treatment of Prisoners (SMR). The SMR are a core text relating to standards of detention for individuals and are routinely referred to in much of the world. They are a floor for human rights, designed to provide basic standards of protection both in the developed world and in countries that have minimal traditions of such safeguards and minimal resources available for compliance. Conditions of detention in prisons and similar criminal facilities are of considerable importance to people with disabilities in general and to people with mental disabilities in particular: people with developmental and psychosocial disabilities are encountered frequently in prisons and similar criminal justice institutions, and may be particularly

singled out for bullying or violence in those environments. Too frequently, little if any regard is paid to the needs that flow from their disabilities.

The purpose of the current discussion is not to argue for what changes are or are not appropriate to the SMR as they relate to people with disabilities; others are engaged in that exercise.¹² Instead, the object is to articulate the sorts of tensions that arise when choosing advocacy positions in the context of an important issue that includes but also extends beyond people with disabilities.

The SMR are an instructive example for current purposes. They are an example where serious human rights violations relating to persons with mental disabilities are occurring, whether one articulates those according to pre- or post-CRPD paradigms. At the same time, the rules involve not just prisoners with disabilities but also prisoners as a whole, and the disability-related issues are, therefore, not free-standing; they must sit within the overall rules relating to prison governance.

Certainly, some changes can and should be introduced into the SMR that are entirely consistent with the CRPD. Non-discrimination, including the requirement of the provision of reasonable accommodation, consistent with Article 5 of the CRPD should be included. Those requirements of reasonable accommodation should be clearly articulated to establish that all persons with disabilities should have access to the reformatory programmes of the prison. Other amendments are consistent both with the CRPD and other pre-existing international law and practice. Thus protections regarding consent to health interventions are certainly required by Art 25 of the CRPD, but also by other international law. Given the interpretation provided by the Special Rapporteur on Torture it is at least arguable that restrictions on the use of solitary confinement and restraints (including chemical restraints) are now required, although other international protocols (eg., the Istanbul Protocol on the use and effects of solitary confinement) are actually clearer on the point.

Other points are more problematic. Ideally, and consistent with the CRPD's requirements of non-discrimination and reasonable accommodation, people with mental disabilities in these environments should have specific programmes and support provided to ensure that they can benefit from the rehabilitative programmes of the prison. They would be housed in the general population where they would be accepted as part of the prison community and where appropriate supports would be in place to meet their needs and ensure their freedom from exploitation, violence, and abuse. Medical care would be available to them, based on free and informed consent, fully to meet their needs and on a basis equivalent to that available to the general public. Tailored educational programmes would be made available for them to develop fully in preparation for taking their place without discrimination in the community once their debt to society is paid.

In wealthy countries with a history of advocacy relating to mental disability, this vision has much to recommend it. These countries should be pushed hard to bring about these conditions. The reality is, however, that this grand vision is unrealistic for the vast bulk of the world. This is partly for financial reasons: the vision noted above is not inexpensive to introduce, and many countries in the world cannot afford it. It also implies a mentality about prisons that is not neces-

¹² See, e.g., Special Rapporteur on Torture, Interim Report, *supra* note 3; Report on the Meeting of the Expert Group on the Standard of Minimum Rules for the Treatment of Prisoners held in Buenos Aires from 11 to 13 December 2012, U.N. Doc. UNODC/CCPCJ/EG.6/2012/4 (Dec. 13, 2012); Comm. on Crime Prevention & Criminal Justice, Proposal of the Governments of Argentina, Brazil, South Africa, United States of America, Uruguay, and Venezuela, U.N. Doc. E/CN.15/2013/CRP.6 (Apr. 10, 2013); Expert Meeting at the University of Essex on the Standard Minimum Rules for the Treatment of Prisoners Review: Summary, U.N. Doc. UNODC/CCPCJ/EG.6/2012/NGO/1 (Nov. 20, 2012); World Network of Users and Survivors of Psychiatry, Statement to the Second Intergovernmental Expert Group Meeting on the Review of the Standard Minimum Rules of on the Treatment of Prisoners, U.N. Doc. UNODC/CCPCJ/EG.6/2012/NGO/5/Add.1 (Dec. 11, 2012).

sarily shared internationally. While a philosophy of rehabilitation may enjoy broad support among human rights theorists, it is less obvious that it is always supported by the public, prison administrations and staff, and politicians. These actors are more likely to view prisons as places where prisoners are subject to hierarchical controls and where their rights are removed. This ethos is difficult to integrate with the empowerment philosophy of the CRPD. It is further not obvious that all prisoners will be accepting of people with mental disabilities in their communities. If people with such disabilities are to be safe, levels of surveillance may be required which are both impractical and raise human rights concerns regarding privacy. The overall conditions that exist in many prison environments in the world are unlikely to be conducive to the health and well-being of people with mental disabilities. This is unsurprising. The attitude in many parts of the world is that prisons are meant to be punitive and, therefore almost by definition may be environments that are inappropriate for people with mental disabilities. For these and other reasons, simply imposing the CRPD vision onto the SMR without taking into account the local conditions is unlikely to have much impact on the ground. It may perhaps still be worth doing- the SMR have a symbolic value as statements of good practice, and symbols do matter- but that increased level of abstraction will affect the way the SMR are perceived by prison administrators. If they become statements of ideals perceived as unattainable and therefore 'pie in the sky' by local administrators, their use will be correspondingly limited in making improvements in the short term.

If advocacy for the CRPD ideal is unattainable and potentially counterproductive, what other options are available? Consistent with much international law prior to the CRPD, the SMRs as they stand tend to favour the removal of people with mental disabilities from prisons into psychiatric hospitals and similar environments. This is also problematic. Often, if the country is one where prison conditions are lacking, the conditions in psychiatric facilities may not be much good either. Further, the move to a psychiatric environment is likely to involve the removal of key legal rights. People in psychiatric facilities often lose the right to consent to all or some medical treatment, particularly when the treatment relates to their mental disorder. That is a significant loss (although it is fair to wonder whether such rights are always respected in prison environments either). Admission to a psychiatric facility may result in stigmatisation, although once again, it is fair to wonder whether this is more or less significant than the stigmatisation that flows from imprisonment. While some programmes in the psychiatric environment may well be more suitable for people with mental disabilities, it would be wrong to assume that these are either of universally high standards internationally or indeed that they are tailored to the needs of the individual. Sometimes they will be, sometimes not.

Whether the approach is one of removal of the individual to a psychiatric environment or the provision of reasonable accommodation within the standard prison system, individualised assessment of the prisoners will be required. Who is to do this? The answer has traditionally been that prison medical officers should do this, ideally with administrative systems providing those officers with some degree of independence from prison authorities. Such officers, the theory has traditionally said, are best placed to determine the needs of individuals with mental disabilities. An idealised CRPD approach would question this. The Convention rejects the medical model of disability, and it is difficult to see how the use of prison medical officers to determine appropriate programmes for people with such disabilities will not reintroduce the medical model squarely into the prison environment. While this is certainly arguable, it does not address the question of who *is* meant to do the assessments to determine what reasonable accommodations are appropriate. In wealthy countries, a range of possible answers may be available, but the SMR are meant to apply

to poor as well as to wealthy countries. In poor countries, options are likely to be much more limited. In such countries, prison staff such as guards are unlikely to have the requisite training and will also potentially be involved in conflicts of interest (running a ‘peaceful ward’ rather than the needs of the individual prisoner). Prison medical staff may well be the only other practical option. At least in theory, they have some independence from the governance of the prison. How real that independence is may well be a fair question, but given the choices available, it may be the best option for prisoners with disabilities in the short to mid-term. Again, the question arises whether the short-term results warrant a departure from the overarching CRPD principle.

The object here is not to advocate for one choice over another in these matters. It is rather to note that the choices taken will have advantages and disadvantages in the short and long term.

Conclusion

In a sense, the problems identified above are those faced by advocates on a daily basis: the tension between short-term and long-term goals; the difficulties in international advocacy in taking into account vastly different geographical, cultural, economic and legal contexts; and trade-offs between the ideal and the attainable in negotiations. The CRPD does introduce a different dynamic, however, because it is meant to constitute a break from previous international law at least as much as a continuation. The efficacy of the CRPD will therefore depend on its new values and norms—its new paradigm—being accepted into the daily life not only of people with disabilities but also of politicians, administrators and other stakeholders. A number of its key articles also require the development of new legal forms within a wide array of laws to bring about disability-neutral policy. All of this will take time. Notwithstanding the triumphalist language of Kofi Annan with which this article began, we are at the beginning of the journey, not the end, and the journey will not be short.

The pressure for reform will therefore need to continue for many years. This is not something we can take for granted. The CRPD is a new Convention, and as a result has been ‘flavour of the month’ since its introduction. That will not continue. New human rights issues will arise, and UN agencies and similar bodies will respond to them as they have to the CRPD. If disability rights are to continue to develop, therefore, disability advocates must be ready to fight our corner to ensure that the fundamental and ongoing developments to disability policy do not slip off international and domestic agendas.

In the course of those fundamental and often long-term reforms, we cannot lose track of the immediate needs and human rights violations that affect people with disabilities on a daily basis. Addressing those needs in the specific geographic, cultural, and legal contexts in which they arise may create tensions with some of the directions of the long-term policy reform. Strategies must be developed in individual instances to address those tensions, but ignoring immediate needs cannot be viewed as consistent with human rights advocacy.

Compliance is Unreasonable: The Human Rights Implications of Compliance-Based Behavioral Interventions Under the Convention Against Torture and the Convention on the Rights of Persons With Disabilities

LYDIA BROWN*

Abstract

Educational professionals, clinicians, and medical personnel largely accept and condone compliance-based behavioral interventions as appropriate or necessary methods for correcting, treating, or ameliorating disability, including psychiatric, learning, developmental, and behavioral disabilities. Such compliance-based interventions are grounded in a philosophy of indistinguishability from non-disabled people that emphasizes purely cosmetic behavioral changes. Yet behavioral changes centered on compliance and control are frequently contrary or detrimental to natural forms of movement, communication, and behavior. Unlike person-centered support services or self-directed therapy and care, compliance-based interventions do not support the development of functional skills or coping mechanisms. Furthermore, compliance-based behavioral interventions, which include restraint, seclusion, and aversive procedures, constitute torture as defined in the Convention Against Torture due both to their inherently and systematically abusive nature as well as their actual applications and methodology. Additionally, they discriminatorily target disabled people for such torture and violation of rights in contravention to the non-discrimination and protections provisions of the Convention on the Rights of Persons with Disabilities. Nevertheless, the prevalence and scope of compliance-based interventions, as well as their inherently discriminatory and abusive nature, have received little attention outside the disability community. Reframing the discussion of compliance-based behavioral interventions through an international human rights lens would strengthen existing advocacy efforts in the disability community as well as bring the issues to the forefront of international human rights activism.

*Lydia Brown is Project Assistant for the Autistic Self Advocacy Network. She would like to thank Shain Neumeier and Ari Ne'eman for outstanding support and guidance. Please direct correspondence to Lydia Brown, Autistic Self Advocacy Network, PO Box 66122, Washington, DC 20035 or by email to lydia@autistichoya.com.

Introduction

On 14 December 2011, a special education teacher punished autistic nine-year-old Christopher Baker for refusing to complete a school assignment by instructing him to climb inside a large bag, pulling the drawstring tightly shut, and placing him inside the bag in the hallway.¹ When Baker's mother came to the school to retrieve him, she learned that this punishment had been used multiple times previously with the purpose of controlling and correcting his behavior.² The bag is intended for therapeutic purposes under carefully controlled conditions, not for punishment, as Baker's special education teachers were using it.³ Over the next month, repeated attempts by the family and the public to demand accountability and redress for the incident resulted in denials of wrongdoing from school officials⁴ and a public statement during a school board meeting that defended the school and its teachers while simultaneously decrying those who criticized the abusive disciplinary practice as uninformed and overreacting.⁵

Christopher Baker's story is not an isolated incident. Behavioral modification and intervention emphasizing compliance for disabled people, particularly disabled children, are widespread in schools, residential institutions, and service provision. Disabled students are frequently subjected to unnecessary, punitive measures for behaviors that in many cases are merely inconvenient or unusual, but not dysfunctional or harmful, as a means to enforce compliance and normalcy rather than to support the development of functional skills. While emerging philosophies of education have begun to emphasize individualized instruction strategies and development of critical engagement skills, trends in education of developmentally disabled children and children with psychiatric disabilities have largely erred toward a medicalized model that pathologizes any deviation from typical modes of thought, movement, and communication as aberrant and in need of medical treatment. Behavioral interventions for disabled people, particularly "treatments" such as applied behavior analysis for autistic and other developmentally disabled people, are primarily used to enforce standards of indistinguishability from non-disabled people rather than to support and promote functional skills and behavior.

Behaviorist Ivar Lovaas, whose work has been foundational to the development of contemporary applied behavior analysis practices, described the autistic youth in his seminal study as achieving the goal of seeming to be indistinguishable from their non-disabled age-peers.⁶ This notion that indistinguishability ought to be the mark of success for autistic or other disabled people presupposes that the ways in which autistic or other disabled people naturally move, think, or communicate are defective or deficient simply because they are associated with disability, and

¹ See Jennifer Hoff, Mercer Co. Mother Upset Over Son's Punishment, WLEX-TV, Dec. 16, 2011, <http://www.lex18.com/news/mercercoco-mother-upset-over-son-s-punishment> (last visited 17 Dec. 2012) and Nat'l Disability Rts. Network, School Is Not Supposed to Hurt: The U.S. Department of Education Must Do More to Protect School Children from Restraint and Seclusion 12 (March 2012), available at http://www.ndrn.org/images/Documents/Resources/Publications/Reports/School_is_Not_Supposed_to_Hurt_3_v7.pdf. [hereinafter NDRN 2012 Report]

² *Id.*

³ Landon Bryce, See Kind of "Ball Bag" Autistic Boy Was Confined To, ThAutcast, Dec. 23, 2011, <http://thautcast.com/drupal5/content/see-kind-ball-bag-autistic-boy-was-confined> (last visited 21 June 2012).

⁴ Email from Dennis Davis, Interim Superintendent, Mercer County Schools, to Kimberly Wombles, Adjunct Instructor of English and Psychology, Cisco College (Dec. 22, 2011, 06:22 CST) (on file with author).

⁵ Greg Kocher, Mercer County Mom Whose Son Was Put in Bag Delivers 170,000 Signatures to School Board, Kentucky.com, Jan. 20, 2012, <http://www.kentucky.com/2012/01/20/2035478/mercercounty-mom-whose-son-was.html> (last visited 17 Dec. 2012).

⁶ O. Ivar Lovaas, Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children, 55 J. OF CONSULTING AND CLINICAL PSYCHOL. 3, 3 (1987).

that they must therefore be rectified through treatment to eradicate them and replace them with more conventional or typical modes. It is necessary to understand that the underlying assumption of the philosophy of indistinguishability is that the goal for disabled people should be to be seen as non-disabled as possible for its own sake and at the expense of necessary and natural means of communicating, moving, or functioning. Compliance-based behavioral interventions attempt to enforce such standards of normalcy.

While the venues where many behavioral intervention practices occur are often nominally educational settings rather than healthcare settings, the medical model underlying the philosophy of indistinguishability itself re-contextualizes these educational settings as healthcare settings by positing disability as a medical condition and behavioral interventions as treatment to mitigate those medical conditions. Disabled children are rarely afforded access to education for its own sake; the denial of this fundamental right is construed as medically necessary in order to treat the symptoms of their disabilities. An article co-authored by Lovaas described decisions related to applied behavior analysis as

*based on information obtained during assessment of the behavior, the risk it poses, and its controlling variables; on a careful consideration of the available treatment options, including their relative effectiveness, risks, restrictiveness, and potential side effects; and on examination of the overall context in which treatment will be applied.*⁷

It is important to note that the development and implementation of the behavioral intervention does not take into consideration the preferences or concerns of the treatment recipient. This attitude is pervasive among many practitioners of Lovaasian applied behavior analysis, and reflects the goals of compliance-based behavioral interventions as emphasizing cosmetic conformity over developing functional support skills.

Compliance-based behavioral interventions have largely gone unquestioned as a result of lack of protections for disabled children in the law, under-prosecution of abusive practices, absence of safeguards for emergency crisis intervention techniques, and pervasive acceptance of behavioral modification as a legitimate practice when used on disabled people. State and federal government entities have also been complicit in subjecting disabled children to compliance-based behavioral interventions through funding and licensing programs that implement these practices, legitimizing their use in the courts, neglecting to promulgate sufficient regulatory standards, and insufficiently enforcing existing standards. There is therefore an urgent need for legal and policy reforms that would address and prevent the continuous, systematic, and pervasive abuse of disabled children in the name of treatment.

Discussion

In the nineteenth and twentieth centuries, the predominant teaching philosophy for instructors of the deaf was oralism, which emphasized reproduction of oral speech and elimination of manual language—sign language—in order to assimilate deaf people into a majority hearing culture.⁸ Generations of deaf students aged into adolescence and adulthood deprived of access to their natural means of communication, as hearing instructors determined that the goal for deaf students

⁷ Ron Van Houten, Saul Axelrod, Jon S. Bailey, Judith E. Favell, Richard M. Foxx, Brian A. Iwata, & O. Ivar Lovaas, *The Right to Effective Behavioral Treatment*, 4 J. OF APPLIED BEHAV. ANALYSIS 381, 384 (1988).

⁸ Joseph P. Shapiro, *NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT*, 90-92 (Three Rivers Press 1994) (1993).

should be to communicate as if they were hearing as much as possible, ultimately depriving them of the right to be part of a collective Deaf community.⁹ Similar emphases on compliance with constructed norms have continued to define many therapeutic and treatment practices for disabled people today.

1. Restraints and Seclusion

In 2009, a U.S. Government Accountability Office report on death and abuse as a result of seclusions and restraints, which are among the most common punitive behavioral interventions, found that these practices are widespread, under-prosecuted, and frequently responsible for traumatizing, physically injuring, and killing their victims.¹⁰ Seclusion and restraint are compliance-based behavioral interventions employed to control, punish, or correct a child's behavior. Seclusion is a particular form of punishment in which the victim is placed alone in a room with a locked or barricaded door and intentionally prevented from leaving voluntarily for a period of time that can last from minutes to hours. Restraint is the physical, mechanical, or chemical inhibition of an individual's freedom of movement, behavior, or action. Physical restraint is when an individual is bodily restrained by one or more other people holding the individual's limbs, sitting on the individual, or otherwise pinning the individual against a wall or floor. Mechanical restraint is when an individual is strapped, tied, or otherwise bound to another object such as a table or board specifically designed for mechanical restraint. Chemical restraint is when an individual is forced or manipulated into taking psychotropic medication for the purpose of chemically inducing compliant, passive, and complacent behavior. Restraint and seclusion are frequently used in conjunction with one another.

Some disabled people have been subjected to mechanical restraint that lasted for weeks or months at a time.¹¹ In 1998, a four-year-old autistic student with cerebral palsy was subjected to prolonged restraint and physical abuse in her West Virginia school that eventually culminated in her mother withdrawing her from the school after her daughter began to return from school with abrasions on her body.¹² School officials described the series of events as follows:

After the girl was enrolled in school for just 10 days, her mother arrived at school to pick her up and was told by a teacher's aide that she was being uncooperative and had been restrained in a chair for medically fragile children. The mother later claimed that, because the child was autistic, she would act up when she needed to use the bathroom. The school and teachers stated that they put her in the chair because she was "uncooperative." According to the mother, the chair resembled an electric chair and was high backed with multiple leather straps across the arms, chest, lap, and legs. The mother told the school to never use the chair again.¹³

Similar stories involve the use of long-term seclusion instead of or in addition to long-term restraint. For example, in 1992–1993, a nine-year-old boy with a learning disability was subjected to repeated seclusion throughout the school year.¹⁴

⁹ See generally Douglas Baynton, *Savages and Deaf-Mutes: Evolutionary theory and the campaign against sign language*, 8 J. ANTHROPOL. STUD. HUM. MOVEMENT 139 (1995).

¹⁰ *Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers Testimony before the Comm. on Educ. And Labor, H.R., 111th Cong.* 15-16 (statement of Gregory D. Kutz, Managing Director of Forensic Audits and Special Investigations, Gov't Accountability Office) [hereinafter "GAO Testimony on Restraint and Seclusion"]

¹¹ Wanda K. Mohr, Margaret M. Mahon, & Megan J. Noone, *A Restraint on Restraints: The Need to Reconsider the Use of Restrictive Interventions*, 12 ARCHIVES OF PSYCHIATRIC NURSING 95, 95 (1998).

¹² GAO Testimony on Restraint and Seclusion, *supra* note 10, at 22.

¹³ *Id.*

¹⁴ *Id.* at 27.

The IEP [individualized education plan] specified that the school may put the child in a “time-out” room to correct inappropriate behavior, but only as a last resort. However, school records show that the student was placed in the time-out room regularly—75 times over a 6 month period during the 1992-1993 school year, occasionally for an hour or longer. The reason for the confinement logged by the teachers included behaviors that were not physically aggressive; examples include “whistling,” “slouching,” and “waving hands.”...Although the door to the room was unlocked, a staff person would hold the door of the room closed to prevent him from leaving, and the child’s hands became blistered at least once while trying to escape. On at least one occasion, the child claims he was physically restrained facedown on the floor...The time-out room was small—approximately the length of an adult’s arm span—and was lined with ripped and dirty padding. In addition, the student’s mother reported that the room lacked ventilation and had an odor of “dirty feet and urine.”¹⁵

As in this case, seclusion and restraint are often nominally last resort techniques of discipline or crisis management, but are frequently used as punitive measures to control or combat any behavior that instructors, staff, or service providers find merely undesirable, inconvenient, or abnormal, even in the absence of any danger to self or others. Seclusion and restraint are commonplace compliance tactics in special education settings,¹⁶ psychiatric institutions,¹⁷ and residential treatment facilities¹⁸ alike, yet the most recent report of the Special Rapporteur on Torture have only condemned these practices in residential treatment settings and failed to specifically address their disturbing prevalence in typical educational settings.¹⁹ The primary purpose of seclusion and restraint as they are used is to enforce compliance for its own sake and not to promote positive learning or therapeutic goals. As opposed to serving as legitimate forms of disciplinary action, seclusion and restraint frequently traumatize those subjected to them and do not meaningfully address actually dangerous behavior.²⁰ For instance, the girl from West Virginia in the above-mentioned example now has post-traumatic stress disorder.²¹

2. Aversive Interventions

Aversive interventions are compliance-based behavioral interventions that seek to eliminate unwanted behavior by causing victims to associate the behavior with an unpleasant, or aversive, stimulus. In practice, aversive interventions have spanned the gamut from beatings, electric shock, deprivation techniques, prolonged restraint and seclusion, forced exercise and labor,

¹⁵ *Id.* at 27-28.

¹⁶ GAO Testimony on Restraint and Seclusion, *supra* note 10, at 7.

¹⁷ See generally UNICEF, Monitoring the rights of mentally disabled children and young people in public institutions (2005-2006), available at http://www.unicef.org/romania/Report_CRJ_engl_FINAL.pdf; Laurie Ahern & Eric Rosenthal, Mental Disability Rts. Int’l, Torment not Treatment: Serbia’s Segregation and Abuse of Children and Adults with Disabilities (November 2007), available at http://www2.ohchr.org/english/bodies/cat/docs/ngos/MDRI_Serbia41.pdf; B. Christopher Frueh, Marc E. Dalton, Michael R. Johnson, Thomas G. Hiers, Paul B. Gold, Kathryn M. Magruder, & Alberto B. Santos, Trauma Within The Psychiatric Setting: Conceptual Framework, Research Directions, and Policy Implications, 28 ADMIN. AND POL’Y IN MENTAL HEALTH 147 (2000).

¹⁸ Jonathan D. Brown, Kirsten Barrett, Henry T. Ireys, Kamala Allen, Sheila A. Pires, Gary Blau, & Melissa Azur, Seclusion and Restraint Practices in Residential Treatment Facilities for Children and Youth, 82 AM. J. OF ORTHOPSYCHIATRY 87 (2012).

¹⁹ Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 1 February 2013, A/HRC/22/53, 14, available at http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf. [hereinafter Méndez Report on Torture]

²⁰ GAO Testimony on Restraint and Seclusion, *supra* note 10, at 1.

²¹ *Id.* at 23.

forced medication or chemical restraint, and verbal abuse. Survivors of such aversive interventions frequently develop post-traumatic stress disorder, increased anxiety, panic attacks, and depression. As opposed to mitigating dangerous and harmful behavior or supporting the development of functional skills, compliance-based behavioral interventions actually often lead to regression in functional skills and exacerbation of pre-existing mental health problems.

The Judge Rotenberg Center in Canton, Massachusetts, is a residential facility for disabled children, youth, and adults with behavioral challenges that uses aversive behavioral interventions including food deprivation, prolonged restraint, sensory assault, and contingent electric shock as punitive measures for unwanted behaviors.²² The JRC's practices are undergirded by "a theory of behaviorism that mental disabilities can be extinguished by an elaborate system of rewards and punishments for acceptable or unacceptable behavior."²³ While the JRC's staff uses a variety of compliance-based aversive interventions, they are particularly well known for their use of the graduated electronic decelerator (GED) device, which administers a two-second electric shock intentionally designed to inflict severe pain.²⁴ Residents are frequently shocked not merely for potentially dangerous behavior, but also for non-compliance when their behavior poses no threat to themselves or anyone else. One resident was repeatedly shocked for cursing and getting out of his seat without permission.²⁵ He was also shocked after refusing to take a shower, and his mother described the incident as follows:

He said that one time a new worker told him it was time to go to bed. He told him that he had extra time to stay up but he said "you are going to bed and I want you to take a shower." So they ripped his clothes off him and he said they said "now we are going to hang you up like Jesus Christ" and they shocked him while he was in the shower.²⁶

While the above represents an extreme example, the JRC's practices are the inevitable result of the philosophy behind compliance-based aversive behavioral interventions. Compliance-based aversive behavioral interventions, whether or not they are ever called "aversives," are commonplace in many behavioral modification facilities and other residential institutions where disabled youth are placed or committed.

In other cases, they also occur in more typical educational settings. From 2001 to 2002, an autistic seven-year-old girl in California was repeatedly confined in the back of her classroom and forced to lie face down on the floor with the teacher sitting on top of her because she refused to do schoolwork.²⁷ The parents described their daughter's experiences as follows:

In April 2002, the parents alleged that the teacher admitted to smearing the contents of a burrito all over the student's face and hair after she refused to eat. In July, the parents removed their daughter from the school after the teacher allegedly physically restrained her at least three times in one day during summer school. Furthermore, according to the parents' complaint, the teacher kicked the student, spun her around, and dropped her on her head. When her mother picked her up from school that day, the child had a severe abrasion to her arm, a one-inch diameter bruise on her right shoulder, and a bump on the

²² Laurie Ahern & Eric Rosenthal, *Mental Disability Rts. Int'l, Torture Not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center: Urgent Appeal to the United Nations Special Rapporteur on Torture 2* (2010).

²³ *Id.* at 1.

²⁴ *Id.*

²⁵ Fredda Brown & Dina A. Traniello, *The Path to Aversive Interventions: Four Mothers' Perceptions*, 35 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 128, 133 (2010).

²⁶ *Id.* at 133.

²⁷ GAO Testimony on Restraint and Seclusion, *supra* note 10, at 26.

*right side of her head. The student told her mother she was “hurt all day” by her teacher. The teacher later said she restrained the student because she was a danger to herself and others.*²⁸

The usual intended purpose of aversive interventions is to control or correct unwanted behavior, regardless of whether the behavior is actually dangerous, aggressive, or a threat to the individual targeted for intervention or to other people. While both the current and previous Special Rapporteurs on Torture have specifically condemned the JRC, the most recent report on torture on healthcare settings failed to meaningfully address the prevalence of aversive and punitive measures in more typical educational settings, particularly segregated classrooms and schools for disabled students.²⁹

3. Lovaasian Applied Behavior Analysis

One of the most common forms of compliance-based behavioral interventions is Lovaasian applied behavior analysis. The fact that Lovaasian applied behavior analysis is commonly recommended by clinicians as an evidence-based therapy for behavioral challenges, especially with autistic children, is a particularly insidious example of the pervasive acceptance by support professionals and educators of the legitimacy of compliance-based behavioral interventions. Further compounding this problem is that fact that Lovaasian applied behavior analysis is rarely differentiated from applied behavior analysis techniques that do support the development of functional skills.

Lovaasian applied behavior analysis as used on disabled children is nominally a “treatment” for problematic behaviors that targets them for elimination through discrete trial training (DTT) in which the child is repeatedly rewarded for displaying the “correct” behavior and punished for displaying the “wrong” behavior. This particular type of compliance-based behavioral intervention frequently targets behaviors that are unusual or odd but not dangerous or harmful, such as hand-flapping, lack of eye contact, or not sitting still. Lovaasian applied behavior analysis often also targets behaviors that disabled people may not be able to control or that may be natural coping mechanisms, such as refusal to eat foods of certain textures or closing eyes when exposed to bright lights.

One mother of an autistic son described their family’s experience with Lovaasian applied behavior analysis practitioners as follows:

This treatment culminated when they destroyed his emotional and psychological health in a 25 minute intervention involving forced restraint and yelling while he cried and attempted to free himself. Our gentle son was very skillfully and purposefully pushed into unbearable and unmanageable anxiety. Our son now carries a dual diagnosis: autism and POST-TRAUMATIC STRESS DISORDER (PTSD). ...Within 24 hours of his final “treatment” our son became unpredictably violent. He is now anxiety filled from day to night and cries frequently. He has flashbacks, intrusive memories, and nightmares. This formerly easygoing boy of four is now constantly fearful, easily startled, and lashes out

²⁸ *Id.* at 26-27.

²⁹ See Méndez Report on Torture, *supra* note 19; Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment: Addendum: Observations on communications transmitted to Governments and replies received, 4 March 2013, A/HRC/22/53/Add.4, 83-84, available at http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53.Add.4_Advance_version.pdf; Kishore Singh, Report of the Special Rapporteur on the right to education, Kishore Singh: Addendum: Communications sent to and replies received from State, 13 May 2011, A/HRC/17/29/Add.1, 17-18, available at http://www2.ohchr.org/english/bodies/hrcouncil/docs/17session/A.HRC.17.29.Add.1_EFSonly.pdf.

*automatically and defensively. His basic trust has been destroyed and he strongly avoids most people. In addition, he cannot even go near any educational materials or manipulatives (building blocks, etc.) without severe panic, since these were used in his behavioral program.*³⁰

While there have been no empirical studies demonstrating a clear link between Lovaasian applied behavior analysis and later diagnoses of post-traumatic stress disorder, the anecdotal evidence supporting such a link is strong, particularly when coupled with innumerable documented cases of post-traumatic stress disorder occurring as a result of other compliance-based behavioral interventions.³¹ One autistic adult wrote of her childhood experiences with Lovaasian applied behavior analysis that targeted her hand-flapping—a common behavior among autistic people frequently associated with autism—for elimination as follows:

*When I was six years old, people who were much bigger than me with loud echoing voices held my hands down in textures that hurt worse than my broken wrist while I cried and begged and pleaded and screamed....In a classroom of language-impaired kids, the most common phrase is a metaphor. "Quiet hands!"...I've yet to meet a student who didn't instinctively know to pull back and put their hands in their lap at this order. Thanks to applied behavioral analysis, each student learned this phrase in preschool at the latest, hands slapped down and held to a table or at their sides for a count of three until they learned to restrain themselves at the words. The literal meaning of the words is irrelevant when you're being abused....When we were in high school, my occasional, accidental flap gave my other autistic friend panic attacks....They actually teach, in applied behavioral analysis, in special education teacher training, that the most important, the most basic, the most foundational thing is behavioral control.*³²

The end goal of Lovaasian applied behavior analysis is indistinguishability. Success is measured by how visibly disabled the child appears to be during and after "therapy," and by how well the child conforms and complies with expectations of "normal" behavior. Practitioners of Lovaasian applied behavior analysis emphasize the elimination of all atypical behaviors while demanding replacement behaviors that serve little more than cosmetic or aesthetic purpose, such as making eye contact, not flapping one's hands, or playing with blocks in a "normal" fashion. The focus on normalization to the point of indistinguishability not only ignores the real need of disabled children to learn functional skills but also deprives them of the right to move, think, and communicate in the ways that come naturally to them.

To provide further context for the techniques that Lovaas espoused for use on autistic and other disabled children, it should be noted that Lovaas is also known for his work on the "feminine boys" project, in which boys with stereotypically feminine patterns of behavior, movement, or speech were subjected to compliance-based behavioral interventions targeted at eliminating stereotypically feminine behaviors and replacing them with stereotypically masculine behaviors.³³ An institutionalized prejudice against men or women affecting behavior, movement, or speech stereotypically attributed to a different gender resulted in the systematic abuse of the boys in Lovaas's project, who were forced to suppress their natural means of gender expression in their behavior, movement, and speech, and who were subjected to harsh punishment for noncompliance. Despite the existence of abusive residential treatment centers and programs that purport to provide repar-

³⁰ Virginia King, An Open Letter to Families Considering Intensive Behavioral Therapy for Their Child with Autism, *Astraea's Politics*, 2006, <http://www.astraeasweb.net/politics/aba.html> (last visited 17 Dec. 2012).

³¹ See examples, *supra* note 16.

³² Julia Bascom, *Quiet Hands*, in *LOUD HANDS: AUTISTIC PEOPLE, SPEAKING*, 177, 177-182 (Julia Bascom ed., 2012). Also available at <http://juststimming.wordpress.com/2011/10/05/quiet-hands/> (last visited 17 Dec. 2012).

³³ See generally George A. Rekers & O. Ivar Lovaas, Behavioral Treatment of Deviant Sex-Role Behaviors in a Male Child, 7 *J. OF APPLIED BEHAVIOR ANALYSIS*, 7(2), 173 (1974).

ative or conversion therapy to eliminate homosexual attractions or cure non-heteronormative people of their sexual orientation, the psychological and psychiatric establishments have joined sexual minority rights activists in condemning mental health treatments targeting homosexuality or sexual minority status as a pathological condition.³⁴ Yet precisely the same abusive tactics used to enforce compulsory heteronormativity on sexual minorities are presently enacted, largely with impunity and even acceptance, on disabled people.

The psychological toll that this type of abusive treatment can have on youth already vulnerable to societally entrenched heterosexism and the demands of compulsory heteronormativity is comparable to the psychological toll exacted on disabled children and youth subjected to the same punitive behavior modification techniques. In fact, the goals are much the same in both instances—abuse is enacted on those who merely inhabit bodies and minds deemed deviant in the name of treatment for socially undesirable or unacceptable characteristics associated with sexual minority or disability status.

Applicability of Torture and Ill-treatment Standards

Compliance-based behavioral interventions, as well as their goal of indistinguishability itself, are consistent with the legal definition of cruel, inhuman and degrading treatment or punishment and torture under international law, which defines torture as

*any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.*³⁵

Compliance-based behavioral interventions meet this definition of torture due both to their inherently and systematically abusive nature as well as their actual applications and methodology. Their underlying philosophy of indistinguishability has a long and brutal history in the disability community that has largely gone unacknowledged in mainstream human rights literature.

1. Intentional Infliction of Severe Pain or Suffering

The social, emotional, and psychological consequences for disabled survivors of compliance-based behavioral interventions range from post-traumatic stress disorder to exacerbation

³⁴ See examples at Am. Psychol. Ass'n, Answers to your questions: For a better understanding of sexual orientation and homosexuality (2008), available at <http://www.apa.org/helpcenter/sexual-orientation.aspx>; Pan Am. Health Org., "Therapies" to change sexual orientation lack medical justification and threaten health (May 2012), available at http://new.paho.org/hq/index.php?option=com_content&view=article&id=6803%3A%5C%22therapies%5C%22-to-change-sexual-orientation-lack-medical-justification-and-threaten-health-&catid=740%3Anews-press-releases&Itemid=1926&lang=en; Am. Psychiatric Ass'n, Therapies Focused on Attempts to Change Sexual Orientation (Reparative or Conversion Therapies) Position Statement (May 2000), available at <http://web.archive.org/web/20110110120228/http://www.psych.org/Departments/EDU/Library/APAOfficialDocumentsandRelated/PositionStatements/200001.aspx>.

³⁵ UN General Assembly. (2008, July 28). Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Note / by the Secretary-General, 28 July 2008, A/63/175, 12, art. 1 available at <http://www.unhcr.org/refworld/docid/48db99e82.html> (last visited 2 Dec. 2012) [hereinafter CAT]

of pre-existing mental health issues.³⁶ There is nothing inherently harmful or dangerous about moving, thinking, or communicating atypically, yet movement and communication differences are frequently targeted for elimination solely because of their association with disability and thus an undesirable state of being. The psychological harm caused by constant reinforcement of the idea that one's natural means of movement, thought, and communication are defective and wrong cannot be understated. Such harm is only further compounded by the abusive and violent nature of compliance-based interventions designed to enact this mentality. The mother of the autistic student from California in one of the previous examples stated that "the girl has never fully recovered from her experience."³⁷

When the environment in which disabled students are placed continually reinforces the notion that indistinguishability rather than functional skills ought to be their goal, it is inevitable that disabled people will internalize this message and be deprived of the right to develop constructive self-image, functional skills, and positive systems of support. Because apparently disabled modes of movement and communication are presumed to be wrong, undesirable, deficient, unhealthy, dangerous, or inconvenient, disabled people must attend school, receive services, and access healthcare through systems and communities that demand conformity with compulsory able-bodiedness and able-mindedness. It is apparent that disabled people from a variety of subcategories of disability are disproportionately victimized by compliance-based behavioral interventions for this reason. Furthermore, U.S. Department of Education statistics suggest that disabled students of color are still further at risk for victimization.³⁸ It would be unsurprising if students multiply marginalized by virtue of poverty, race, sexuality, and disability face higher levels of risk associated with more extreme vulnerability, let alone those rendered further powerless by custodial status or criminal justice supervision.

2. Pain Inflicted for Prohibited Purposes

Compliance-based behavioral interventions are used as punishment, coercion, and discrimination against disabled people, which are prohibited purposes under the definition of torture given in Article 1 of the Convention Against Torture.³⁹

a. Punishment for Natural Ways of Communicating and Moving

Aversive interventions, seclusion and restraint, and Lovaasian applied behavior analysis are frequently used as punishment for behavior, movement, or communication that poses no danger to the disabled person or to other people. Additionally, natural ways of moving such as rocking in autistic people, atypical gait and posture in people with cerebral palsy, and naturally developed coping mechanisms for sensory impairments such as closing eyes or covering ears are often targeted for punishment as unwanted behaviors.

³⁶ See generally the cases cited in GAO Testimony on Restraint and Seclusion, *supra* note 8; NDRN 2012 Report, *supra* note 1; and Jessica Butler, The Council of Parent Att'ys and Advoc. Inc., Unsafe In The Schoolhouse: Abuse Of Children With Disabilities (May 2009), available at http://c.ymcdn.com/sites/www.copaa.org/resource/collection/662B1866-952D-41FA-B7F3-D3CF68639918/UnsafeCOPAAMay_27_2009.pdf.

³⁷ GAO Testimony on Restraint and Seclusion, *supra* note 8, at 27.

³⁸ Tamar Lewin, Black Students Punished More, Data Suggests, *The N.Y. Times*, A11, Mar. 6, 2012. also available at <http://www.nytimes.com/2012/03/06/education/black-students-face-more-harsh-discipline-data-shows.html?pagewanted=all>.

³⁹ CAT at art. 1.

b. Intimidation and Coercion

In the same way that compliance-based behavioral interventions are inherently punitive, they are also coercive and used for purposes of intimidation. The philosophy of indistinguishability demands conformity to arbitrarily defined standards of normalcy, and these techniques are used as means to enforce compliance with those standards. Disabled people are frequently required to receive compliance-based behavioral interventions as determined by parents or guardians, program staff, or treatment providers, even in settings where the disabled people may nominally provide input or give consent for treatment. For example, a student in Kansas with intellectual disabilities, speech impairments, and epilepsy has been subjected to extensive seclusion for arbitrarily designated behaviors.

The child has a behavior plan which prohibits him from touching anybody without permission. Impermissible touching includes a hug, high five, or fist bump. If he does not follow the plan, he is sent immediately without warning to the in-school suspension room (ISS) in the principal's office. The school also has a separate seclusion room in each classroom which is also called an ISS room. All rooms have no windows and only a door. The mother has learned that in the past several weeks her son has spent 8-1/2 days in a seclusion room. The child has been sent to the room for as long as the entire day and sometimes into the following day. The door is always closed.⁴⁰

The societally created and legally enforced power differentials between disabled people and those who have authority over them can only exacerbate the risk of coercion in the treatment process, where disabled people rarely have any meaningful options at all and may even face retaliation for advocating for alternative interventions.

c. Discrimination on the Basis of Disability

Article 2 of the Convention on the Rights of Persons with Disabilities states that discrimination on the basis of disability is “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including lack of reasonable accommodation.”⁴¹ The requirement of intent in the CAT is effectively met where a person has been discriminated against on the basis of disability.⁴²

As compliance-based behavioral interventions are most often framed as treatment or therapy, their use is consistent with a medical model of disability that sees disability as an individual problem to be treated or “fixed” as part of the larger paradigm of compulsory able-bodiedness and able-mindedness. While not limited to disabled children, these techniques disproportionately victimize those who are disabled.⁴³ They are often specifically targeted toward disabled children with the aim of eradicating characteristics associated with disabilities, even when those characteristics pose no harm to the child or to others or when they cause no pain or suffering to the child. Thus, compliance-based behavioral interventions discriminatorily target disabled people for such torture and violation of rights in contravention to the provisions of the CRPD.

⁴⁰ NDRN 2012 Report, *supra* note 1, 12.

⁴¹ UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106, art. 2, available at: <http://www.unhcr.org/refworld/docid/45f973632.html> [accessed 9 December 2012].

⁴² CAT at art. 1.

⁴³ GAO Testimony on Restraint and Seclusion, *supra* note 10, at 7-8.

3. Acquiescence of a Public Official

Through funding, licensing, and other legal means of establishing legitimacy, the state has condoned compliance-based behavioral interventions as well as carrying them out through teachers, who are public employees. These practices are widely used and accepted by educational professionals, clinicians, and treatment providers, whose programs and schools are generally required to be licensed by state regulatory authorities and typically receive state funding upon licensure. Lovaasian applied behavior analysis, in particular, is routinely and widely lauded throughout the mental health and educational fields as the best evidenced-based treatment for autism and similar developmental and psycho-social disabilities.⁴⁴ Successful multistate advocacy in the United States has resulted in several laws requiring insurance providers to include applied behavior analysis as a covered treatment further compounds the complicity of public officials and the widespread condonance of Lovaasian methods.⁴⁵ The Association for Behavior Analysis International maintains active chapters in over thirty countries to promote the use of applied behavior analysis internationally.⁴⁶

When teachers in public schools refer disabled students to programs and service providers that use compliance-based behavioral interventions, they are directly participating in subjecting disabled children and youth to these techniques on the basis of their individual authority. Government entities contribute to this abuse through funding programs and schools that use compliance-based behavioral interventions. Any program or other entity that claims to provide educational services, including public and private schools, may be eligible to receive federal special education funds under the Individuals with Disabilities Education Act.⁴⁷

Currently, there is no federal law in the United States that protects students from aversive interventions, seclusion, or restraint in educational or residential settings. Such a law has been proposed and filed three times, but has yet to be passed.⁴⁸ Instead of a federal law, there are a number of state laws and regulations regarding behavioral interventions, abuse of disabled people, and treatment of disabled students in schools. These standards and protections vary significantly in strength from state to state, with some state laws explicitly permitting and thus legitimizing specific compliance-based behavioral interventions that constitute torture. As of January 2012, only twenty-nine states had any legally binding statutes or regulations regarding restraint or seclusion, which represent only a small portion of compliance-based behavioral interventions. Furthermore, of those laws and regulations, only some of them include specific safeguards against abusive practices.⁴⁹

⁴⁴ See generally Beth Rosenwasser & Saul Axelrod, The Contributions of Applied Behavior Analysis to the Education of People With Autism, 25 BEHAVIOR MODIFICATION 671 (October 2001), available at <http://www.analisticomportamentale.com/media/Rossenware%20and%20Axelrod%202001%20contributions%20ABA%20autism%201.pdf>.

⁴⁵ See some examples in Ariz. Rev. Stat. Ann. § 20-826.04, § 20-1057.11, § 20-1402.03 and § 20-1404.03; Cal. Insurance Code § 10144.51 and § 10144.52; Colo. Rev. Stat. § 10-16-104 (1.3)(g), § 10-16-104 (1.4) and § 25.-5-8-107 (a)(IV); Conn. Gen. Stat. § 38a-514b; Fla. Stat. § 627.6686 and § 641.31098; Ill. Rev. Stat. ch. 215, § 5/356z.14 et seq.; Kan. Stat. Ann. § 75-6524; Ky. Rev. Stat. § 319C; Me. Rev. Stat. Ann. Tit. 24-A § 2768; 2011 W. Va. Act, Chap. 13; Vt. Stat. Ann. Tit. 8 § 4088i; Tex. Insurance Code § 1355.015; N.H. Rev. Stat. Ann. § 417-E:2.

⁴⁶ Ass'n for Behav. Analysis, Non-U.S.A. Chapters (2013), available at <http://www.abainternational.org/constituents/chapters/non-usa-chapters.aspx>.

⁴⁷ Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

⁴⁸ See Keeping All Students Safe Act, S. 2020, 112th Cong. (2011); Keeping All Students Safe Act, H. R. 1381, 112th Cong. (2011); Preventing Harmful Restraint and Seclusion in Schools Act, H. R. 4247, 111th Cong. (2009); and Keeping All Students Safe Act, H.R. 1893, 113th Cong. (2013).

⁴⁹ Jessica Butler, Autism Nat'l Comm., How Safe Is The Schoolhouse? An Analysis of State Seclusion and Restraint Laws and Policies 4 (2012).

After two student deaths caused by restraint, the Michigan State Board of Education modified its policies on seclusion and restraint;

*However, though the policy encourages local school districts to collect and report data on the use of these techniques to the Michigan Department of Education, the board member expressed doubt that this was actually done. In each year since the policy was enacted, the member said that she has requested any statistics or reports on the use of seclusion and restraints but has never received any information.*⁵⁰

Further compounding the problem of insufficient monitoring of these practices, the judiciary is largely complicit in allowing abuse to continue through under-prosecution of educators and treatment providers who abuse or injure disabled children as part of treatment. Employees from the State's Attorney Office and Equip for Equality (Illinois Protection and Advocacy Service) explained the reasons for low prosecution rates in seclusion and restraint cases of disabled people as

*The reluctance to further traumatize victims by having them testify, the stereotype that special needs children are unreliable witnesses, and sympathy for teachers and other staff seen as working with challenging individuals who might need to be secluded or restrained.*⁵¹

In the case of the autistic girl from West Virginia in one of the earlier examples, the State Board of Education provided no assistance or support after the child's mother reported the abuse and restraint.⁵² After the mother sued the school district for its complicity in causing great psychological harm to her daughter, "the jury found that the defendants did not discriminate against the child, violate the child's constitutional rights, commit assault and battery against the child, or falsely imprison the child."⁵³ The jury's decision to award the family \$460,000 for "negligently supervising and training three teachers in the use of restraints" provides further evidence for the legal legitimization of these techniques by finding fault with training about restraints rather than the use of restraints.⁵⁴

4. Powerlessness of the Victims

In defining torture as a distinct form of cruel, inhuman and degrading treatment or punishment, the UN Special Rapporteur on Torture notes that torture presumes powerlessness of the victims.⁵⁵ Multiple factors considerably increase the powerlessness of disabled children and youth in educational and residential settings, putting them at extreme risk of torture perpetrated under the guise of treatment or therapy. Disabled children under the age of eighteen are almost always minors in parental custody, while many disabled youth over the age of eighteen are placed under legal guardianship that grants their parents or other caretakers significant legal rights over them as though they were still minors. Disabled people of all ages, and particularly disabled children and youth, are rarely able to make autonomous decisions about education, healthcare, or treatment. Placement in any setting where staff—whether educators, service providers, or clinicians—have sole authority over program development and implementation inherently creates power differentials highly conducive to depriving disabled people of their civil rights and right to self-determination.

⁵⁰ GAO Testimony on Restraint and Seclusion, *supra* note 10, at 22.

⁵¹ *Id.* at 25.

⁵² *Id.* at 22.

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ Manfred Nowak, Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Promotion and Protection of all Human Rights, Civil, Political, Economic, Social and Cultural Rights, Including the Right to Development, H.R. COUNCIL, U.N. Doc. A/HRC/7/3, 8 (January 15, 2008).

Conclusion

It is imperative for human rights advocates to turn the conversation on compliance-based behavioral interventions from one that creates a false dichotomy between the abuses perpetrated in institutional settings and those perpetrated in educational settings toward one that recognizes the unity of philosophy and methodology. Broad and explicit recognition of the roles that complicity of public officials and professionals and pervasive socio-cultural paradigms about disability play in the perpetuation of these abuses will go a long way toward countering the philosophy of indistinguishability and the unnecessary pathologization of disability inherent to these techniques. Claims by unscrupulous professionals and service providers that these practices are treatment or therapy have served quite effectively to shield them from scrutiny by both national and regional governments and the public.

Human rights organizations and advocates who only acknowledge abuse in residential treatment settings fail to recognize the extent to which education and healthcare settings overlap. Widespread lack of access to education about legal rights and opportunities for redress have further hindered disabled people and their families from seeking legal remedies or injunctions against clearly abusive practices, while the impunity of the healthcare and education professions serves to legitimize torture as valid educational and therapeutic practice, leaving little room for criticism or questioning. Laws that explicitly establish state condonance of traumatic and abusive techniques coupled with lax and unenforced regulations pose additional barriers to meaningful reform.

Specifying violence and emotional abuse against disabled people as a form of torture would afford victims stronger legal protections and undermine the legitimacy of abuse in the name of treatment. By recognizing the use of compliance-based behavioral interventions as a form of torture and ill-treatment rather than a legitimate form of treatment, the work of international human rights advocates and disability activists in addressing the issues presented in this article could provide a robust platform for advocacy efforts against these techniques and the underlying philosophy of compliance. Such recognition could also potentially provide new means of enacting policies and laws that can end the use of torture as treatment and diminish the structural power of educational institutions that claim separate status from medical establishments.

“You That Hide Behind Walls”: The Relationship Between the Convention on the Rights of Persons with Disabilities and the Convention Against Torture and the Treatment of Institutionalized Forensic Patients

PROFESSOR MICHAEL L. PERLIN* & MEREDITH R. SCHRIVER**

Abstract

This paper discusses how forensic patients (mostly those awaiting incompetency-to-stand trial determinations, those found permanently incompetent to stand trial, those who acquitted by reason of insanity, and those transferred from correctional facilities) remain unaffected by the ratification of the United Nations' Convention on the Rights of the Persons with Disabilities (CRPD) and the United Nations Convention Against Torture (CAT).

The CRPD and the CAT must be read “hand-in-glove” because together, these documents should make it more likely that attention will be paid to the conditions of confinement of forensic populations. The paper discusses the lack of academic consideration of forensic patients in the context of the CRPD and the CAT, a factor that has contributed to the maintenance of a status quo in this area. It then provides evidence from several nations of the conditions at forensic facilities, which continue to “shock the conscience” despite the ratification of both CRPD and CAT, both of which should have logically led to an amelioration of conditions and an expansion of humane treatment. The paper explains how misconceptions about forensic patients in society in general, and the presence of stigmatic stereotypes (sanism) dealing with people with mental disabilities exacerbate this problem.

The paper then discusses how even when regional courts and commissions deal with violations of human rights in cases involving forensic patients, case decisions ignore issues specific to that cohort of patients. It then discusses the lack of appropriate advocacy services from organizations and lawyers provided to this population, and the lack of proper legal training for lawyers who

* A.B., Rutgers University; J.D., Columbia University School of Law ; Professor of Law; Director, International Mental Disability Law Reform Project; Director, Online Mental Disability Law Program, New York Law School, 185 West Broadway, New York, NY 10013, USA, michael.perlin@nyls.edu.

** B.A., Arizona State University; M.A., John Jay College (forensic psychology); M.A., New York Law School (mental disability law studies). Graduate Researcher, New York Law School, 185 West Broadway, New York, NY 10013, USA, mschriv@osborneny.org.

represent these individuals. The paper then discusses the lack of “survivor movement” literature about the specific plight of forensic patients, and how forensic patients in facilities for people with intellectual disabilities are not involved in the conversation either. It then concludes by exploring these issues through the lens of therapeutic jurisprudence and argues that human rights law must reach out to therapeutic jurisprudence to ensure that the principles of voluntariness, voice, and validation be fulfilled in the case of forensic patients.

Introduction

Persons institutionalized in psychiatric institutions and facilities for persons with intellectual disabilities have always been hidden from view.¹ Facilities were often constructed far from major urban centers, availability of transportation to such institutions was often limited, and those whom were locked up were, to the public, faceless and often seen as less than human.² Although there were sporadic exposés in the nineteenth century and the mid-twentieth century,³ it was not until the civil rights revolution reached psychiatric hospitals and facilities for persons with intellectual disabilities in the early 1970s that there was any true public awareness of the conditions in such facilities.⁴

A series of court cases brought by young public interest lawyers shone a harsh light on the brutal and inhuman conditions in such facilities—one expert referred to the Pennhurst State School, in suburban Philadelphia, as “Dachau without ovens”⁵—in many US jurisdictions in the early and mid-1970s,⁶ and similar cases soon followed in Western Europe.⁷ These cases led to the predictable empowerment of blue-ribbon commissions, the issuance of lengthy reports excoriating states for the shameful conditions in which individuals were treated, and eventually, if tardily, the legislative passage of the so-called “Patients Bills of Rights,”⁸ that created substantive and procedural protections for those in danger of being deprived of their liberty and those who had been so deprived.⁹

A similar progression occurred in Western Europe at this time. Community-based treatment was scrutinized and discussed in government policies known as ‘Better Services for the Mentally Ill’ and ‘Community Care with Special Reference to Mentally Ill and Mentally Handicapped people’.¹⁰

¹ For a graphic example, see Mental Disability Rights Int'l, *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities* (2006), available at http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/romania-May-9-final_with-photos.pdf (reporting on human rights abuses against children with disabilities in institutions in Romania).

² See, e.g., MICHAEL L. PERLIN, *THE HIDDEN PREJUDICE: MENTAL DISABILITY ON TRIAL* 43 (2000); E.W. Lusthaus, *Involuntary Euthanasia and Current Attempts to Define Persons with Mental Retardation as Less Than Human*, 23 *MENTAL RETARDATION* 148 (1985).

³ See MICHAEL L. PERLIN, *MENTAL DISABILITY LAW: CIVIL AND CRIMINAL* § 2A-2.1b, at 52-58 (2d ed. 1998) (discussing work of Dorothea Dix, E.P.W. Packard and Albert Deutsch).

⁴ See, e.g., Michael L. Perlin, *State Constitutions and Statutes as Sources of Rights for the Mentally Disabled: The Last Frontier?* 20 *LOY.L.A. L.REV.* 1249, 1250-51 (1987).

⁵ LEOPOLD LIPPMAN & I. IGNANCY GOLDBERG, *THE RIGHT TO EDUCATION: ANATOMY OF THE PENNSYLVANIA CASE AND ITS IMPLICATION FOR EXCEPTIONAL CHILDREN* 17 (1973), quoted in Michael L. Perlin, *Competency, Deinstitutionalization, and Homelessness: A Story of Marginalization*, 28 *HOUS. L. REV.* 63, 100 n. 215 (1991).

⁶ See PERLIN, *supra* note 3, § 1-2.1, at 8-9.

⁷ See MICHAEL L. PERLIN ET AL., *INTERNATIONAL HUMAN RIGHTS LAW AND COMPARATIVE MENTAL DISABILITY LAW: CASES AND MATERIALS* 451-782 (2006).

⁸ See PERLIN, *supra* note 3, § 3A-3.2c, at 54-55.

⁹ See, e.g., Michael L. Perlin, *“Everybody Is Making Love/Or Else Expecting Rain”: Considering the Sexual Autonomy Rights of Persons Institutionalized Because of Mental Disability in Forensic Hospitals and in Asia*, 83 *WASH. L. REV.* 481, 487 (2008).

¹⁰ Helen Killaspy, *From the Asylum to Community Care: Learning from Experience* (2006), available at <http://bmb.oxfordjournals.org/content/79-80/1/245.full>.

Perhaps as a by-product of all of this, those individuals who had been hidden and whose voices had been silenced began to raise their voices to protest the inhumane conditions of their confinement.¹¹

Much of the case law ignores forensic patients entirely.¹² By and large (although not exclusively),¹³ the facilities that were the subject of this litigation (and the concomitant press scrutiny)¹⁴ mostly housed patients who had never been charged with or tried on criminal charges; a fact that is, interestingly and ironically, discordant with the false “ordinary common sense”¹⁵ that posits that “most mentally ill individuals are dangerous and frightening [and] are invariably more dangerous than non-mentally ill persons.”¹⁶ Even in the hidden world of persons institutionalized because of a psychiatric disability (or alleged disability), forensic patients—mostly those awaiting incompetency-to-stand trial determinations, those found permanently incompetent to stand trial, those who had been acquitted by reason of insanity, and, in some jurisdictions, individuals transferred from correctional facilities—remain the most hidden.

This extra level of social isolation, moreover, was generally just fine with most of those who had been involved in the patients’ rights revolution, which has restructured mental health care around the world. It was fine to the advocacy groups that came forward at that time because the existence of a forensic “world” could be used as evidence that there was a causal relationship between mental illness (or intellectual disability) and “dangerousness.”¹⁷ It was fine to the lawyers who brought the bulk of the first generation of public interest cases since one of the significant underpinnings

¹¹ The involvement of such groups in test case litigation—exercising the right of self-determination in an effort to control, to the greatest extent possible, their own destinies, *see, e.g.*, JUDI CHAMBERLIN, *ON OUR OWN: PATIENT-CONTROLLED ALTERNATIVES TO THE MENTAL HEALTH SYSTEM* (1979), is a major development that cannot be overlooked by any participants in subsequent mental disability litigation. *See, e.g.*, Neal Milner, *The Right to Refuse Treatment: Four Case Studies of Legal Mobilization*, 21 *LAW & SOC’Y REV.* 447 (1987) (discussing impact of ex-patient groups on course of right to refuse treatment litigation); Judi Chamberlin & Joseph Rogers, *Planning a Community-Based Mental Health System: Perspective of Service Recipients*, 45 *AM. PSYCHOLOGIST* 1241 (1990). *See generally* Symposium, *Challenging the Therapeutic State: Critical Perspectives of Psychiatry and the Mental Health System*, 11 *J. MIND & BEHAV.* 1-318 (1990); Symposium, *Challenging the Therapeutic State, Part Two: Further Disquisitions on the Mental Health System*, 15 *J. MIND & BEHAV.* 1-198 (1994); Peter Margulies, *The Cognitive Politics of Professional Conflict: Law Reform, Mental Health Treatment Technology, and Citizen Governance*, 5 *HARV. J.L. & TECH.* 25, 57-58 n.132 (1992); Jennifer Honig & Susan Fendell, *Meeting the Needs of Female Trauma Survivors: The Effectiveness of the Massachusetts Mental Health Managed Care System*, 15 *BERKELEY WOMEN’S L.J.* 161, 185 (2000).

¹² Perlin, *supra* note 9, at 488.

¹³ *See, e.g.*, *Davis v. Watkins*, 384 F. Supp. 1196, 1201-02 (N.D. Ohio 1974). *See* Perlin, *supra* note 9, at 488 (“Of the important [first generation right-to-treatment institutional conditions cases], forensic patients were part of the plaintiff class only in the Ohio case of *Davis v. Watkins*”). For a full discussion of *Davis*, *see generally*, PERLIN, *supra* note 3, § 3A-3.3, at 57-59.

¹⁴ For the role of the press, *see* Paul Davis, *Wyatt v. Stickney: Did We Get It Right This Time?*, 35 *LAW & PSYCHOL. REV.* 143 (2011).

¹⁵ *See* Heather Ellis Cucolo & Michael L. Perlin, *Preventing Sex-Offender Recidivism through Therapeutic Jurisprudence Approaches and Specialized Community Integration*, 22 *TEMP. POL. & CIV. RTS. L. REV.* 1, 38 (2012) (“[ordinary common sense] is self-referential and non-reflective (‘I see it that way, therefore everyone sees it that way; I see it that way, therefore that’s the way it is’).”).

¹⁶ Michael L. Perlin, “*You Have Discussed Lepers and Crooks*”: *Sanism in Clinical Teaching*, 9 *CLINICAL L. REV.* 683, 724 n.220 (2003).

¹⁷ This relationship has often been extraordinarily strained. *See e.g.*, Michael L. Perlin, “*Half-Wracked Prejudice Leaped Forth*”: *Sanism, Pretextuality, and Why and How Mental Disability Law Developed As It Did*, 10 *J. CONTEMP. LEGAL ISSUES* 3, 30 n.158 (1999) (“Compare, e.g., the factual settings in *Addington v. Texas*, 441 U.S. 418 (1979), with *Jones v. United States*, 463 U.S. 354 (1983). *Addington*—whose case ultimately settled the question of the constitutional burden of proof quantum in civil cases—had originally been apprehended following an alleged “assault by threat” on his mother. *Addington*, 441 U.S. at 420. *Jones*—whose case ultimately gave constitutional sanction to providing insanity acquittees with fewer procedural due process protections in a retention hearing—had originally been apprehended after he allegedly attempted to shoplift a jacket in a downtown Washington, D.C. department store. *Jones*, 463 U.S. at 359. *Addington*’s acts appear to have been more serious (and more “dangerous”) than did *Jones*’s; yet, for undisclosed, and unarticulated extra-judicial

of the initial right to liberty or least restrictive alternative civil rights suits was that the plaintiff had never been “alleged to have committed any crime.”¹⁸ It was fine to the state hospital system because if a *forensic* population was released or deinstitutionalized, there would be a predictable public outcry.¹⁹ And it was fine to prosecutors and police officials since it insured that this population would remain locked up indefinitely.²⁰ As a result of all of this, the *status quo* has remained in tact for about forty years, and the changes in conditions for civil patients have had very little impact on those in forensic facilities.

This state of affairs, however, must be radically reconsidered in light of the ratification of the United Nations' Convention on the Rights of Persons with Disabilities²¹ (CRPD), which is “regarded as having finally empowered the ‘world’s largest minority’ to claim their rights, and to participate in international and national affairs on an equal basis with others who have achieved specific treaty recognition and protection.”²² The Convention is the most revolutionary international human rights document applicable to persons with disabilities ever created.²³ It furthers the human rights approach to disability and recognizes the right of people with disabilities to equality in most every aspect of life.²⁴ It firmly endorses a social model of disability and reconceptualizes mental health rights as disability rights; accordingly, it is a clear and direct repudiation of the medical model that traditionally was part-and-parcel of mental disability law.²⁵ “The Convention sketches the full range of human rights that apply to all human beings, all with a particular application to the lives

reasons, Addington was brought into the mental health system while Jones was arrested and thus brought into the criminal justice system.”)

¹⁸ See, e.g., *Lessard v. Schmidt*, 349 F. Supp. 1078, 1096 (E.D. Wis. 1972).

¹⁹ Raymond A. Lemay, *Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature*, available at <http://www.turningforward.org/documents/Lemay2009-Deinstitutionalization.pdf> (last visited July 24, 2013).

²⁰ One of the authors (MLP) filed a class action suit *Dixon v. Cahill*, No. L30977/y-71 P.W. (N.J. Super. Ct. Law Div. 1973), reprinted in PERLIN, *supra* note 3, § 14-7, at 119-21 (2d ed. 2002), and discussed in Michael L. Perlin, “For the Misdemeanor Outlaw”: *The Impact of the ADA on the Institutionalization of Criminal Defendants with Mental Disabilities*, 52 Ala. L. Rev. 193, 206-07 n.94 (2000) (citing *Jackson v. Indiana*, 406 U.S. 715 (1972) (applying Due Process Clause to incompetent-to-stand-trial defendants)), resulting in a ruling that the indefinite incarceration of individuals in the Vroom Building (NJ’s maximum security facility for the “criminally insane”) violated *Jackson*, and ordered individual hearings for each inmate. The courts ultimately found that 185 of the 225 patients in that facility were illegally detained. See Michael L. Perlin, “May He Stay Forever Young”: *Robert Sadoff and the History of Mental Health Law*, 33 J. AMER. ACAD. PSYCHIATRY & L. 236, 236-37 (2005).

²¹ See generally, MICHAEL L. PERLIN, *INTERNATIONAL HUMAN RIGHTS AND MENTAL DISABILITY LAW: WHEN THE SILENCED ARE HEARD* (2011).

²² Rosemary Kayess & Phillip French, *Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities*, 8 HUM. RTS. L. REV. 1, 4 n.17 (2008). See , UN Human Rights Chief urges States to Implement New Treaty to Protect Disabled, UN NEWS CENTRE (Mar. 26, 2007), <http://www.un.org/apps/news/story.asp?NewsID=22016#U11BVIOfm0> (discussing statements made by the High Commissioner For Human Rights, Louise Arbour, and the permanent representative of New Zealand and chair of the ad-hoc committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Ambassador Don Mackay, at a special event on the Convention on the Rights of Persons with Disabilities convened by the UN Human Rights Council).

²³ See generally, Michael L. Perlin & Eva Szeli, *Mental Health Law and Human Rights: Evolution and Contemporary Challenges*, in MENTAL HEALTH AND HUMAN RIGHTS: VISION, PRAXIS, AND COURAGE 98 (Michael Dudley et al eds., 2012); PERLIN, *supra* note 21, at 3-21; Michael L. Perlin, “A Change Is Gonna Come”: *The Implications of the United Nations Convention on the Rights of Persons with Disabilities for the Domestic Practice of Constitutional Mental Disability Law*, 29 NO. ILL. U. L. REV. 483 (2009).

²⁴ See e.g., Aaron Dhir, *Human Rights Treaty Drafting Through the Lens of Mental Disability: The Proposed International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, 41 STAN. J. INT’L L. 181 (2005).

²⁵ Phillip Fennel, *Human Rights, Bioethics, and Mental Disorder*, 27 MED. & L. 95 (2008). See generally, Michael L. Perlin, “Abandoned Love”: *The Impact of Wyatt v. Stickney On The Intersection Between International Human Rights And Domestic Mental Disability Law*, 35 LAW & PSYCHOL. REV. 121 (2011).

of persons with disabilities.”²⁶ It provides a framework for ensuring that mental health laws “fully recognize the rights of those with mental illness.”²⁷ There is no question that it has “ushered in a new era of disability rights policy.”²⁸

It describes disability as a condition arising from “interaction with various barriers [that] may hinder their full and effective participation in society on an equal basis with others” instead of inherent limitations.²⁹ It extends existing human rights to account for the specific experiences of persons with disabilities,³⁰ and it calls for “respect for inherent dignity”³¹ and “non-discrimination.”³² Subsequent articles guarantee freedom from “arbitrary or unlawful interference” with privacy;³³ “freedom from torture or cruel, inhuman or degrading treatment or punishment;”³⁴ “freedom from exploitation, violence and abuse;”³⁵ and a right to protection of the “integrity of the person.”³⁶

The CRPD is the first legally binding instrument devoted to the comprehensive protection of the rights of persons with disabilities.³⁷ It not only clearly prohibits States from discriminating against persons with disabilities, but also explicitly sets out the steps States must take to enable persons with disabilities to enjoy authentic equality in society.³⁸

One of the most critical issues in bringing life to mental disability law under international human rights law is the right to adequate and dedicated counsel. The CRPD mandates that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”³⁹ Elsewhere, the convention commands:

²⁶ Janet E. Lord & Michael A. Stein, *Social Rights and the Relational Value of the Rights to Participate in Sport, Recreation, and Play*, 27 B.U. INT’L L.J. 249, 256 (2009); see also Ronald McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: Some Reflections* (2010), available at <http://Ssrn.Com/Abstract=1563883>

²⁷ Bernadette McSherry, *International Trends in Mental Health Laws: Introduction*, 26 LAW IN CONTEXT 1, 8 (2008).

²⁸ Paul Harpur, *Time to Be Heard: How Advocates Can Use the Convention on the Rights of Persons with Disabilities to Drive Change*, 45 VAL. U. L. REV. 1271, 1295 (2011).

²⁹ UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, Dec. 13, 2006, 2515 U.N.T.S. 3, at art. 1 and Pmbl., Para. E [hereinafter UN CONVENTION].

³⁰ Frédéric Mégret, *The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?*, 30 HUM. RTS. Q. 514 (2008); see PERLIN, *supra* note 21, at 143-58.

³¹ UN CONVENTION, *supra* note 29, at art. 3(A).

³² *Id.* at art. 3(B).

³³ *Id.* at art. 14 (1).

³⁴ *Id.* at art. 15.

³⁵ *Id.* at art. 16.

³⁶ *Id.* at art. 17.

³⁷ See generally, Michael L. Perlin, *Promoting Social Change in Asia and the Pacific: The Need for a Disability Rights Tribunal to Give Life to the UN Convention on the Rights of Persons with Disabilities*, 44 GEO. WASH. INT’L L. REV. 1 (2012).

³⁸ For the changes that ratifying states need to make in their domestic involuntary civil commitment laws to comply with Convention mandates see Bryan Y. Lee, *The U.N. Convention on the Rights of Persons with Disabilities and Its Impact upon Involuntary Civil Commitment of Individuals with Developmental Disabilities*, 44 COLUM. J. L. & SOC. PROBS. 393 (2011); see also, István Hoffman & György Könczei, *Legal Regulations Relating to the Passive and Active Legal Capacity of Persons with Intellectual and Psychosocial Disabilities in Light of the Convention on the Rights of Persons with Disabilities and the Impending Reform of the Hungarian Civil Code*, 33 LOY. L.A. INT’L & COMP. L. REV. 143 (2010) (describing the application of the CRPD to capacity issues); Kathryn D. DeMarco, *Disabled by Solitude: The Convention on the Rights of Persons with Disabilities and Its Impact on The Use of Supermax Solitary Confinement*, 66 U. MIAMI L. REV. 523 (2012) (describing application of the CRPD to solitary confinement in correctional institutions).

³⁹ See Michael L. Perlin, “I Might Need a Good Lawyer, Could Be Your Funeral, My Trial”: A Global Perspective on the Right to Counsel in Civil Commitment Cases, and Its Implications for Clinical Legal Education, 28 WASH. U. J.L. & POL’Y 241, 252-53 (2008) (quoting UN CONVENTION, *supra* note 29, at art. 12).

*States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*⁴⁰

The ratification of the Convention must be read together with the United Nations Convention Against Torture (CAT).⁴¹ Together, these documents make it more likely—or *should* make it more likely—that, for the first time, attention will be paid to this population's conditions of confinement world-wide, how those conditions regularly violate international human rights law, and how those who are in charge of these institutions do so with impunity.

In 1988, the U.S. ratified the United Nations Convention Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (CAT);⁴² as this treaty was not self-executing, Congress passed domestic legislation to make it enforceable under domestic law.⁴³ The purpose of the Convention was to establish a comprehensive scheme aimed at ultimately ending torture around the world,⁴⁴ and it was motivated by a desire “to make more effective the struggle against torture and other cruel, inhuman or degrading treatment or punishment throughout the world.”⁴⁵

The CAT defines the term “torture” to mean any act by which

*severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.*⁴⁶

The intent of the Convention Against Torture was to strengthen existing prohibitions on torture in international law.⁴⁷ However, torture under CAT must be “severe” and requires specific intent to cause severe pain and suffering.⁴⁸

The relationship between the CAT and the CRPD has come under scrutiny. Importantly, the Special Rapporteur on Torture indicated that involuntary treatment and confinement are contrary

⁴⁰ UN CONVENTION, *supra* note 29, at art. 13.

⁴¹ UNITED NATIONS, CONVENTION AGAINST TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT, Dec. 10, 1984, S. Treaty Doc. No. 100-20 (1988), 1465 U.N.T.S. 85, [hereinafter UN CONVENTION AGAINST TORTURE], available at <http://www.un.org/documents/ga/res/39/a39r046.htm>.

⁴² The Convention Against Torture is based principally on Article 5 of the Universal Declaration of Human Rights and Article 7 of the Covenant of Civil and Political Rights. See David Weissbrodt & Isabel Hörtreiter, *The Principle of Non-Refoulement: Article 3 of the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment in Comparison with the Non-Refoulement Provisions of Other International Human Rights Treaties*, 5 BUFF. HUM. RTS. L. REV. 1, 6 (1999).

⁴³ Jeffrey H. Fisher, *Detainee Transfers After Munaf: Executive Deference and the Convention Against Torture*, 43 GA. L. REV. 953, 960 (2009); Jane C. Kim, *Nonrefoulement Under the Convention Against Torture: How U.S. Allowances for Diplomatic Assurances Contravene Treaty Obligations and Federal Law*, 32 BROOK. J. INT'L L. 1227, 1235 (2007).

⁴⁴ Christopher Keith Hall, *The Duty of States Parties to the Convention Against Torture to Provide Procedures Permitting Victims to Recover Reparations or Torture Committed Abroad*, 18 EUR. J. INT'L L. 921, 921 (2007).

⁴⁵ UN CONVENTION AGAINST TORTURE, *supra* note 41.

⁴⁶ *Id.* at art. 1.

⁴⁷ J. HERMAN BURGERS & HANS DANIELIUS, THE UNITED NATIONS CONVENTION AGAINST TORTURE: A HANDBOOK ON THE CONVENTION AGAINST TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT 1 (1988).

⁴⁸ Mario Silva, *Extraordinary Rendition: A Challenge to Canadian and United States Legal Obligations under the Convention Against Torture*, 39 CAL. W. INT'L L.J. 313, 334-35 (2009).

to Articles 14 and 15 of the CRPD.⁴⁹ In writing about prison “supermax confinement,” Kathryn DeMarco considers the Convention against Torture to be “quite relevant to the interpretation of Article 15 of the CRPD.”⁵⁰

Janet Lord has written eloquently about the “anti-torture” framework of the CRPD,⁵¹ concluding:

*The adoption of the CRPD clearly constitutes an important development in the anti-torture framework under international human rights law. Its principal contribution is to apply the torture prohibition within a disability context, consistent with core principles of the CRPD including dignity, non-discrimination, autonomy, and independence. It also contributes to the framework by introducing explicitly, for the first time in an international human rights treaty, the requirement that reasonable accommodations be provided and that the failure to do so results in a finding of discrimination. These principles add content to the overall anti-torture framework and should thus find ready application as a guide to regional and international regimes applying the prohibition against torture and other cruel, inhuman, and degrading treatment or punishment.*⁵²

But, there has been little follow-up literature on this connection, and the resulting gap is truly problematic if we are ever to fully and effectively contextualize the two Conventions in the context of the treatment of persons with disabilities, especially those institutionalized because of mental disabilities. In this paper, we will focus on the relationship between the CRPD and the CAT in the context of the treatment of institutionalized forensic patients (those admitted to psychiatric institutions following involvement in the criminal justice system), highlight some of the key issues that must be examined in this context, examine the issues in question through the lens of therapeutic jurisprudence,⁵³ and conclude with some recommendations.

As part of this enterprise, we will consider six core issues that must be “on the table” if the scope of the underlying problems is to be understood:

- a. Although there is a robust literature on the CRPD and the CAT, there is virtually no mention of the plight of forensic patients. So, even within the world of those who focus broadly on these human rights issues, this population has remained invisible.

⁴⁹ Sheila Wildeman, *Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities*, 41 J.L. MED. & ETHICS 48, 57 n.138 (2013) (quoting *Interim Report of the Special Rapporteur on Torture and other Cruel, Inhuman and Degrading Treatment or Punishment*, ¶ 44, UN Doc A/63/175 (July 28, 2008) (Article 14 guarantees “the right to liberty and security of person,” and Article 15 the right to be free from “torture or cruel, inhuman or degrading treatment or punishment.”)); see also, on the significance of Article 14 in another context, Carole Petersen, *Sexual Orientation and Gender Identity in Hong Kong: A Case for the Strategic Use of Human Rights Treaties and the International Reporting Process*, 14 ASIAN-PAC. L. & POL’Y J. 28 (2013). But see Wildeman, *supra*, at 57 (“Predictably, this is not a position that has impressed governments otherwise inclined to defend their mental health regimes as at the cutting edge of human rights-regarding policy. Australia, for one, has registered an interpretive declaration/reservation asserting its view that the CRPD permits involuntary hospitalization and treatment in accordance with that country’s mental health laws.”).

⁵⁰ DeMarco, *supra* note 38, at 550.

⁵¹ Janet Lord, *Shared Understanding or Consensus-Masked Disagreement? The Anti-Torture Framework in the Convention on the Rights of Persons with Disabilities*, 33 LOY. L.A. INT’L & COMP. L. REV. 27 (2010).

⁵² *Id.* at 78-79.

⁵³ See generally, Michael L. Perlin, “Striking for the Guardians and Protectors of the Mind”: *The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 PENN ST. L. REV. 1159 (2013) [hereinafter Perlin, *Guardians*]; Michael L. Perlin, “Wisdom Is Thrown into Jail”: *Using Therapeutic Jurisprudence to Remediate the Criminalization of Persons with Mental Illness*,—MICH. ST. U. J. L & MED. (2013) (forthcoming 2013) [hereinafter Perlin, *Wisdom*]; Michael L. Perlin, “Yonder Stands Your Orphan with His Gun”: *The International Human Rights Implications of Juvenile Punishment Schemes*,—TEXAS TECH L. REV. (2013) (forthcoming 2013) [hereinafter Perlin, *Yonder*].

- b. Conditions at forensic facilities around the world continue to “shock the conscience,” and it is essential that any “anti-torture” publication (such as this one) highlight this.
- c. Even when regional courts and commissions have found international human rights violations in cases involving forensic patients (e.g., *Victor Rosario Congo v. Ecuador*),⁵⁴ the discussion of these cases largely ignores the plaintiffs’ statuses as forensic patients.
- d. There are few lawyers and fewer “mental disability advocates” providing legal and advocacy services to this population.
- e. The survivor movement literature rarely mentions the specific plight of forensic patients.
- f. Forensic patients in facilities for persons with intellectual disabilities are particularly absent from the discourse.

The title of this paper draws in part on Bob Dylan’s magisterial song, *Masters of War*.⁵⁵ In this song, Dylan acerbically calls out those—he mentions war profiteers, munitions manufacturers, and the lords of the military-industrial complex—who “hide behind walls” while others’ lives are impacted and destroyed. They deceive and impart fear without a second thought about what their actions could do to populations other than themselves.

Writing about this song four years ago, one of the authors of this article (MLP) said this:

The song is a “blistering indictment of war profiteers,” and as an indictment of the military-industrial complex, it is as vibrant and angry today as it was when it was first recorded in 1963.⁵⁶

In the context of forensic facilities, the lyrics take on a double meaning. On the one hand, those who run forensic facilities that violate basic human rights can comfortably hide behind walls with impunity. On the other hand, those who are *hidden* behind walls now, optimally, have tools that will bring public scrutiny to this forsaken part of society.

The Six Factors

1. How Forensic Patients are Ignored

Scholars have for years written extensively about the CAT and, for the past five years, robustly about the CRPD.⁵⁷ But there has been little—shockingly little—about the applications of either of these Conventions to forensic patients.⁵⁸ A WESTLAW search, as an example, reveals *no* relevant articles other than ones written by one of this article’s authors (MLP).⁵⁹

⁵⁴ *Victor Rosario Congo v. Ecuador*, Case 11.427, Inter-Am. Comm’n H.R., Report No. 63/99, OEA/Ser.L/V/II.95, doc. 7 rev. ¶ 66 (1999) (*Matter of Congo*).

⁵⁵ See BOB DYLAN, *MASTERS OF WAR, ON THE FREEWHEELIN’ BOB DYLAN* (Sony Entertainment 1963), available at <http://www.bobdylan.com/us/songs/masters-war>.

⁵⁶ Michael L. Perlin, “*And I See Through Your Brain*”: Access to Experts, Competency to Consent, and the Impact of Antipsychotic Medications in Neuroimaging Cases in the Criminal Trial Process, 2009 STAN. TECH. L. REV. 4, *8 (2009) (quoting, in part, ROBERT SHELTON, NO DIRECTION HOME: THE LIFE AND MUSIC OF BOB DYLAN 155 (1997)).

⁵⁷ See PERLIN, *supra* note 21, at 292-322 (listing relevant references).

⁵⁸ The need for Convention enforcement to focus on other “traditionally excluded groups” is the centerpiece of Stephanie Ortoleva, *Who’s Missing? Women with Disabilities in U.N. Security Council Resolution 1325 National Action Plans*, 18 ILSA J. INT’L & COMP. L. 395, 411 (2012) (focusing on specific issues related to women with disabilities).

⁵⁹ Search in WESTLAW-JLR database: <(crpd “convention on the rights of persons with disabilities” “convention against torture”) /p forensic >(search conducted July 24, 2013).

Six years ago, one of the co-authors of this article (MLP) listed what he saw as the five core factors of the overlap between mental disability law and international human rights law. On one of those factors, “Failure to Provide Humane Services to Forensic Patients,”⁶⁰ he wrote:

Virtually all studies and reports referred to in this article have focused on the status (and plight) of civil patients: those whose commitments to the mental health system were not occasioned by arrest or other involvement in the criminal court process. Depressingly, persons in the forensic system generally receive—if this even seems possible—less humane services than do civil patients.⁶¹

Although this article has been referred to in the literature frequently, not a single reference deals with this issue.⁶² Given the conditions in such facilities,⁶³ this lack of academic interest raises serious questions as to the extent to which ongoing and serious violations of both Conventions will ever come into the public light.

2. Conditions in Forensic Facilities

Studies about forensic facilities provide—with deadening similarity—stories of mistreatment, lack of treatment, wholesale violations of civil and constitutional rights, and abuse.⁶⁴ It is as if the CAT and the CRPD were not intended to apply to the forensic patient population. More stunningly, there is virtually no mention in the legal academic literature of ratification of these treaties, and their relationship, in this context.

Historically, psychiatric facilities around the world have such deplorable and inhumane conditions that their very existences have been a shock to the collective conscience.⁶⁵ Revelations that residents were subjected to excessive electroshock therapy, prolonged isolation, hours of being shackled to the walls, and other practices raised awareness of this vulnerable population and sparked advocates to begin a slow journey toward change and equality. The ratification of the Convention for the Rights of Persons with Disabilities (CRPD) and the Convention Against Torture (CAT), logically, should have led to an amelioration of conditions and an expansion of humane treatment options, but in many jurisdictions, this has not happened. Instead, “these practices have

⁶⁰ Michael L. Perlin, *International Human Rights Law and Comparative Mental Disability Law: The Universal Factors*, 34 SYRACUSE J. INT’L L. & COM. 333, 354 (2007).

⁶¹ *Id.* (citing, inter alia, Jamie Fellner, *A Corrections Quandary: Mental Illness and Prison Rules*, 41 HARV. C.R.-C.L. L. REV. 391 (2006)).

⁶² See e.g., Kevin Cremin, *Challenges to Institutionalization: The Definition of “Institution” and the Future of Olmstead Litigation*, 17 TEX. J. C.L. & C.R. 143, 173 n.229 (2012); Meghan Flynn, *Olmstead Plans Revisited: Lessons Learned from the U.N. Convention on the Rights of Persons with Disabilities*, 28 LAW & INEQ. 407, 410 n.22 (2010); Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 195 n.125 (2010); Peter Margulies, *True Believers at Law: Legal Ethics, National Security Agendas, and the Separation of Powers*, 68 MD. L. REV. 1, 16 n.59 (2008); Carole Petersen, *Inclusive Education and Conflict Resolution: Building a Model to Implement Article 24 of the Convention on the Rights of Persons with Disabilities in the Asia Pacific*, 40 HONG KONG L.J. 481, 510 n.132 (2010).

⁶³ See *infra* text accompanying notes 64-98.

⁶⁴ For an exhaustive and comprehensive survey, see Thomas L. Hafemeister & John Petrila, *Treating the Mentally Disordered Offender: Society’s Uncertain, Conflicted and Changing Views*, 21 FLA. ST. U. L. REV. 729 (1994). For considerations of litigation challenging the forensic system in place in Missouri, see Kyle A. Loring, *The Catalyst Theory Meets the Supreme Court—Common Sense Takes a Vacation*, 43 B.C. L. REV. 973 (2002) (criticizing the Supreme Court’s decision in *Hensley v. Eckerhart*, 461 U.S. 424 (1983), on the question of attorneys’ fees).

⁶⁵ Cf. *Rochin v. California*, 342 U.S. 165, 172-73 (1952). Although the Court was referring to a particularly objectionable and unconstitutional invasion of the privacy of a criminal defendant, this language applies equally to conditions in some psychiatric institutions.

simply been transformed rather than abandoned.”⁶⁶ Forensic psychiatric patients, in particular, still suffer in unlivable conditions, which offer no hope for rehabilitation and little optimism for the future. Research has shown conditions in forensic facilities tend to be even more abysmal than in civil facilities.⁶⁷ Torture is still widespread in the treatment of forensic patients and vastly ignored by advocates and policymakers, despite advances in the world of mental disability law and advocacy.

The 1984 Convention Against Torture (CAT) established guidelines for preventing cruel, inhuman, and degrading treatment and punishment with the goal of maintaining basic human rights for individuals.⁶⁸ The convention, however, does not include “pain or suffering arising only from, inherent in, or incidental to lawful sanction,”⁶⁹ and the result is the forensic population continues to be excluded from further discussion regarding their basic human rights. This exclusion is largely due to a vast misunderstanding of the treatment and rehabilitation of persons with mental disabilities and how those disabilities may affect their involvement in the criminal justice system. Remarkably, the CRPD also fails to specifically mention forensic facilities or forensic populations. How does this continue to happen?⁷⁰ What needs to change so that the rights of all human beings are taken into consideration? What makes it so easy to overlook an entire population and subject them to less than human conditions around the world?

Heuristics regarding individuals with mental disabilities come into play when they are linked with the criminal justice system.⁷¹ While statistics make clear that the majority of individuals with mental disabilities and disorders are not more prone to violence than those without a mental illness diagnosis,⁷² the public generally operates under the impression that mental illness breeds violence and that a person with a disability or disorder is unpredictably violent and capable of unfathomable heinous acts.⁷³ The media exacerbates these distortions by prioritizing crime stories with perpetrators who are suspected of having a mental illness and promotes a subculture of fear and misunderstanding,⁷⁴ which feeds into sanism⁷⁵ and pretextuality.⁷⁶ It is no surprise, therefore, that

⁶⁶ Janos Fiala Butora, *The Obligation to Investigate Ill-treatment of Persons with Disabilities: The Way Forward* (2013), available at: http://works.bepress.com/janos_fiala-butora/1.

⁶⁷ Michael L. Perlin, “*There Are No Trials Inside the Gates of Eden*”: *Mental Health Courts, the Convention on the Rights of Persons with Disabilities, Dignity, and the Promise of Therapeutic Jurisprudence*, in *COERCIVE CARE: LAW AND POLICY* 193 (Bernadette McSherry & Ian Freckelton eds., 2013).

⁶⁸ UN CONVENTION AGAINST TORTURE, *supra* note 41.

⁶⁹ *Id.* at art. 1.

⁷⁰ See *infra* at text accompanying note 144 (discussing Prof. Janet Lord’s insights on the drafting process of the CRPD for a possible partial solution).

⁷¹ See also, Cucolo & Perlin, *supra* note 15, at 38 (discussing the “pernicious impact of heuristic thinking” in mental disability law). See generally Michael L. Perlin, “*The Borderline Which Separated You From Me*”: *The Insanity Defense, the Authoritarian Spirit, the Fear of Faking, and the Culture of Punishment*, 82 IOWA L. REV. 1375, 1417 (1997) (defining vividness heuristic as “a cognitive-simplifying device through which a ‘single vivid, memorable case overwhelms mountains of abstract, colorless data upon which rational choices should be made’”); MICHAEL L. PERLIN, A PRESCRIPTION FOR DIGNITY: RETHINKING CRIMINAL JUSTICE AND MENTAL DISABILITY LAW 109-217 (2013).

⁷² *Director’s Blog: Understanding Severe Mental Illness*, NATIONAL INSTITUTE OF MENTAL HEALTH, <http://www.nimh.nih.gov/about/director/2011/understanding-severe-mental-illness.shtml> (last visited October 8, 2013).

⁷³ See Perlin, *supra* note 16, at 724 n. 220; Perlin, *Wisdom*, *supra* note 53, manuscript at 13-19.

⁷⁴ See e.g., Heather Ellis Cucolo & Michael L. Perlin, “*They’re Planting Stories In the Press*”: *The Impact of Media Distortions on Sex Offender Law and Policy*, 3 U. DENV. CRIM. L. REV. 185 (2013) (considering “how the role of the media has framed our conceptualizations of offenders and influenced resulting legal decisions and legislation”).

⁷⁵ “Sanism” is an irrational prejudice of the same quality and character of other irrational prejudices that cause and are reflected in prevailing social attitudes of racism, sexism, homophobia and ethnic bigotry. See e.g., Michael L. Perlin, *On “Sanism,”* 46 S.M.U. L. REV. 373 (1992).

⁷⁶ “Pretextuality” refers to ways that courts accept and even encourage, either implicitly or explicitly, testimonial dishonesty, especially on the part of expert witnesses. See e.g., Michael L. Perlin, *Pretexts and Mental*

the public attitude towards the care and rehabilitation of persons with mental disabilities when they enter into the criminal justice system reflects this fear.

This is not only a domestic issue but also an international one. Consider the following:

- Studies conducted at two Argentinean forensic wards showed unlivable conditions where individuals were housed in small, extremely overcrowded cells by approximately 75 percent, with no running water or toilets. Many were denied routine medical care, a basic human right for all individuals regardless of legal status, and some were subjected to unwanted sexual practices and rape. In extreme cases, there were no appropriate treatment facilities in which to release the patients, and some were housed in the facility for over twenty years, receiving no medication or other treatment.⁷⁷
- Prison facilities in England revealed a number of discrepancies, including “the lack of treatment facilities, lack of a clear legal framework for treating prisoners with severe mental illness, inadequately designed prison health care wings, and considerable delays in hospital transfers.”⁷⁸
- Convicted prisoners from a Budapest prison were used to “keep an eye on” patients housed in the nation’s only high security forensic psychiatric institution. Many of the patients in the institution were deemed “high suicide risk.” One can opine that the prisoners tasked with this responsibility were not given adequate training in the treatment of those with mental illnesses or disabilities, especially those in such vulnerable conditions, begging the question of how appropriate care could be rendered.⁷⁹
- Many institutions use prolonged confinement as a way of managing or disciplining individuals deemed dangerous. Tamms Correctional Center in Illinois, for example, held a prisoner with a well-documented history of schizophrenia in solitary for nearly six years.⁸⁰ While solitary conditions can be psychologically harmful to any individual, they are particularly damaging to one with a mental disability. In fact, a federal judge once equated putting mentally ill prisoners in isolated confinement with “putting an asthmatic in a place with little air...”⁸¹
- Albanian law requires that individuals with mental disabilities who have been convicted of criminal offenses be housed in prison units and must comply by all prison rules. Some were institutionalized for five years before their conditions were re-evaluated.⁸²

Conditions in forensic facilities thus continue to “violate the ‘decencies of civilized conduct’”⁸³ and highlight the dire need for intervention on behalf of those with mental disabilities who are subjected to such treatment. Anti-torture initiatives must highlight these issues and work to expand the reach of the CRPD and any subsequent UN treaties or conventions to include forensic patients.

Disability Law: The Case of Competency, 47 U. MIAMI L. REV. 625, 669-70 (1993).

⁷⁷ Mental Disability Rights International (MDRI), *Ruined Lives: Segregation from Society in Argentina’s Psychiatric Asylums* (2009).

⁷⁸ Tim Exworthy, et al., *Asserting Prisoners’ Right to Health: Progressing Beyond Equivalence*, 63 PSYCHIATRIC SERV. 270-5 (2012).

⁷⁹ Perlin, *supra* note 60, at 354 (citing Mental Disability Advocacy Center (MDAC), *Press Release Prisoners or Patents* (2005), , discussed in <http://www.mdac.info/en/Hungary>).

⁸⁰ HUMAN RIGHTS WATCH, HUMAN RIGHTS WATCH STATEMENT FOR THE RECORD TO THE SENATE JUDICIARY COMMITTEE SUBCOMMITTEE ON HUMAN RIGHTS AND THE LAW: MENTAL ILLNESS, HUMAN RIGHTS, AND US PRISONS (2009), available at <http://www.hrw.org/news/2009/09/22/mental-illness-human-rights-and-us-prisons>.

⁸¹ *Madrid v. Gomez*, 889 F. Supp. 1146, 1265 (N.D. Cal. 1995).

⁸² Perlin, *supra* note 60, at 354 (citing Harvey Weinstein, Ira Burnim & Robert Okin, *Protecting the Mentally Disabled*, CARNEGIE COUNCIL (May 6, 2001), accessible at http://www.carnegiecouncil.org/publications/archive/dialogue/2_06/online_exclusive/654.html).

⁸³ Perlin, *supra* note 23.

This marginalized and often forgotten population continues to be neglected by the very individuals working to end such injustices. How can this be rectified?

In order to begin the transformation of the current policies and views of mental illness, we must first examine, understand, and reject the pretexts before us. Individuals who are mentally ill and involved in the criminal justice system face a vast amount of discrimination from multiple perspectives, making them more susceptible to ill treatment.⁸⁴ Within the community, persons with mental disabilities are often stigmatized and defenseless against a number of different abuses, resulting in further victimization.⁸⁵ For example, persons with mental disabilities are typically barred from engaging in public affairs, such as policy decision-making processes,⁸⁶ and are often restricted from fully exercising their civil rights because of incorrect assumptions that their diagnoses make them unable to responsibly manage their own affairs.⁸⁷ According to Article 29 of the CRPD, those with a disability have the right to participate in political and public life, which includes the right to vote.⁸⁸ Regardless, those who have “bought into” the myths of sanism often curtail this right and continue to deny fundamental rights to those with mental disabilities.

There are additional barriers preventing access to appropriate healthcare for mentally disabled individuals who are racial minorities and/or of immigrant status,⁸⁹ and lack of treatment can oftentimes cause individuals with mental disabilities to be inappropriately and disproportionately arrested.⁹⁰ Many persons with mental illness are brought to jails *in the first place* rather than mental hospitals.⁹¹ This is due to a variety of reasons, including the time-consuming nature of mental hospital drop-offs, the work conditions of the police officers involved, and the perceived lack of support of mental health facilities. Additionally, a lack of coordination between the police and mental health professionals persists, and the police place more significance on the arrest itself than on the acts and clinical conditions of the apprehended individuals.⁹²

⁸⁴ WORLD HEALTH ORGANIZATION, *MENTAL HEALTH AND DEVELOPMENT: TARGETING PEOPLE WITH MENTAL HEALTH CONDITIONS AS A VULNERABLE GROUP* (2010).

⁸⁵ Butora, *supra* note 66.

⁸⁶ See e.g., Pamela S. Karlan, *Framing the Voting Rights Claims of Cognitively Impaired Individuals*, 38 McGEORGE L. REV. 917 (2007); Michael Waterstone, *Fundamental Rights and Voting*, 56 ALA. L. REV. 793 (2005).

⁸⁷ WORLD HEALTH ORGANIZATION, *supra* note 84.

⁸⁸ UN CONVENTION, *supra* note 29, at art. 29.

⁸⁹ Michelle Chen, *Breaking Down Barriers To Mental Health Care*, GOTHAM GAZETTE (Jan. 18, 2008), <http://www.gothamgazette.com/index.php/health/3859-breaking-down-barriers-to-mental-health-care>.

⁹⁰ *Treatment of Mental Illness Lowers Arrest Rates, Saves Money*, SCIENCE DAILY (June 10, 2013), <http://www.sciencedaily.com/releases/2013/06/130610112722.htm>. See generally, Perlin, *Wisdom*, *supra* note 53.

⁹¹ These are sometimes referred to as “mercy bookings.” See Christina Canales, *Prisons: The New Mental Health System*, 44 CONN. L. REV. 1725, 1735 (2012) (citing H. Richard Lamb et al., *The Police and Mental Health*, 53 PSYCHIATRIC SERVICES 1266, 1267 (2002)).

⁹² RISDON N. SLATE & W. WESLEY JOHNSON, *THE CRIMINALIZATION OF THE MENTALLY ILL: CRISIS AND OPPORTUNITY FOR THE JUSTICE SYSTEM* 87, 89 (2008) (citing Randy Borum et al., *Police Perspectives on Responding to Mentally Ill People In Crisis: Perceptions of Program Effectiveness*, 16 BEHAV. SCI. & L. 393 (1998); Randy Borum et al., *Substance Abuse, Violent Behaviors and Police Encounters among Persons with Severe Mental Disorder*, 13 J. CONTEMP. CRIM. JUST. 236 (1997); Virginia G. Cooper et al., *Dispositional Decisions with the Mentally Ill: Police Perceptions and Characteristics*, 7 POLICE Q. 295 (2004); J.R. Husted et al., *California Law Enforcement Agencies and the Mentally Ill Offender*, 23 BULL. AM. ACAD. PSYCHIATRY & L. 315 (1995)); see also, Lamb et al., *supra* note 91, at 1267. On how police departments’ organizational structures need to be changed so as to better optimize such coordination, see Robert Panzarella & Justin Alicea, *Police Tactics in Incidents with Mentally Disturbed Persons*, 20 POLICING: INT’L J. POLICE STRATEGIES & MGMT. 326, 337 (1997). On the need for enhanced collaboration, see Lamb et al., *supra* note 39. Encouragingly, in one study, over 90% of police officers reported that they felt mental health training was either fairly or very important. See Marilyn Price, *Commentary: The Challenge of Training Police Officers*, 33 J. AM. ACAD. PSYCHIATRY & L. 50, 50 (2005) (discussing findings reported in Heidi S. Vermette et al., *Mental Health Training for Law Enforcement Professionals*, 33 J. AM. ACAD. PSYCHIATRY & L. 42 (2005)).

Once members of this population enter the criminal justice system, they face an entirely new set of barriers. There is a prevalent underlying “culture of blame”⁹³ that follows the individuals and continues to accuse them for their mental illnesses and disabilities.⁹⁴ After criminal justice involvement, they are categorized not only as “mentally ill” but also as a “criminal.”⁹⁵ Society in general adopts a “lock them up” mentality when it comes to this dual marker, believing that rehabilitation is not an option.⁹⁶ Once again, sanism and fear come into play. The public sees locking someone up behind prison or forensic facility walls as easier and safer than focusing on rehabilitation. While this attitude is enraging, it is doubly upsetting when many of the patients in forensic facilities have not been convicted of a crime (awaiting determination as to incompetency to stand trial; permanently incompetent to stand trial; awaiting trial; post-insanity acquittal). These individuals are placed into inhumane conditions, often kept longer than their criminal counterparts, and may not even receive the rehabilitation that would allow for successful reintegration back into the community.⁹⁷ Both the general public and institutional staff and officials operate under the impression that punishment is the main objective of the criminal justice system, which reinforces the belief that harsh conditions are acceptable.⁹⁸ A shift of focus is needed from reliance on punitive measures to that of rehabilitation. This is especially crucial when it comes to those in the criminal justice system with a mental illness. Rather than locking them away, the goal of forensic facilities should be to help the patients so that they may re-enter society as productive members of their communities.

Shedding light on the deplorable conditions of forensic facilities and spreading awareness about the treatment to which patients are subjected is the first step in ensuring equality. Once this population is seen as human beings who are entitled to healthcare and humane conditions, the stigma of mental illness will begin to fade, and we can begin to focus on people rather than labels.

3. Regional Courts and Commissions

Although some of the most important cases decided by regional human rights courts and commissions have dealt with forensic patients, this fact is ignored, even in the decisions themselves. *Victor Rosario Congo v. Ecuador* involved a 48 year-old Ecuadorian who died of malnutrition, hydro-electrolytic imbalance, and heart and lung failure because of the State’s gross negligence and willful acts. Specifically, a guard beat Mr. Congo with a club on the scalp, deprived him of medical treatment, kept him naked, and forced him to endure complete isolation.⁹⁹

The Inter-American Commission on Human Rights (Inter-American Commission)¹⁰⁰ found that the State was responsible for its agents’ conduct that violated Mr. Congo’s right to humane treat-

⁹³ See e.g., Neil R. Feigenson, *Sympathy and Legal Judgment: A Psychological Analysis*, 65 TENN. L. REV. 1, 60 & n.258 (1997).

⁹⁴ On this demonization, see Michael L. Perlin, “Where the Winds Hit Heavy on the Borderline”: *Mental Disability Law, Theory and Practice, Us and Them*, 31 LOYOLA L.A. L. REV. 775, 789 (1998).

⁹⁵ On the significance of the duality of the “mad”/“bad” label, see e.g., Ania Wilczynski, *Images of Women Who Kill Their Infants: The Mad and the Bad*, 2 WOMEN & CRIM. JUST. 71 (1991); Peter Margulies, *The “Pandemonium Between the Mad and the Bad”: Procedures for the Commitment and Release of Insanity Acquittees After Jones v. United States*, 36 RUTGERS L. REV. 793 (1984).

⁹⁶ David Farabee, *Reinventing Criminal Justice*, WASH. POST, Feb. 11 2006, at A9, accessible at <http://www.washingtonpost.com/wp-dyn/content/article/2006/02/10/AR2006021001699.html>.

⁹⁷ HUMAN RIGHTS WATCH, *supra* note 80.

⁹⁸ Francis T. Cullen, et al., *Nothing Works Revisited: Deconstructing Farabee’s “Rethinking Rehabilitation,”* 4 VICTIMS & OFFENDERS 101 (2009).

⁹⁹ *Matter of Congo*, *supra* note 54, ¶ 9.

¹⁰⁰ On the differences between the Court and the Commission, see Terrence Rogers, *Using International Human Rights Law to Combat Racial Discrimination in the U. S. Criminal Justice System*, 14 SCHOLAR 375, (2011).

ment under Article 5 of the American Convention on Human Rights (American Convention).¹⁰¹ The Inter-American Commission determined that Article 5 of the American Convention must be interpreted in light of the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles).¹⁰² This decision made the MI Principles hard law, or in other words, binding upon the U.N. members who have signed it.¹⁰³ Thus, it guarantees more extensive rights for persons with mental disabilities.

The Inter-American Commission found that the solitary confinement of Mr. Congo constituted inhuman and degrading treatment in violation of Article 5(2) of the American Convention, especially in light of the fact he was left in isolation unable to satisfy his basic needs.¹⁰⁴ Thus, the State violated Mr. Congo's right to "be treated with respect for the inherent dignity of the human person."¹⁰⁵ Further, the Inter-American Commission found that the State has a duty to ensure the physical, mental and moral integrity of persons suffering from mental illness.¹⁰⁶

The Inter-American Commission also found that the State violated Article 4(1) of the American Convention because the State failed to take measures in its power to ensure the right to life of a person who "partly because of his state of health and in part owing to injuries inflicted on him by a State agent, was defenseless, isolated and under its control."¹⁰⁷ Under Article 25(1) of the American Convention, Mr. Congo had a right to judicial protection, which the State violated because there were no judicial avenues available to establish the responsibility for his sustained injuries and death.¹⁰⁸ As a result of this case, the Inter-American Commission recommended that the persons responsible for the violations be punished, the family of Mr. Congo be compensated, medical and psychiatric care be provided for persons suffering from mental illness, and individuals confined to the penitentiary system be assigned specialists to identify any psychiatric disorders.¹⁰⁹

¹⁰¹ American Convention on Human Rights "Pact of San Jose, Costa Rica," opened for signature Nov. 22, 1969, 1144 U.N.T.S. 123, available at <http://www.oas.org/juridico/english/treaties/b-32.html>.

¹⁰² *Matter of Congo*, supra note 54, ¶ 54; see The Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care ("MI Principles"), G.A. Res. 56/119, U.N. Doc. A/46/49 (Dec. 17, 1991). The MI Principles are the predecessor to the CRPD. Their publication "inspired lawyers, advocates, professors and progressive mental health professionals to begin thinking seriously about the intersection between international human rights law and mental disability law." See Michael L. Perlin, "There Must Be Some Way Out of Here": Why the Convention on the Rights of Persons with Disabilities Is Potentially the Best Weapon in the Fight Against Sanism, 20 PSYCHIATRY, PSYCHOL. & L. 462, 463 (2013). But see Tina Minkowitz, *The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions*, 34 SYRACUSE J. INT'L L. & COM. 405, 407 (2007) (criticizing MI Principles for not being sufficiently protective of the rights of persons with psychosocial disabilities, especially in the context of the right to refuse treatment); T.W. Harding, *Human Rights Law in the Field of Mental Health: A Critical Review*, 101 ACTA PSYCHIATRICA SCANDINAVICA 24, 24 (2000) (discussing how the MI Principles are "basically flawed" and specifically referring to the right to refuse treatment). The MI Principles retain significance today in those nations that have neither signed nor ratified the CRPD. See PERLIN, supra note 21, at 9-10 n.13. On how the discrediting of the MI Principles made them "virtually invisible throughout the disability convention process," see Janet E. Lord, *Mirror, Mirror on the Wall: Voice Accountability and NGOs in Human Rights Standard Setting*, 5 SETON HALL J. DIPL. & INT'L REL. 93, 101 (2004).

¹⁰³ On how soft law becomes hard law via court decisions, see Gerald L. Neuman, *Import, Export, and Regional Consent in the Inter-American Court of Human Rights*, 19 EUR. J. INT'L L. 101, 111 (2008). See generally Gregory C. Shaffer & Mark A. Pollack, *Hard Versus Soft Law in International Security*, 52 B.C. L. REV. 1147, 1165 (2011).

¹⁰⁴ *Matter of Congo*, supra note 54, ¶ 59.

¹⁰⁵ *Id.*

¹⁰⁶ *Id.* ¶ 62.

¹⁰⁷ *Id.* ¶ 69.

¹⁰⁸ *Id.* ¶ 86; see American Convention on Human Rights, supra note 101, at art. 25(1).

¹⁰⁹ *Matter of Congo*, supra note 54, ¶ 98. On how Congo "[broke] new ground" in this area of the law, see PERLIN, supra note 21, at 12.

This case is just one of the many¹¹⁰ that highlights the need for mental health advocates and services within forensic settings. Shocking examples such as these underscore the extent to which the forensic population is particularly bereft of legal advocacy. Again, this lack of advocacy flies in the face of both the proscriptions and the prescriptions of the CRPD and the CAT.

4. Lack of Lawyers and Advocacy Services

There are, however, few lawyers and fewer mental disability advocates providing legal and advocacy services to this population, adding to the continued inequity and misuse of punitive measures. Treatment options that would provide appropriate services in the least restrictive alternative have dwindled causing jails and prisons to become, in essence, the new mental hospitals.¹¹¹ Aside from the issues inside the cell walls, such as inappropriate treatment and less than humane conditions that arise in jails and prisons, lawyers and mental disability advocates alike face numerous hurdles in assuring that their clients are treated with dignity and receive the care that they need and deserve. Because victories in this area are so few and far between, the burnout rate of advocates tends to be extremely high, and the job itself is often underpaid.¹¹² As such, there are few advocates willing and able to do such hard work for little chance of success. Recent budget cuts in mental health services also contribute to the lack of advocates.¹¹³ In fact, “twenty-two out of forty state correctional systems reported in a recent study that they did not have an adequate number of mental health staff.”¹¹⁴ In response, overburdened staff may find it difficult to provide the most appropriate treatment that would encourage rehabilitation.¹¹⁵ Often times, such recourse perpetuates the “revolving door” trend between the community and the criminal justice system without getting to the root of the issue, which is appropriate mental healthcare.¹¹⁶ This practice violates Article 26 of the CRPD, which grants the right to habilitation and rehabilitation.¹¹⁷ In essence, each individual possesses the right “to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.”¹¹⁸

¹¹⁰ See e.g., Perlin, *supra* note 37, at 7-10 (discussing Purohit & Moore v. The Gambia, Afr. Comm’n on Hum. and Peoples’ Rts., Comm. No. 241/2001, para. 85 (2003) (finding unlawful both the way that persons with mental disabilities were treated in Gambia as well as prevailing sections of the Lunatic Detention Act of Gambia)). In the Matter of the Neuro-Psychiatric Hospital of Paraguay, the Inter-American Commission granted immediate, life-saving measures to protect the lives and physical, mental, and moral integrity of 460 individuals detained in the state-run hospital. (unreported case) (discussed in Alison A. Hillman, *Protecting Mental Disability Rights: A Success Story in the Inter-American Human Rights System*, HUM. RTS. BRIEF, Spring 2005, at 25-28; Perlin, *supra* note 60, at 345-46; Paraguay, DISABILITY RTS. INT’L, <http://www.disabilityrightsintl.org/work/country-projects/paraguay> (last visited July 5, 2013)).

¹¹¹ It is a truism that (depending on where you live) Rikers Island or the Cook County House of Detention or the Los Angeles County Jail is the “largest mental health facility in the nation.” See e.g., Gregory L. Acquaviva, *Mental Health Courts: No Longer Experimental*, 36 Seton Hall L. Rev. 971, 978 (2006) (observing that “in 1992, the Los Angeles County jail became the nation’s largest mental institution, with Cook County Jail, Illinois, and Riker’s Island, New York, as second and third respectively”). Judges concur with this finding. See Judge Stephen S. Goss, *Mental Health Court Programs in Rural and Nonaffluent Jurisdictions*, 33 CRIM. JUST. REV. 405, 405 (2008) (“Our jails have become the de facto mental health treatment centers for many persons.”).

¹¹² HUMAN RIGHTS WATCH, *supra* note 80.

¹¹³ Philip J. Kinsler & Anna Saxman, *Traumatized Offenders: Don’t Look Now, But Your Jail’s Also Your Mental Health Center*, 8 J. TRAUMA & DISSOCIATION 81 (2007).

¹¹⁴ HUMAN RIGHTS WATCH, *supra* note 80.

¹¹⁵ *Id.*

¹¹⁶ See e.g., Heather Barr, *Prisons and Jails: Hospitals of Last Resort* (1999) available at <http://www.urbanjustice.org/pdf/publications/mentalhealth/PrisonsJails.pdf>; LeRoy L. Kondo, *Advocacy of the Establishment of Mental Health Specialty Courts in the Provision of Therapeutic Justice for Mentally Ill Offenders*, 28 Am. J. Crim. L. 225, 258 (2001).

¹¹⁷ UN CONVENTION, *supra* note 29, at art. 26.

¹¹⁸ *Id.*

Burnt-out staff, who may not be able to provide the best services, and budget cuts, which impede on adequate , do little to uphold the principles mandated by this Article.

A lack of training and of adequate education in the field of mental disability also contributes to the lack of effective counsel and advocacy services in this area.¹¹⁹ Lawyers do not receive enough education about individuals with mental illnesses and their specific needs, and this affects how they advocate for their clients. As such, they may shy away from cases with defendants with mental illnesses. Additionally, they may be overwhelmed “by the tsunami of prisoners with serious mental health needs,”¹²⁰ be hard-pressed to take the time to consider the most appropriate course of action with each client, and may inadvertently do their client an injustice. Also, even in instances in which training has been adequate, some advocates may still have an underlying fear when it comes to the mentally ill population, making effective representation nearly impossible.¹²¹

Consequently, people who have mental and intellectual disabilities and are in the criminal justice system have a pressing need for advocates. Because this population is marginalized, it is essential that lawyers and advocates step forward to aid this population in finding its voice and providing it with the tools to fight for equality. This will educate the general public about this population, leading to real and lasting change, a change that will stop the demonization of people living with mental and intellectual illnesses and focus, rather, on the person’s humanity and his or her treatment and well-being.

Both the CAT and the CRPD attempt to correct this academic deficit. Article 10 of the CAT and Article 4 of the CRPD both promote proper education and training to professionals. Article 10 of the CAT states that “Each State Party shall ensure that education and information regarding the prohibition against torture are fully included in the training of law enforcement personnel, civil or military, medical personnel, public officials and other persons who may be involved in the custody, interrogation or treatment of any individual subjected to any form of arrest, detention or imprisonment.”¹²² Similarly, Article 4 (i) of the CRPD tell us that it is essential “to promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.”¹²³ With such protections in place, it would seem that those working directly with individuals with a mental disability in any capacity would—or, at least, *should*—receive formal training as to appropriate treatment and care of such individuals. Education is the first step to changing the persistent misconceptions and “nurtur[ing] receptiveness to the rights of persons with disabilities.”¹²⁴

In regard to the education of the general population, Article 8 of the CRPD promotes “awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities.”¹²⁵ This includes combating the “stereotypes, prejudices and harmful practices relating to persons with disabilities...”¹²⁶

¹¹⁹ See generally Michael L. Perlin, “They Keep It All Hid”: *The Ghettoization of Mental Disability Law and Its Implications for Legal Education*, 54 St. Louis U. L. J. 857 (2010).

¹²⁰ HUMAN RIGHTS WATCH, *supra* note 80.

¹²¹ On how lawyers who represent patients may be as sanist as—or *more* sanist than—the general public, see Perlin, *supra* note 16, at 684 (“Sanist myths exert especially great power over lawyers who represent persons with mental disabilities”).

¹²² UN CONVENTION AGAINST TORTURE, *supra* note 41, at art. 10.

¹²³ UN CONVENTION, *supra* note 29, at art. 4 (i).

¹²⁴ *Id.*

¹²⁵ *Id.* at art. 8.

¹²⁶ *Id.*

The situation in the United States is uniquely vexing. In many jurisdictions, statutory limitations prevent public defenders from representing those not currently subject to criminal prosecutions,¹²⁷ and, of course, in many jurisdictions there is no state-wide public defender service of any sort.¹²⁸ An illustrative example is the failure in the United States to implement the 1972 decision of *Jackson v. Indiana*,¹²⁹ which held that persons incompetent to stand trial could not be kept indefinitely in maximum-security forensic hospitals. In fact, an individual cannot be held for more than a “reasonable period of time necessary to determine whether there is a substantial probability that he will attain competency in the foreseeable future.”¹³⁰ The *Jackson* ruling, however, did not determine guidelines to define a “reasonable period of time”, leaving the decision to each individual state.¹³¹ And, as of 1985, about half of the jurisdictions still statutorily permitted indefinite hospitalization based solely on a finding of continuing incompetency to stand trial,¹³² often in the “worst institution in the state.”¹³³ When the 1985 research was repeated in 1993, there was virtually no significant change,¹³⁴ nor was there any significant change found when the research was reviewed in 2000¹³⁵ or in 2012.¹³⁶ Startlingly, the highest court in at least one state has specifically sanctioned procedures that ignore the *Jackson* holding.¹³⁷

Again, one of the reasons for this scandal is the lack of adequate counsel available to this population.¹³⁸ Certainly, without such counsel, the likelihood that the CRPD and the CAT are considered as sources of rights for this population is negligible.

¹²⁷ See e.g., Jeffrey Gilbert, *In Defense of Public Defenders: Polk County v. Dodson*, 36 U. MIAMI L. REV. 599, 612 n.82 (1982) (discussing the amicus brief filed by the National Legal Aid and Defenders Association); *Nat'l Ass'n of Criminal Def. Lawyers v. Dodson*, 454 U.S. 312, 322 (1981) (holding that a public defender does not act under color of state law “when performing a lawyer’s ‘traditional functions’ as counsel to a defendant in a criminal proceeding”); Brief for Amici Curiae at 13, *Polk County*, 454 U.S. 312 (1981) (discussing how a public defender’s decisions about how to allocate his time and resources are “affected by office policies, statutory limitations or funding levels, the attorney’s choice has clearly been made while cloaked in the mantle of state authority, and the client should have a [federal] remedy” (emphasis added)).

¹²⁸ See e.g., Lisa R. Pruitt & Beth A. Colgan, *Justice Deserts: Spatial Inequality and Local Funding of Indigent Defense*, 52 ARIZ. L. REV. 219, 224 (2010) (in 18 states, public defender systems exist at the county or local level); Susanne M. Bookser, *Making Gault Meaningful: Access to Counsel and Quality of Representation in Delinquency Proceedings for Indigent Youth*, 3 WHITTIER J. CHILD. & FAM. ADVOC. 297, 304 (2004) (some state systems are a mixture of “public defenders, appointed attorneys selected from a panel of available attorneys, and/or individual attorneys who have contracted with the local government unit to provide ... representation”).

¹²⁹ 406 U.S. 715 (1972).

¹³⁰ *Id.* at 733. In *Jackson*, the Court found that three and a half years of confinement “establishe[d] the lack of a substantial probability that [the defendant] will ever be able to participate fully in a trial.” *Id.* at 738-39.

¹³¹ *Id.* at 740.

¹³² Barbara Weiner, *Mental Disability and the Criminal Law*, in *THE MENTALLY DISABLED AND THE LAW* 693, 695 (3d ed. 1985).

¹³³ Bruce Winick, *Restructuring Competency to Stand Trial*, 32 UCLA L. REV. 921, 942 (1985).

¹³⁴ See Grant Morris & J. Reid Meloy, *Out of Mind? Out of Sight: The Uncivil Commitment of Permanently Incompetent Criminal Defendants*, 27 U.C. DAVIS L. REV. 1 (1993); *id.* at 9 (“Many states still have not implemented *Jackson*.”).

¹³⁵ See Perlin, *supra* note 20, at 204-05.

¹³⁶ See Andrew R. Kaufman, Bruce B. Way & Enrico Suardi, *Forty Years After Jackson v. Indiana: States’ Compliance with “Reasonable Period of Time” Ruling*, 40 J. AM. ACAD. PSYCHIATRY & L. 261 (2012) (showing most states are not in compliance with *Jackson*).

¹³⁷ See *State v. Werner*, 796 P.2d 610, 613 (N.M. Ct. App. 1990) (not error to treat dangerous patients committed pursuant to *Jackson* differently from civil patients).

¹³⁸ See e.g., Michael L. Perlin, *“Everything’s a Little Upside Down, As a Matter of Fact the Wheels Have Stopped”: The Fraudulence of the Incompetency Evaluation Process*, 4 HOUS. J. HEALTH L. & POL’Y 239 (2004).

5. Absence of Specific Consideration by the Survivor Movement

Articles written by those who self-identify with the “psychiatric survivor movement” largely ignore this population as well. So, even within the world of those who focus broadly on these human rights issues, this population has remained invisible. Survivors may feel forced into continued silence because of the additional stigma that plagues individuals with mental and intellectual disabilities in forensic settings. Speaking out about their personal experiences in a forensic facility, for example, may further ostracize survivors in their communities, causing supplementary discrimination, which paves the way for additional victimization and abandonment and for the negation of positive strides in rehabilitation.¹³⁹ There may be a fear that bringing disabilities to the forefront of the conversation may further categorize individuals into “us” and “them” or “undiagnosed” and “the other,” demeaning the very purpose of the psychiatric survivor movement. Furthermore, those in the community who are undereducated in the field of mental and intellectual disabilities may then make judgments regarding the entire population with very limited information, only to reinforce the stigma that survivors and advocates alike seek to transform.¹⁴⁰

Survivors may also be hesitant to speak out because of learned helplessness while in forensic institutions.¹⁴¹ Living in deplorable conditions and contending with staff who may not completely understand the population may make one hesitant to speak about what she endured and to advocate for change.¹⁴² Lasting feelings and issues around being voiceless forces many into further silence. Such silence makes it far less likely that international law will be a source of remedies in cases involving this population.

In discussing the split in approaches to CRPD issues taken by NGOs representing persons who have been institutionalized, Professor Janet Lord makes the critical point that many important issues “have received little breadth of dialogue within the NGO community and appear to have narrowed the terms of the debate among States as well.”¹⁴³ Although forensic issues are not the focal point of Lord’s paper, we believe that this observation holds equally true in this precise context.

6. Absence from the Discourse on Forensic Patients in Facilities Designated for Persons with Intellectual Disabilities

It is imperative that, as we continue to focus on this population, we do not omit the rights of persons with intellectual disabilities who are in forensic facilities as they are particularly absent from discourse.¹⁴⁴ Although there is “increasing recognition” that this cohort of individuals “are a particularly complex patient group whose needs are not well met,”¹⁴⁵ there has still been minimal

¹³⁹ It should be made clear that there is significant tension between those who characterize themselves as anti-psychiatry survivors and those who adopt alternative perspectives to the impact that institutionalization had on their lives. See Lord, *supra* note 51, at 39 n.60 (referring to the “fraught and embittered advocacy” between these groups).

¹⁴⁰ María Jimena & Alvarado Chavarria, *Let’s Try to Change it: Psychiatric Stigmatization, Consumer/Survivor Activism, and the Link and Phelan Model*, accessible at <http://dr.archives.pdx.edu/xmlui/handle/psu/7988>.

¹⁴¹ See generally sources cited at Bruce J. Winick, *Therapeutic Jurisprudence and the Treatment of People with Mental Illness in Eastern Europe: Construing International Human Rights Law*, 21 N.Y. L. SCH. J. INT’L & COMP. L. 537, 555 n.137 (2002).

¹⁴² Jimena & Chavarria, *supra* note 140.

¹⁴³ Lord, *supra* note 102, at 101.

¹⁴⁴ In one study, such patients were found to comprise 12.8% of all patients with forensic involvement. See Yona Lunskey et al., *The Clinical Profile and Service Needs of Psychiatric Inpatients with Intellectual Disabilities and Forensic Involvement*, 17 PSYCHOLOGY, CRIME & L. 9, 19 (2011).

¹⁴⁵ *Id.* at 9.

focus on the high rates of abuse and neglect experienced by this population.¹⁴⁶ Aside from the issues that plague those with mental disabilities in forensic facilities, individuals with intellectual disabilities face a unique set of circumstances because of the perception that the disability is permanent.¹⁴⁷ Unlike mental illnesses that can be treated with a prescribed medication regimen, which seeks to quell active symptoms of the disorder, intellectual disabilities are believed to be more permanent, making it less likely that potentially ameliorative interventions are attempted in forensic facilities.¹⁴⁸ Without proper training and rehabilitation programs, holding an individual with intellectual disabilities under such circumstances can be defined as a form of torture, especially if he or she is detained indefinitely.¹⁴⁹

In Queensland, Australia, the Forensic Disability Act of 2011 established a protocol for the treatment and housing of an individual “with an intellectual or cognitive disability who has been ordered by the Queensland Mental Health Court to be detained for treatment or care in the forensic disability service.”¹⁵⁰ These individuals have not yet been convicted of a crime but have been found unfit to proceed with court procedures because of an “unsound mind.” The forensic order can then remain in place indefinitely, and the individual can be detained much longer than if he or she was convicted of a crime.¹⁵¹ Even more disturbing, in some Australian states, those who have been found unfit because of intellectual disabilities are detained in maximum-security prisons.¹⁵² Such placements certainly raise core questions as to potential violations of the CRPD and the CAT.

As prison facilities are not the appropriate place to treat individuals with mental illnesses, so are they not the appropriate place to treat persons with intellectual disorders and doing so may even exacerbate secondary symptoms.¹⁵³ Community-based treatment alternatives are crucial for this population; this treatment option along with proper education regarding persons with intellectual disabilities’ various stages of functioning can help to reduce the fear and uncertainty that surrounds the population and help them to be seen in a different, more human, light.

Therapeutic Jurisprudence¹⁵⁴

One of the most important legal theoretical developments of the past two decades has been the creation of therapeutic jurisprudence.¹⁵⁵ Initially employed in cases involving individuals with

¹⁴⁶ *Id.* at 20; see also, e.g., William Glaser & David Florio, *Beyond Specialist Programmes: A Study of the Needs of Offenders with Intellectual Disability Requiring Psychiatric Attention*, 48 J. INTELL. DISABILITY RESEARCH 591 (2004).

¹⁴⁷ By way of example, in *Heller v. Doe*, 509 U.S. 312 (1993), the Supreme Court countenanced a lesser commitment standard in cases in individuals with intellectual disabilities than those with psychosocial disabilities, in part, because it was purportedly easier to establish danger to self or others in cases of persons with intellectual disabilities. *Id.* at 323. *But see id.* at 337-45 (Souter, J., dissenting) (critiquing majority view). One of the authors (MLP) critiques this prong of *Heller* in 1 PERLIN, *supra* note 3, § 2C-5.1, at 405-09.

¹⁴⁸ J.A. Tsiouris, *Pharmacotherapy for Aggressive Behaviours in Persons With Intellectual Disabilities: Treatment or Mistreatment?*, available at <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2009.01232.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>.

¹⁴⁹ See *supra* text accompanying notes 132-38.

¹⁵⁰ Bernadette McSherry, *The Involuntary Detention of People with Intellectual Disabilities*, available at <http://rightnow.org.au/topics/disability/the-involuntary-detention-of-people-with-intellectual-disabilities/>.

¹⁵¹ *Id.*

¹⁵² *Id.*

¹⁵³ Human Rights Watch, *supra* note 80.

¹⁵⁴ This section is generally adapted from Perlin, *Guardians*, *supra* note 53; Perlin, *Wisdom*, *supra* note 53; and Perlin, *Yonder*, *supra* note 53.

¹⁵⁵ See e.g., DAVID B. WEXLER, THERAPEUTIC JURISPRUDENCE: THE LAW AS A THERAPEUTIC AGENT (1990); DAVID B. WEXLER & BRUCE J. WINICK, LAW IN A THERAPEUTIC KEY: RECENT DEVELOPMENTS IN THERAPEUTIC JURISPRUDENCE (1996); BRUCE J. WINICK, CIVIL COMMITMENT: A THERAPEUTIC JURISPRUDENCE MODEL (2005); David B. Wexler, *Two Decades of Therapeutic Jurisprudence*, 24 TOURO L. REV. 17 (2008); 1 PERLIN, *supra* note 3, § 2D-3, at 534-41. Wexler first

mental disabilities but subsequently expanded far beyond that narrow area, therapeutic jurisprudence presents a new model for assessing the impact of case law and legislation, recognizing that, as a therapeutic agent, the law that can have therapeutic or anti-therapeutic consequences.¹⁵⁶ The ultimate aim of therapeutic jurisprudence is to determine whether legal rules, procedures, and the role of lawyers can or should be reshaped to enhance their therapeutic potential while not subordinating due process principles.¹⁵⁷ David Wexler identifies how the inherent tension in this inquiry must be resolved: "the law's use of mental health information to improve therapeutic functioning [cannot] impinge upon justice concerns."¹⁵⁸ As one of the authors of this article (MLP) has written elsewhere, "An inquiry into therapeutic outcomes does not mean that therapeutic concerns 'trump' civil rights and civil liberties."¹⁵⁹

Therapeutic jurisprudence "asks us to look at law as it actually impacts people's lives"¹⁶⁰ and focuses on the law's influence on emotional life and psychological well-being.¹⁶¹ It suggests that "law should value psychological health, should strive to avoid imposing anti-therapeutic consequences whenever possible, and when consistent with other values served by law should attempt to bring about healing and wellness."¹⁶²

Therapeutic jurisprudence "is a tool for gaining a new and distinctive perspective utilizing socio-psychological insights into the law and its applications."¹⁶³ It is also part of a growing comprehensive movement towards establishing more humane and psychologically optimal ways of handling legal issues collaboratively, creatively, and respectfully.¹⁶⁴ In its aim to use the law to empower individuals, enhance rights, and promote well-being, therapeutic jurisprudence has been described as "a sea-change in ethical thinking about the role of law...a movement towards a more distinctly relational approach to the practice of law...which emphasises psychological wellness

used the term in a paper he presented to the National Institute of Mental Health in 1987. See David B. Wexler, *Putting Mental Health into Mental Health Law: Therapeutic Jurisprudence*, 16 L. & HUM. BEHAV. 27, 27, 32-33 (1992).

¹⁵⁶ See Michael L. Perlin, "His Brain Has Been Mismanaged with Great Skill": How Will Jurors Respond to Neuroimaging Testimony in Insanity Defense Cases?, 42 AKRON L. REV. 885, 912 (2009); Kate Diesfeld & Ian Freckelton, *Mental Health Law and Therapeutic Jurisprudence*, in DISPUTES AND DILEMMAS IN HEALTH LAW 91 (Ian Freckelton & Kate Peterson eds., 2006) (for a transnational perspective).

¹⁵⁷ Perlin, *supra* note 16; Perlin, *supra* note 9. On how therapeutic jurisprudence "might be a redemptive tool in efforts to combat sanism, as a means of 'strip[ping] bare the law's sanist façade,'" see Michael L. Perlin, "Baby, Look Inside Your Mirror": The Legal Profession's Willful and Sanist Blindness to Lawyers with Mental Disabilities, 69 U. PITT. L. REV. 589, 591 (2008) (quoting, in part, MICHAEL L. PERLIN, THE HIDDEN PREJUDICE: MENTAL DISABILITY ON TRIAL 301 (2000)). See also, Bernard P. Perlmutter, *George's Story: Voice and Transformation through the Teaching and Practice of Therapeutic Jurisprudence in a Law School Child Advocacy Clinic*, 17 ST. THOMAS L. REV. 561, 599 n.111 (2005); Ian Freckelton, *Therapeutic Jurisprudence Misunderstood and Misrepresented: The Price and Risks of Influence*, 30 T. JEFFERSON L. REV. 575, 585-86 (2008).

¹⁵⁸ David B. Wexler, *Therapeutic Jurisprudence and Changing Concepts of Legal Scholarship*, 11 BEHAV. SCI. & L. 17, 21 (1993); see also, e.g., David Wexler, *Applying the Law Therapeutically*, 5 APPL. & PREVENTITIVE PSYCHOL. 179 (1996).

¹⁵⁹ Michael L. Perlin, *A Law of Healing*, 68 U. CIN. L. REV. 407, 412 (2000); Perlin, *supra* note 94, at 782.

¹⁶⁰ Bruce J. Winick, *Foreword: Therapeutic Jurisprudence Perspectives on Dealing With Victims of Crime*, 33 NOVA L. REV. 535, 535 (2009).

¹⁶¹ David B. Wexler, *Practicing Therapeutic Jurisprudence: Psychological Soft Spots and Strategies*, in DANIEL P. STOLLE, DAVID B. WEXLER & BRUCE J. WINICK, *PRACTICING THERAPEUTIC JURISPRUDENCE: LAW AS A HELPING PROFESSION* 45 (2006) [hereinafter STOLLE].

¹⁶² Bruce Winick, *A Therapeutic Jurisprudence Model for Civil Commitment*, in INVOLUNTARY DETENTION AND THERAPEUTIC JURISPRUDENCE: INTERNATIONAL PERSPECTIVE ON CIVIL COMMITMENT 23, 26 (Kate Diesfeld & Ian Freckelton, eds., 2003).

¹⁶³ Diesfeld & Freckelton, *supra* note 156, at 582.

¹⁶⁴ Susan Daicoff, *The Role of Therapeutic Jurisprudence Within The Comprehensive Law Movement*, in STOLLE, *supra* note 161, at 365.

over adversarial triumphalism.”¹⁶⁵ Accordingly, therapeutic jurisprudence supports an ethic of care.¹⁶⁶

One of the central principles of therapeutic jurisprudence is a commitment to dignity.¹⁶⁷ Professor Amy Ronner describes the “three Vs”: voice, validation and voluntariness,¹⁶⁸ arguing:

*What “the three Vs” commend is pretty basic: litigants must have a sense of voice or a chance to tell their story to a decision maker. If that litigant feels that the tribunal has genuinely listened to, heard, and taken seriously the litigant’s story, the litigant feels a sense of validation. When litigants emerge from a legal proceeding with a sense of voice and validation, they are more at peace with the outcome. Voice and validation create a sense of voluntary participation, one in which the litigant experiences the proceeding as less coercive. Specifically, the feeling on the part of litigants that they voluntarily partook in the very process that engendered the end result or the very judicial pronouncement that affects their own lives can initiate healing and bring about improved behavior in the future. In general, human beings prosper when they feel that they are making, or at least participating in, their own decisions.*¹⁶⁹

The question to be posed here is this: to what extent can international human rights law reach out to therapeutic jurisprudence to best insure that these principles written about by Professor Ronner—the principles of voluntariness, voice and validation—be fulfilled in matters involving residents of forensic institutions?

There has been astonishingly little written about this question. There *has been* some important work done on the relationship of TJ to the application of international human rights principles to prisoners and detainees with a mental illness, but much of it is a response to the reality that the conditions of prison facilities and forensic facilities around the world are textbook examples of anti-therapeutic conditions.¹⁷⁰ Astrid Birgden argues forcefully that “applying therapeutic jurisprudence can assist forensic psychologists in actively addressing human rights in general, as well as prisoners and detainees with mental disabilities in particular.”¹⁷¹ By way of example, in relation

¹⁶⁵ Warren Brookbanks, *Therapeutic Jurisprudence: Conceiving an Ethical Framework*, 8 J.L. & MED. 328, 329-30 (2001); see also Bruce J. Winick, *Overcoming Psychological Barriers to Settlement: Challenges for the TJ Lawyer*, in *THE AFFECTIVE ASSISTANCE OF COUNSEL: PRACTICING LAW AS A HEALING PROFESSION* 342 (Marjorie A. Silver ed., 2007); Bruce J. Winick & David B. Wexler, *The Use of Therapeutic Jurisprudence in Law School Clinical Education: Transforming the Criminal Law Clinic*, 13 CLINICAL L. REV. 605, 605-06 (2006). The use of the phrase dates to CAROL GILLIGAN, *IN A DIFFERENT VOICE* (1982).

¹⁶⁶ See e.g., Bruce J. Winick & David B. Wexler, *The Use of Therapeutic Jurisprudence in Law School Clinical Education: Transforming the Criminal Law Clinic*, 13 CLINICAL L. REV. 605, 605-07 (2006); David B. Wexler, *Not Such a Party Pooper: An Attempt to Accommodate (Many of) Professor Quinn’s Concerns about Therapeutic Jurisprudence Criminal Defense Lawyering*, 48 B.C. L. REV. 597, 599 (2007); Brookbanks, *supra* note 165; Gregory Baker, *Do You Hear the Knocking at the Door? A “Therapeutic” Approach to Enriching Clinical Legal Education Comes Calling*, 28 WHITTIER L. REV. 379, 385 (2006).

¹⁶⁷ See BRUCE J. WINICK, *CIVIL COMMITMENT: A THERAPEUTIC JURISPRUDENCE MODEL* 161 (2005).

¹⁶⁸ Amy D. Ronner, *The Learned-Helpless Lawyer: Clinical Legal Education and Therapeutic Jurisprudence as Antidotes to Bartleby Syndrome*, 24 *TOURO L. REV.* 601, 627 (2008). On the importance of “voice,” see also, Diesfeld & Freckelton, *supra* note 156, at 588.

¹⁶⁹ Amy D. Ronner, *Songs of Validation, Voice, and Voluntary Participation: Therapeutic Jurisprudence, Miranda and Juveniles*, 71 *U. CIN. L. REV.* 89, 94-95 (2002). See generally, AMY D. RONNER, *LAW, LITERATURE AND THERAPEUTIC JURISPRUDENCE* (2010).

¹⁷⁰ See e.g., Dirk van ZylSmit, *Regulation of Prison Conditions*, 39 *CRIME & JUST.* 503 (2010); Fred Cohen & Joel A. Dvoskin, *Therapeutic Jurisprudence and Corrections: A Glimpse*, 10 *N.Y. L. SCH. J. HUM. RTS.* 777 (1993).

¹⁷¹ Astrid Birgden, *Therapeutic Jurisprudence and Offender Rights: A Normative Stance Is Required*, 78 *REV. JURIDICA UPR* 43, 59 (2009); see also Astrid Birgden & Michael L. Perlin, “Where The Home In The Valley Meets The Damp Dirty Prison”: A Human Rights Perspective on Therapeutic Jurisprudence and the Role of Forensic Psychologists in Correctional Settings, 14 *AGGRESSION & VIOLENT BEHAV.* 256 (2009); Astrid Birgden & Michael L. Perlin, “Tolling for the Luckless, the Abandoned and Forsaked”: Community Safety, Therapeutic Jurisprudence and International Human Rights Law As Applied to Prisoners and Detainees, 13 *LEGIS. & CRIMINOLOGICAL PSYCHOL.* 231 (2008); Michael L.

to prisons, Ivan Zinger has argued that the best approach to ensure that the rule of law is upheld is to view corrections within the realm of human rights:

The best argument for observing human rights standards is not merely that they are required by international or domestic law but that they actually work better than any known alternative—for offenders, for correctional staff, and for society at large. Compliance with human rights obligations increases, though it does not guarantee, the odds of releasing a more responsible citizen. In essence, a prison environment respectful of human rights is conducive to positive change, whereas an environment of abuse, disrespect, and discrimination has the opposite effect: Treating prisoners with humanity actually enhances public safety. Moreover, through respecting the human rights of prisoners, society conveys a strong message that everyone, regardless of their circumstance, race, social status, gender, religion, and so on, is to be treated with inherent respect and dignity.¹⁷²

But again, this focus is on prisons and not on forensic facilities. Conditions in forensic facilities across the world shock the conscience and, in some instances, are so bereft of humanity that they challenge the notion that we are a civilized society.¹⁷³ As one of the authors of this article (MLP) has written recently, “[t]hese conditions scream out for an in-depth TJ analysis, to demonstrate their destructiveness and their negative impact on the mental health of those unlucky enough to be housed in such facilities,”¹⁷⁴ noting elsewhere that, “the CRPD is a document that resonates with TJ values.”¹⁷⁵ Although there has been recent interest in the overlap between TJ and the CRPD,¹⁷⁶ this has not extended to the specific problems raised by forensic institutions.¹⁷⁷ We hope that this chapter will lead others to consider these issues.

Conclusion

Forensic facilities and their populations have classically been hidden from view. As we have noted, there has been scarce notice of the human rights violations in such facilities, and most of those involved in all the relevant systems seem passively comfortable with the *status quo*. But this state of affairs violates international human rights law as well as the precepts of therapeutic jurisprudence. We can no longer keep this state of affairs “hid[den] behind walls.”¹⁷⁸

Perlin, “With Faces Hidden While the Walls Were Tightening”: Applying International Human Rights Standards to Forensic Psychology, 7 U.S.-CHINA L. REV. 1 (2010).

¹⁷² Ivan Zinger, *Human Rights Compliance and the Role of External Prison Oversight*, 48 CAN. J. OF CRIMINOLOGY & CRIM. JUST. 127, 127 (2006). Similarly, Ida Dickie notes how a TJ emphasis on procedural fairness and respect for autonomy can help all stakeholders in the criminal justice system. Ellen Waldman, *Therapeutic Jurisprudence: Growing Up and Looking Forward*, 30 T. JEFFERSON L. REV. 345, 347 (2008) (discussing Ida Dickie, *Ethical Dilemmas, Forensic Psychology, and Therapeutic Jurisprudence*, 30 T. JEFFERSON L. REV. 455 (2008)).

¹⁷³ See e.g., Perlin, *supra* note 60, at 343, 349; Perlin, *supra* note 67; Michael L. Perlin, *Understanding the Intersection between International Human Rights and Mental Disability Law: The Role of Dignity*, in THE ROUTLEDGE HANDBOOK OF INTERNATIONAL CRIME AND JUSTICE STUDIES 191 (Bruce Arrigo & Heather Bersot, eds.) (2013)

¹⁷⁴ Michael L. Perlin, “The Ladder of the Law Has No Top and No Bottom”: How Therapeutic Jurisprudence Can Give Life to International Human Rights, 36 INT’L J.L. & PSYCHIATRY (forthcoming 2013).

¹⁷⁵ Perlin, *supra* note 37, at 36.

¹⁷⁶ See PERLIN, *supra* note 21, at 203-38; Perlin, *Guardians*, *supra* note 53, at 1187-89.

¹⁷⁷ But see, Perlin, *supra* note 174, manuscript at 36 (calling for, as part of a new TJ research agenda, the study of “the TJ implications of instituting reform of forensic facilities”).

¹⁷⁸ See BOB DYLAN, MASTERS OF WAR, on THE FREEWHEELIN’ BOB DYLAN (Sony Entertainment 1963), available at <http://www.bobdylan.com/us/songs/masters-war>.

In *Masters of War*, Bob Dylan sang with “hardness and anger” about the military-industrial complex¹⁷⁹ in ways that were “relentless [and] unforgiving.”¹⁸⁰ Oliver Trager writes of Dylan’s focus on the “reckless, mongering ways” of the war masters.¹⁸¹ There is, unfortunately, little, if any relevant scholarly literature that treats the issues at hand in the same way: relentlessly and unforgivingly. It is time to turn our attention to this problem and to take it seriously.

¹⁷⁹ HOWARD SOUNES, *DOWN THE HIGHWAY: THE LIFE OF BOB DYLAN* 164 (2001).

¹⁸⁰ DANIEL MARK EPSTEIN, *THE BALLAD OF BOB DYLAN: A PORTRAIT* 35 (2011).

¹⁸¹ OLIVER TRAGER, *KEYS TO THE RAIN: THE DEFINITIVE BOB DYLAN ENCYCLOPEDIA* 420 (2004).

On Torture, Ill-Treatment and People with Psychosocial and Intellectual Disabilities: Some Thoughts About the Report of the Special Rapporteur

ROBERT DINERSTEIN*

Abstract

This article explores the relationship between the Special Rapporteur's Report and the UN Convention on the Rights of Persons with Disabilities (CRPD), addressing in particular the Report's treatment of the rights of people with psychosocial and intellectual disabilities. Welcoming the Report's recognition that coercive treatment and confinement can amount to torture and ill-treatment as an important addition to the disability rights discourse, the article analyzes in particular two controversial aspects of the Report's characterization and interpretation of the CRPD. Specifically, the article proposes that the Report's characterization of the CRPD recognition of legal capacity in Article 12 is inconsistent and insufficiently protective of that right, and that its interpretation of Article 14 to ban all forms of coercive treatment on the basis of disability raises questions that require further thought and analysis.

Introduction

I am pleased to have the opportunity to contribute my observations on the recent Report of the Special Rapporteur on torture and other cruel, inhuman or degrading punishment, Juan E. Méndez.¹ The Special Rapporteur's Report is a wide-ranging examination of the kinds of abuses that can and do occur in health-care settings or the procedures that States use to confine or treat individuals in them. It closely analyzes these phenomena in the context of proscriptions against torture or cruel, inhuman or degrading treatment (ill-treatment). Critically, the Report attempts to link the protections against torture and ill-treatment of people with intellectual and psychosocial disabilities² with the rights guaranteed to these and other people with disabilities under the UN Convention on the Rights of Persons with Disabilities ("CRPD").³ The fit is not always a comfort-

*Professor of Law, American University, Washington College of Law.

¹ Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb. 11, 2013) [hereinafter "Special Rapporteur's Report"]. Further references in this article to the Special Rapporteur's Report are in the form of Special Rapporteur's Report, para. [].

² The Special Rapporteur's Report covers other vulnerable or marginalized groups, in a number of settings, but my focus here is on people with intellectual and psychosocial disabilities.

³ Convention on the Rights of Persons with Disabilities, Gen. A. Res. 61/106 (Dec. 13, 2006). See Special Rapporteur's Report, para. 60.

able one but the task could not be more important for people with disabilities, disability rights advocates, States, and academics and other legal commentators.

At some level, this report is a radical document. To use the terminology of the report itself (and a phrase that has become de rigeur in discussing the CRPD), it reflects a paradigm shift in its effort to apply concepts of torture and ill-treatment to a broad array of health-care settings.⁴ To be sure, the Special Rapporteur's Report is not written on a clean slate. It draws upon prior UN reports and developing though nascent jurisprudence of the UN Committee on the Rights of Persons with Disabilities⁵ to identify such common practices in institutions for people with intellectual and psychosocial disabilities as involuntary (and non-consensual) commitment, involuntary treatment, solitary confinement, seclusion, restraint, sterilization, electroshock treatment and psychosurgery as in some cases torture and in all cases ill-treatment. But the report is a major policy statement and in many ways a long-awaited one, as for too many years institutions for people with disabilities, whether psychiatric hospitals or social care homes, have benefited from describing serious institutional harm in euphemistic terms (where aggravated assaults are "abuse and neglect" or "unusual incidents," and solitary confinement is described as time out) that obfuscate their true significance and harm. As the Special Rapporteur notes, merely labeling practices therapeutic or medically necessary, or the result of financial constraints or good intentions, is not enough to remove them from scrutiny through the lens of torture or ill-treatment.⁶

There are a number of subjects that the Special Rapporteur's Report addresses, or positions it takes, that are relatively uncontroversial within mainstream disability rights thinking. In these areas, the Report can serve an important purpose in underlining their continuing significance as issues of concern to people with disabilities and their allies. Involuntary sterilization and forced abortions, subjection of people with disabilities to mental and physical abuse and sexual violence¹, and continued use of restraints and seclusion (the latter of which, in some cases, can constitute solitary confinement) cannot be justified under any theory of recognizing human dignity. As the Report trenchantly observes:

It is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities should apply in all places of deprivation of liberty, including in psychiatric and social care institutions. The environment of patient powerlessness and abusive treatment of persons with disabilities in which restraint and seclusion is used can lead to other non-consensual treatment, such as forced medication and electroshock procedures.⁷

The Report's acknowledgement of the powerlessness and stigma that many people with psychosocial and intellectual disabilities experience, in and out of institutional settings, provides a critical underpinning for understanding the cruel persistence of abusive practices toward these groups.

⁴ Special Rapporteur's Report, para. 15.

⁵ See Annual Report of the United Nations High Commissioner for Human Rights and Reports to the Office of the High Commissioner and the Secretary-General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, Human Rights Council, Tenth Sess., Agenda Item 2, A/HRC/10/48 (January 26, 2009); Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175 (July 28, 2008) (Special Rapporteur Manfred Nowak). Reports of the actions of the UN Committee on Rights of Persons with Disabilities, which has conducted ten sessions to date (with consideration of particular States starting in the fifth session, which was held from April 11-15, 2011), are available at http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD.

⁶ See Special Rapporteur's Report at paras. 20, 22, 33-35, 83.

⁷ *Id.*, para. 63.

Its recommendation that States replace forced treatment and commitment with community-based services “that respect the autonomy, choices, dignity and privacy of the persons concerned”⁸ is exactly right, irrespective of one’s position regarding whether any non-emergency imposition of treatment or confinement of people with disabilities can ever be justified. Moreover, as the Report notes, “community living, with support, is no longer [merely] a favourable policy development but an internationally recognized right.”⁹

In the remainder of this brief essay, however, I wish to address two more controversial or problematic aspects of the Special Rapporteur’s Report’s treatment of the rights of people with psychosocial and intellectual disabilities: its characterization of rights protected by the CRPD and its interpretations of CRPD provisions that, while plausible (and based on precedent), may lead to unintended consequences or at the least raise questions about how disability rights concepts operate in the real world. Specifically, the Report’s characterization of the CRPD’s recognition (in Article 12) of legal capacity is inconsistent and insufficiently protective of that right. Its adoption of an interpretation of Article 14 of the CRPD to ban all forms of coercive treatment on the basis of disability (including all forms of civil commitment without informed consent) raises questions that need further exploration. Moreover, there are internal inconsistencies in how the Report addresses both of these issues that could cause interpretive mischief unless they are resolved. These observations are offered in the spirit of the continuing dialogue that the Special Rapporteur’s Report has initiated and that the essays in this volume reflect.

The Special Rapporteur’s Report’s Treatment of Legal Capacity

The Special Rapporteur’s Report makes a number of important (and timely) observations about the extent to which people with psychosocial and intellectual disabilities are subjected to practices that deny them legal capacity and contribute to the abuses and indignities that they experience. It notes, for example, “the intimate link” between the deprivation of legal capacity and forced, discriminatory medical interventions in the lives of people with disabilities.¹⁰ It notes that the sense of powerlessness and dependency of people with disabilities in health-care settings is exacerbated by the “[d]eprivation of legal capacity when a person’s exercise of decision-making is taken away and given to others...” Its recommendations include the need for States to abrogate statutory provisions or practices that would authorize confinement or compulsory treatment of people with disabilities through guardianship and other forms of substituted decision-making,¹¹ a problem that has received increasing attention in human rights jurisprudence.¹² The Special Rapporteur’s Report reflects a solid understanding of how the deprivation of legal capacity creates an environment and set of circumstances in which abuse can thrive and complaints can go unheeded.

⁸ *Id.*, para. 89 (c).

⁹ *Id.*, para. 68 (citing CRPD/C/CHN/CO/1 and Corr. 1, paras. 92-93). I have interpolated the word “merely” because on a first reading the sentence might be thought to express opposition to community-based services, though, in context, it is clear that the intention is to elevate its importance from policy to a matter of right. The interpretation of community living as a fundamental right is based on Art. 19 of the CRPD, Living independently and being included in the community.

¹⁰ *Id.*, para. 30 (citing observations of the previous Special Rapporteur on Torture and the Committee on the Rights of Persons with Disabilities).

¹¹ *Id.*, para. 85 (e).

¹² *Stanev v. Bulgaria*, App. No. 36760/06, Eur. Ct. H.R. (2012); Oliver Lewis, *Stanev v. Bulgaria: On the Pathway to Freedom*, 19 (2) HUM. RTS. BRIEF 2 (Winter 2012); *Shtukaturov v. Russia*, App. No. 44009/05, Eur. Ct. H.R. (2008).

Paragraph 65 of the Report is worth quoting in full for its recognition of the problem of denying people their legal capacity and its consequences:

*Millions of people with disabilities are stripped of their legal capacity worldwide, due to stigma and discrimination, through judicial declaration of incompetency or merely by a doctor's decision that the person 'lacks capacity' to make a decision. Deprived of legal capacity, people are assigned a guardian or other substitute decision maker, whose consent will be deemed sufficient to justify forced treatment.*¹³

The Report recognizes that “[o]nce a determination of incapacity is made, the person’s expressed choices cease to be treated meaningfully,” and cites with approval the CRPD and interpretations by the Committee on the Rights of Persons with Disabilities of Articles 3 (a) and 12 of the CRPD to urge replacement of guardianship and other forms of substituted decision-making with supported decision-making “which respects the person’s autonomy, will and preferences.”¹⁴

So far, so good. These interpretations of legal capacity and the effect of its denial are fully consistent with Article 12 of the CRPD and the Concluding Observations the Committee on the Rights of Persons with Disabilities has issued to date.¹⁵ But, crucially, and perhaps inadvertently, the Special Rapporteur’s Report describes capacity as “a rebuttable presumption,”¹⁶ such that incapacity must be proven before a person can lose his or her right to make decisions. Actual practice in States around the world, however, has demonstrated that it is far too easy to overcome this presumption and deny capacity to people with disabilities to a shocking degree. Consequently, Article 12 of the CRPD does more than establish a rebuttable presumption of capacity: it establishes that everyone has legal capacity; that there is no distinction between legal capacity in theory and the capacity to act; and that there are no legitimate grounds on which capacity may be denied, no matter how stringent the process for doing so.¹⁷ It is in this context that the Committee on the Rights of People with Disabilities has consistently called on States to move from surrogate decision-making regimes such as guardianship to supported decision making. For whereas surrogacy requires a determination of loss of decision-making capacity to at least some extent, supported decision making uncouples the need for decision-making assistance (at the person’s request, and in a manner that reflects the person’s will and preferences) from such determinations and keeps the focus on the person as the primary decision maker.¹⁸ If there is a presumption of capacity, then, it is an irrebuttable one.

My guess is that the Special Rapporteur would not disagree with this interpretation of the CRPD, and seeing legal capacity as a non-derogable right is fully consistent with the above comments and recommendations about capacity and its absence that are in the Report. But precisely because States’ practices have demonstrated how easy it has been to overcome the presumption of capacity and authorize others to act for (and against) people with disabilities, clarification of this point is important.

¹³ Special Rapporteur’s Report, para. 65 (citing E/CN.4/2005/51, para. 79).

¹⁴ *Id.*, para. 27. I addressed the relationship between Article 12 of the CRPD and supported decision making in Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making*, 19 (2) HUMAN RIGHTS BRIEF 8 (Winter 2012).

¹⁵ See *supra*, note 5.

¹⁶ Special Rapporteur’s Report, para. 27.

¹⁷ See generally Dinerstein, *supra* note 14.

¹⁸ Committee on the Rights of Persons with Disabilities, Draft General comment on Article 12 of the Convention-Equal Recognition before the Law, CRPD/C/11/4 (Adopted by the Committee at its tenth session, September 2-13, 2013), available at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>. The Draft General comment is open for comments until February 21, 2014.

Non-consensual Confinement/Treatment under Article 14 of the CRPD

The Special Rapporteur's Report weighs in forcefully on an issue of ongoing importance to people with psychosocial disabilities and their allies: the role of non-consensual treatment and deprivation of liberty on the basis of disability. With the possible exception of denial of legal capacity (to which it is often connected), the imposition of treatment or confinement without the informed consent of the individual is the most pivotal issue people with psychosocial disabilities face. The relationship between consent and treatment strikes at the heart of the balance between individual liberty and autonomy on the one hand and society's desire to relieve unnecessary suffering on the other. Non-discrimination on the basis of disability means little if the presence of disability alone, whether based on diagnosis or perceived aberrant behavior, can serve as a basis to confine individuals against their will and abuse and neglect them with impunity.

The Special Rapporteur's Report accurately observes that "[i]n many countries where mental health policies and laws do exist, they focus on confinement of people with mental disabilities in psychiatric institutions but fail to effectively safeguard their human rights."¹⁹ In Paragraph 68, it lays out the essence of its interpretation of Article 14 of the CRPD:

*The Convention radically departs from this approach [civil commitment and compulsory institutionalization or confinement based on disability] by forbidding deprivation of liberty based on the existence of any disability, including mental or intellectual, as discriminatory. Article 14, paragraph 1 (b), of the Convention unambiguously states that 'the existence of a disability shall in no case justify deprivation of liberty.' Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished. This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care or treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.*²⁰

The Report then goes on to address non-consensual treatment and confinement in the context of torture and ill-treatment:

*Deprivation of liberty on grounds of mental illness is unjustified if its basis is discrimination or prejudice against persons with disabilities... As detention in a psychiatric context may lead to non-consensual psychiatric treatment, the mandate [of the Special Rapporteur] has stated that deprivation of liberty that is based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture (A/63/175, para. 65). In making such an assessment, factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.*²¹

Consistent with these observations, the Report's Recommendations include calling upon States to "[i]mpose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities" and to "[r]evise the legal provisions that allow detention on mental health grounds or in mental health facilities, and any coercive interventions or treatments in the mental

¹⁹ Special Rapporteur's Report, para. 67.

²⁰ *Id.*, para. 68 (citing A/HRC/10/48, paras. 48, 49).

²¹ *Id.*, para. 69 (citing Stop Torture in Healthcare, "Torture and ill-treatment of people with disabilities in healthcare settings," Campaign Briefing (2012)).

health setting without the free and informed consent by the person concerned,” adding that “[l]egislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished.”²²

At the same time as including this ringing denunciation of non-consensual treatment and confinement in all circumstances, however, the Report seems to accept a limited dangerousness or emergency exception to this rule. In Paragraph 69, the Special Rapporteur’s Report, while criticizing interpretations under the European Convention on Human Rights that would permit detention based on the severity of the person’s alleged mental illness, states that “the State must also show that detention is necessary to protect the safety of the person or of others. Except in emergency cases, the individual concerned should not be deprived of his liberty unless he has been reliably shown to be of ‘unsound mind.’”²³ Although, in context, it seems that the Report is criticizing the “unsound mind” basis of commitment, it is not clear if that criticism extends to commitment based on mental disability linked to dangerousness. If it is, as several commentators have noted, then there is a clear conflict between the jurisprudence under the European Convention and this proposed interpretation of the CRPD and the Convention against Torture.²⁴

Beyond the possible inconsistency, however, the crucial question is whether there is any exception to the rule that deprivation of liberty cannot be based on disability in whole or in part. As noted, the “no exceptions” interpretation has some significant support in the report of the UN High Commissioner and the Concluding Observations of the Committee on the Rights of Persons with Disabilities.²⁵ Although the relevant language of Article 14—States Parties must ensure that persons with disabilities “are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty”²⁶—could allow for an interpretation that such deprivation cannot be based “solely” on disability, Tina Minkowitz and others argue that the drafting of and contemporaneous debate regarding the Article makes it clear that such interpretations were considered and rejected.²⁷ The same might be said for an interpretation that Article 14 refers to the status of disability only; such an interpretation would seem inconsistent with the strong substantive thrust of the CRPD. In essence, no means no.

For these authorities, deprivation of liberty of people with disabilities can only be justified if it would be carried out in similar circumstances against people without disabilities. Thus, if a person with a disability were to be charged with a crime, the person would be subject to the operation of the criminal justice system in the same manner as a person without a disability who committed the same act. A person with a disability who committed an assault against another would be guilty of a crime and could be sentenced to a term of imprisonment or other sanction in the same way that a person without a disability could. However, because we do not detain individuals preventively just because we think they might commit such a crime, we could not use preventive detention

²² *Id.*, paras. 89 (b), (d).

²³ *Id.*, para. 69 (citing ECHR cases).

²⁴ See, e.g., Charles O’Mahony, *Legal capacity and detention: implications of the UN disability convention for the inspection standards of human rights monitoring bodies*, 16 (6) THE INT’L J. OF HUMAN RTS. 883 (2012); Peter Bartlett, *A mental disorder of a kind or degree warranting confinement; examining justifications for psychiatric detention*, 16 (6) THE INT’L J. OF HUMAN RTS. 831, 835 (2012).

²⁵ See *supra*, note 5, .

²⁶ CRPD, art. 14(1)(b).

²⁷ Tina Minkowitz has made this point in a number of settings, including at the workshop “In from the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century,” sponsored by the Open Society Foundations in Vancouver, British Columbia, Canada, April 29-May 3, 2011, which the author attended.

against people with disabilities merely because we think they might be dangerous to self or others if not confined.

What are the consequences of such a view? We do not have to look far to determine them. After the U.S. Supreme Court case of *O'Connor v. Donaldson* in 1975, civil commitment laws in the United States must require some version of dangerousness to self or others for involuntary confinement to be permissible.²⁸ In combination with a significant decrease in hospital beds for people with psychosocial disabilities (which may be due as much to a state's desire to cut costs as to its commitment to provide more humane treatment), and the proliferation of neuroleptic medications, the result is that many people with psychosocial disabilities have wound up in jails or prisons (convicted of offenses that might not have been charged or prosecuted in the days when civil commitment was more common), facilities that are woefully inadequate in the services they provide to this population.²⁹ As has been the case so often in the history of treatment of people with disabilities, we have pursued a policy that is more accurately described as transinstitutionalization than deinstitutionalization: jails and prisons have become the new mental hospitals.

Apart from these pragmatic concerns, there is another one that must be addressed. If we posit that everyone has legal capacity, and that no one can receive treatment to which he has not given free, informed consent, do we have any legitimate way to intervene in the lives of people whose very illness may prevent them from the desirability of seeking treatment? Granted, the history of this field is replete with doctors' tautological and overbroad assumptions that the very resistance to treatment or confinement demonstrates the individual's lack of insight into his or her condition such as to justify coercive intervention. History also has shown that loose standards such as "in need of care or treatment" can be used to justify the involuntary commitment of almost anyone. But to recognize these serious abuses is not the equivalent of concluding that there are never cases in which the person's illness interferes with her ability to consent to treatment.

As I write this essay, for example, people in the Washington, DC area have read reports just in the last week or so of several people apparently with a history of mental illness charged with horrific crimes involving murders of family members and strangers.³⁰ We do not know the full history of the alleged perpetrators—whether they sought treatment for their illness or whether they recognized they were ill. And by referencing these stories I do not by any means wish to be interpreted as arguing that people with psychosocial disabilities are more prone to violence than people without disabilities. (The research is clear that the risk of violence by people with psychosocial disabilities is very low, and, in the limited cases in which it is higher than the risk posed by people with disabilities (for example, when psychosocial disability is linked to substance abuse), the greater risk is violence against self—suicide—rather than others.) Rather, I mention them to point out that we have a long way to go before we can say that we have devised a system of health-care services that is extensive, of high-quality, humane, and built exclusively on the basis of free, informed consent by its users.

²⁸ *O'Connor v. Donaldson*, 422 U.S. 563 (1975).

²⁹ See, e.g., The disability Law Center of Virginia, *Broken Promises—The Failure of Mental Health Services in Virginia* (December 2013); Michael Martz, *Mental health debate widens to long-term care*, Richmond Times-Dispatch, Jan. 17, 2014.

³⁰ See, e.g., Dan Morse, *Prosecutor: Md. women held in toddlers' deaths called themselves 'demon assassins,'* WASH. POST, Jan. 21, 2014; Peter Hermann & Matt Zapotosky, *Bradford Elliott, suspect in fatal stabbing of father, 88, in Georgetown, dies of heart attack*, WASH. POST, Jan. 22, 2014; Petula Dvorak, *Devastating toll of mental illness demands our attention*, WASH. POST, Jan. 21, 2014; Peter Hermann & Luz Lazo, *Mother charged with killing newborn son in D.C. in November*, WASH. POST, Jan. 24, 2014; Dan Morse, *7-Eleven clerk in Montgomery County was slashed and stabbed 75 times*, WASH. POST, Jan. 24, 2014.

It would be unreasonable, of course, to expect the Special Rapporteur's Report to have resolved these vexing conundrums. One thing upon which all can agree, and which the Report supports, is the need for increased community-based services for people with psychosocial disabilities such that individuals might be more willing to seek needed treatment without having to be coerced to do so. But even if Article 14 of the CRPD in fact bans coercive confinement in all circumstances—a full discussion of which is beyond the scope of this essay—it is nevertheless true that involuntary civil commitment is not going to disappear overnight. Under the circumstances, entities responsible for interpretation of the CRPD and people with disabilities themselves (as well as their allies) will need to continue to struggle with the complexities of these issues.

The Special Rapporteur can and should be part of this struggle, and the Report reflects his willingness to engage with it. In particular, the Report's recognition that coercive treatment and confinement can amount to torture and ill-treatment is a welcome addition to the disability rights discourse. But that engagement needs to be mindful of where the pitfalls lie, especially in interpreting the CRPD.

Conclusion

The Report of the Special Rapporteur is an important milestone in the assertion of the human rights of people with disabilities in health-care settings. It does not shy away from the critical controversies in the disability rights field even if it does not fully resolve them. The very dialogue the Report has stimulated proves its inestimable value.

A Response to the Report by Juan E Mendez, Special Rapporteur on Torture, Dealing With Torture in the Context of Healthcare, as it Pertains to Nonconsensual Psychiatric Interventions

TINA MINKOWITZ*

Abstract

The recommendation by the Special Rapporteur on Torture for an absolute ban on nonconsensual psychiatric interventions is a major step forward. Other recommendations, such as, in particular, to revise legal provisions authorizing confinement or compulsory treatment in mental health settings and to replace commitment and forced treatment with services that meet needs expressed by persons with disabilities, are welcome in support of this key and unequivocal call for change. Furthermore, the report recognizes that these violations always amount to ill-treatment or torture and that reparation is due to persons who have been victimized. There remain issues in the report that merit further discussion in light of the Convention on the Rights of Persons with Disabilities, in particular the prohibition of any detention in mental health facilities, standards related to legal capacity and free and informed consent, the implications of a right to remedy and reparation, and stigmatized identities. Related areas of work, such as the rights of older persons and the rights of prisoners, can benefit from the abolitionist articulated in the report and are outlined for further exploration.

Highlights of the Recommendations and Report

1. Absolute Ban on Nonconsensual Psychiatric Interventions

The Special Rapporteur on Torture calls on all States to “impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as neuroleptics, the use of restraint and solitary confinement, for both long- and short-term application.”¹ He

*Tina Minkowitz, a lawyer admitted in the State of New York, is President of the Center for the Human Rights of Users and Survivors of Psychiatry, and International Representative of the World Network of Users and Survivors of Psychiatry. She played a role in drafting and negotiating the Convention on the Rights of Persons with Disabilities as a civil society representative on behalf of the World Network of Users and Survivors of Psychiatry and the International Disability Caucus.

¹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 89(b), Human Rights Council, U.N. Doc. A/HRC/22/53 (Feb. 1, 2013) [hereinafter *Report of the Special Rapporteur on Torture*] (by Juan E. Méndez).

asserts that the examples of torture and ill-treatment in health care settings described in the report “always amount at least to inhuman and degrading treatment, often they arguably meet the criteria for torture, and they are always prohibited by international law.”² Furthermore, he reminds us that the obligation of remedy and reparation extends to all acts of ill-treatment as well as torture, and that this includes “proactive measures required to prevent forced interventions.”³ The reparations framework “offers guidance as to opens new possibilities for holistic social processes that foster appreciation of the lived experiences of persons, including measures of satisfaction and guarantees of non-repetition, and the repeal of inconsistent legal provisions.”⁴ These recommendations present a clear and unequivocal call to action that vindicates decades-long human rights advocacy by users and survivors of psychiatry for the abolition of nonconsensual interventions; what remains is to put them into practice.

He adds, “The obligation to end forced psychiatric interventions based solely on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation.”⁵ The wording “based solely on disability” would appear superfluous, particularly given the Special Rapporteur’s rejection of the doctrine of medical necessity.⁶ However, it emphasizes the discriminatory character of the interventions on people with psychosocial disabilities;⁷ the immediate obligation is to enact an effective, absolute ban on all nonconsensual psychiatric interventions.

The Special Rapporteur emphasizes the connection between the use of restraint and solitary confinement and the creation of a context in which other forced interventions take place, such as forced medication and electroshock.⁸ He elaborates on the mandate’s rejection of the doctrine of medical necessity as an excuse for nonconsensual interventions⁹ and reiterates the standard that “intent, required in Article 1 of the Convention against Torture, can be effectively implied where a person has been discriminated against based on disability,”¹⁰ adding:

*The mandate has held that the discriminatory character of forced psychiatric interventions, when committed against persons with psychosocial disabilities, satisfies both intent and purpose required under the article 1 of the Convention against Torture, notwithstanding claims of ‘good intentions’ by medical professionals.*¹¹

Nonconsensual interventions that take place outside institutional settings under orders for compulsory treatment in the community¹² are not specifically mentioned by the Special Rapporteur but, nevertheless, fall under the recommendations for an absolute ban and the repeal of inconsistent legal provisions.

² *Id.* ¶ 81.

³ *Id.* ¶ 84.

⁴ *Id.*

⁵ *Id.* ¶ 89(b).

⁶ *See id.* ¶¶ 31-35 (rejecting the doctrine of “medical necessity”).

⁷ *See also id.* ¶ 58 (“In 2008 the mandate made significant strides in the development of norms for the abolition of forced psychiatric interventions on the basis of disability alone as a form of torture and ill-treatment.”). The 2008 report noted that abuses of psychiatry in the context of political repression, the fight against terrorism, and to change individuals’ sexual orientations were well documented but that it was necessary to address such abuses against persons with mental (psychosocial) and intellectual disabilities. Special Rapporteur on Torture, *Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment*, ¶¶ 62-63, U.N. Doc. A/63/175 (July 28, 2008) [hereinafter *Interim Report*].

⁸ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 63.

⁹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶¶ 31-35.

¹⁰ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 20.

¹¹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 32.

¹² Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶ 63.

2. Repeal of Legal Provisions Authorizing Confinement and Compulsory Treatment

The Special Rapporteur expands on obligations to conform the legal framework so as to “safeguard the free and informed consent on an equal basis for all individuals without any exception.... Any legal provisions to the contrary, such as provisions allowing confinement or compulsory treatment in mental health settings, including through guardianship and other substituted decision-making, must be revised.”¹³ This is echoed by a recommendation to “revise legal provisions authorizing detention on mental health grounds or in mental health facilities, or any coercive interventions or treatments in the mental health setting without free and informed consent of the person concerned. Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished.”¹⁴ States must “replace forced treatment and commitment by services in the community . . . [that] meet needs expressed by persons with disabilities and respect the autonomy, choices, dignity and privacy of the person concerned.”¹⁵ While the term “revise” in paragraphs 85(e) and 89(d) is potentially ambiguous, the context (including the second sentence in paragraph 89) implies it is used synonymously with “repeal,”¹⁶ and the terminology also reflects customary practices in the discourse on torture and ill-treatment.¹⁷ Inconsistencies in the body of the report regarding detention on mental health grounds must be resolved by referring to the CRPD, which requires repeal of all such legal provisions. See section two below for further discussion on this topic.

The report, amplifying on the standards articulated in 2008, finds that deprivation of liberty based on disability, which inflicts severe suffering, falls under the scope of the Convention against Torture: “Factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.”¹⁸ As such detention is prohibited by the CRPD, and the Special Rapporteur recognizes that all the abuses mentioned in the report amount to ill-treatment or torture and always violate international law,¹⁹ there should be no need for a case-by-case assessment on this threshold question, but the factors listed are relevant as support to the systemic recommendations and for the purpose of providing reparations to individuals.

3. Free and Informed Consent of the Person Concerned; Respecting Legal Capacity

The formulation “free and informed consent of the person concerned,” as used in paragraphs 85(e) and 89(d), adopts a standard set earlier by the mandate²⁰ and by the Committee on the Rights of Persons with Disabilities,²¹ which concisely incorporates into the standard for health care an

¹³ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 85(e).

¹⁴ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(d).

¹⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(c).

¹⁶ See also Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 84.

¹⁷ See Committee against Torture, General Comment No. 3, *Implementation of Article 14 by States Parties*, ¶ 18, U.N. Doc. CAT/C/GC/3 (Dec. 13, 2012) [hereinafter General Comment 3].

¹⁸ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 69; See also Special Rapporteur on Torture, Statement by Mr. Juan E. Méndez, at 5, (Mar. 4, 2013) [hereinafter Statement to Council], <http://www.madinamerica.com/wp-content/uploads/2013/03/torture.pdf>.

¹⁹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 81.

²⁰ Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶¶ 38, 44, 47, 59, 60, 61, 63, 64.

²¹ Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations of the Committee on the Rights of Persons with Disabilities, ¶ 36 U.N. Doc. CRPD/C/ESP/CO/1 (Oct. 5, 2010) [hereinafter Concluding Observations on Spain]; Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations of the Committee on the Rights of Persons with Disabilities, ¶¶ 26, 38 U.N. Doc. CRPD/C/CHN/CO/1 (Feb. 8, 2011) [hereinafter Concluding

obligation to respect the legal capacity of all individuals to give or withdraw consent to medical treatment.²² While this might have been implicit in most contexts, prior to the CRPD the right was commonly denied to persons with disabilities, who were deemed to lack the requisite capacity.

Incorporation of the CRPD standard on legal capacity is reinforced by the recommendation to “invest in and offer marginalized individuals a wide range of voluntary supports that enable them to exercise their legal capacity and that fully respect their individual autonomy, will and preferences.”²³ The report recognizes that the Committee on the Rights of Persons with Disabilities has called for “the replacement of substituted decision-making by supported decision-making, which respects the person’s autonomy, will and preferences”²⁴ and that “fully respecting each person’s legal capacity is a first step in the prevention of torture and ill-treatment.”²⁵

The report mentions the decision-making rights of children with disabilities: “[A]n actual or perceived disability may diminish the weight given to the child’s views in determining their best interests, or may be taken as the basis of substitution of determination and decision-making by parents, guardians, care givers or public authorities.”²⁶ The reference to availability of support for the exercise of legal capacity for marginalized groups applies to children with disabilities as well as to adults, as provided in CRPD Article 7.3 (age- and disability-appropriate assistance to exercise the rights recognized).

Paragraph 66 of the report posits a limitation on free and informed consent in situations of life-threatening emergencies and discusses its relationship to legal capacity. This should not impact freedom from nonconsensual psychiatric interventions, but the standard proposed by the Special Rapporteur should be adjusted to conform with CRPD Article 12. See further discussion on this below.

Inconsistency in Approach to Mental Health Detention

The recommendations oppose “detention on mental health grounds or in mental health facilities,” stating that legal provisions authorizing such detention or compulsory treatment and interventions must be revised and that disability-based institutionalization without free and informed consent must be abolished.²⁷ The report reflects in many places an understanding that there is no distinction between disability and mental health issues or psychiatric labels and that the term “psy-

Observations on China]; Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Periodic Report of Hungary, adopted by the Committee in its eighth session (17-28 September 2012), ¶ 28, U.N. Doc. CRPD/C/HUN/CO/1 (Oct. 22, 2012) [hereinafter Concluding Observations on Hungary].

²² Committee on the Rights of Persons with Disabilities, Concluding Observations on Hungary, *supra* note 21, ¶ 26; Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of Paraguay, adopted by the Committee at its ninth session 15-19 April 2013, ¶ 30, U.N. Doc. CRPD/C/PRY/CO/1 (May 15, 2013) [hereinafter Observations on Paraguay]; See also Special Rapporteur on Torture, Statement to Council, *supra* note 18, at 4.

²³ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 85(f).

²⁴ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 27; See Concluding Observations on Spain, *supra* note 21, ¶ 34; Committee on the Rights of Persons with Disabilities, Consideration of Reports Submitted States Parties under Article 35 of the Convention, Peru, ¶ 25 U.N. Doc. CRPD/C/PER/CO/1 (Apr. 20, 2012); Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of Argentina as approved by the Committee at its eighth session (17-28 September 2012), ¶ 20, U.N. Doc. CRPD/C/ARG/CO/1 (Oct. 8, 2012) [hereinafter Observations on Argentina]; Concluding Observations on China, *supra* note 21, ¶ 22; Committee on the Rights of Persons with Disabilities, Concluding Observations on Hungary, *supra* note 21, ¶ 30.

²⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, at 15.

²⁶ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 80.

²⁷ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶¶ 85(e) and 89(d).

chosocial disability” covers all persons who come in contact with mental health services and who experience resulting disablement, including that caused by legal and medical discrimination.²⁸ The Special Rapporteur refers to the advances made by the 2008 mandate “in the development of norms for the abolition of psychiatric interventions on the basis of disability alone as a form of torture and ill-treatment.”²⁹ The 2008 report characterized such interventions as being “for treatment of a mental condition.”³⁰ He asserts, citing a study by the Office of the High Commissioner for Human Rights,³¹ that the abolition of legislation authorizing disability-based institutionalization without the person’s free and informed consent

*must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.*³²

It is then inconsistent to find in paragraph 69 that in the opinion of the Special Rapporteur, “the severity of the mental illness is not by itself sufficient to justify detention; the State must also show that detention is necessary to protect the safety of the person or of others.” The Special Rapporteur reconsidered his position in his statement to the Human Rights Council on March 4, 2013,³³ saying, “Deprivation of liberty on grounds of mental illness is unjustified.... I believe that the severity of the mental illness cannot justify detention nor can it be justified by a motivation to protect the safety of the person or of others.”

While the Special Rapporteur’s statement to the Council was welcome, it may be insufficient to dispel the confusion created by these inconsistencies. This is particularly unfortunate in light of the fact that the prohibition of detention on mental health grounds or in mental health facilities represents a departure from earlier approaches in international human rights law, so that promotion of the new standard based on the CRPD is much needed. The statement is distributed less widely than the report and is only available on the password protected UN Extranet and on NGO websites.

Given the inconsistency, it is worthwhile to review the basis for concluding that all mental health detention is unjustified under the CRPD, a core treaty in the international human rights framework, which in turn provides authoritative guidance throughout the UN system on the rights of persons with disabilities.

CRPD Article 14(1)(b) requires states to ensure that “the existence of a disability shall in no case justify a deprivation of liberty.”³⁴ The travaux préparatoires reflect the following summation of discussion on the provision in question:

The Chair noted proposals to amend 14(1)(b), however he asserted that the changes were either not substantive or represented issues that had already been thoroughly debated. He believed that the text as written is reasonably balanced and should be retained. This is essentially a non-discrimination pro-

²⁸ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, supra note 1, ¶¶ 32, 57, 58, 63, 64, 66, 68, 80, 85, 89.

²⁹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, supra note 1, ¶ 58.

³⁰ Special Rapporteur on Torture, *Interim Report*, supra note 7, ¶ 63.

³¹ U.N. High Commissioner for Human Rights, *Thematic study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*, ¶¶ 48, 49 U.N. Doc. A/HRC/10/48 (Jan. 26, 2009) [hereinafter OHCHR Study].

³² Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, supra note 1, ¶ 58.

³³ Special Rapporteur on Torture, *Statement to Council*, supra note 18, at 5.

³⁴ Convention on The Rights of Persons with Disabilities, art. 14(1)(b), May 3, 2008, 2515 U.N.T.S. 3.

*vision. The debate has focused on the treatment of persons with disabilities on the same basis as others. Persons with disabilities who represent a legitimate threat to someone else should be treated as any other person would be. The Chair believed that the text achieves this balance and encouraged informal discussion if delegates still had concerns.*³⁵

As a non-discrimination provision, paragraph 1(b) works in tandem with paragraph 2 of Article 14, which entitles persons with disabilities to equal guarantees as others, and to the provision of reasonable accommodation, when deprived of their liberty under any process. The balance alluded to by the Chair comes from the fact that persons with disabilities are subject to criminal proceedings and other lawful proceedings that may result in detention, on an equal basis with other members of society.³⁶ Detention on mental health grounds is a regime of detention inextricably linked to the existence of a disability and cannot by any stretch of the imagination be interpreted as neutral or as applicable to all persons.

As noted by the Office of the UN High Commissioner for Human Rights in its 2009 thematic study on the CRPD, negotiating parties specifically rejected proposals to create a loophole allowing detention based on disability plus other factors so that only detention based “solely” on disability would have been prohibited.

*As a result, unlawful detention encompasses situations where the deprivation of liberty is grounded in the combination between a mental or intellectual disability and other elements such as dangerousness, or care and treatment. Since such measures are partly justified by the person's disability, they are to be considered discriminatory and in violation of the prohibition of deprivation of liberty on the grounds of disability, and the right to liberty on an equal basis with others prescribed by article 14.*³⁷

Since its earliest sessions, the Committee on the Rights of Persons with Disabilities has consistently pronounced that laws permitting the deprivation of liberty of people with psychosocial disabilities must be repealed, including “provisions which authorize involuntary internment based on an apparent or diagnosed disability,” and that mental health services must be based on free and informed consent of the person concerned.³⁸ In its most recent session of September 2013, the Committee has provided unmistakable guidance that confirms the prohibition of mental health detention. In its Concluding Observations on Austria, the Committee stated explicitly that legislation that authorizes mental health detention based on a “forecast that the person will cause harm

³⁵ UN Convention on the Rights of Persons with Disabilities Ad Hoc Committee, Daily Summary of Discussion at the Seventh Session, 19 January 2006, (Vol. 8 #4), available at <http://www.un.org/esa/socdev/enable/rights/ahc7sum19jan.htm>.

³⁶ U.N. High Commissioner for Human Rights, OHCHR Study, *supra* note 31, ¶ 47, 49.

³⁷ U.N. High Commissioner for Human Rights, OHCHR Study, *supra* note 31, ¶ para 48. See also Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶ 64.

³⁸ Committee on the Rights of Persons with Disabilities, Concluding Observations on Spain, *supra* note 21, ¶ 36; Committee on the Rights of Persons with Disabilities, Concluding Observations on China, *supra* note 21, ¶¶ 26, 38; Committee on the Rights of Persons with Disabilities, Concluding Observations on Hungary, *supra* note 21, ¶ 28. In its Concluding Observations on Argentina (Examination of Reports Presented by States Parties under Article 35 of the Convention, Concluding Observations of the Committee on the Rights of Persons with Disabilities, ¶¶ 23-24, 41-42, U.N. Doc. CRPD/C/ARG/CO/1, September 27, 2012) and Paraguay (Concluding Observations on the Initial Report of Paraguay, ¶36, U.N. Doc. CRPD/C/PRY/CO/1, May 15, 2013) the Committee's approach was somewhat different, praising the “human rights basis” of Argentina's national mental health law without considering whether the law authorized involuntary commitment and forced interventions, and urging Paraguay to establish mechanisms whereby persons with disabilities can exercise legal capacity in the process of committal to institutions. With respect to Paraguay, it is likely that the Committee meant “committal” not in the sense of an involuntary measure but rather as admission to a facility, and was addressing the problem of committal based on the consent of substitute decision-makers. With its most recent set of Concluding Observations, the Committee has put any doubts to rest.

to self or others” conflicts with Article 14, and that the State Party should “take all necessary legislative, administrative and judicial measures to ensure that no one is detained against their will in any kind of mental health facility.”³⁹ The Concluding Observations on El Salvador and on Australia have been similarly explicit as to the prohibition of any mental health detention and the rejection of standards that “attribute to disability the possibility to cause harm to the person or others, or that ascribe to it the need for care and treatment.”⁴⁰

As recognized by the Special Rapporteur and his predecessor, the CRPD supersedes earlier non-binding standards found in the 1991 Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care [MI Principles],⁴¹ which had accepted involuntary treatment and involuntary confinement. Both Rapporteurs acknowledge further that mental health detention is a significant cause of suffering that can amount to ill-treatment or torture in its own right.⁴² Detention is part and parcel of nonconsensual psychiatric interventions;⁴³ detention constitutes the primary physical and legal force used to accomplish forced drugging and forced electroshock. Without a ban on psychiatric detention, any attempt to ban nonconsensual psychiatric interventions, as called for unambiguously by the Rapporteur in paragraph 89(b), would prove ineffective.

The recommendations and report, together with the statement to the Council, substantially advance the development of jurisprudence for the protection of the rights of persons with psychosocial disabilities, including the abolition of detention on mental health grounds.

Nevertheless the inconsistency in paragraph 69 is a flaw that will surely be seized upon as a justification for inaction by governments that resist the obligations imposed on them by the CRPD. The Special Rapporteur may wish to publicize his statement to the Council along with the report to avoid a potential source of confusion not only about his own recommendations but also about the extent to which the human rights framework accepts the authoritative guidance of the CRPD.

Additional Issues Raised in the Report

1. Rejection of the Doctrine of Medical Necessity

The Special Rapporteur rejects the doctrine of medical necessity, which has been an obstacle to protection against abuses in the context of health care. He recalls, “The mandate has held that the discriminatory character of forced psychiatric interventions, when committed against persons with psychosocial disabilities, satisfies both intent and purpose required under the arti-

³⁹ Committee on the Rights of Persons with Disabilities, Concluding Observations on Austria, U.N. Doc. CRPD/C/AUT/CO/1, ¶ 29, 30.

⁴⁰ Committee on the Rights of Persons with Disabilities, Concluding Observations on El Salvador, CRPD/C/SLV/CO/1, ¶ 32 [my translation], see also Committee on the Rights of Persons with Disabilities, Concluding Observations on Australia, ¶ 34. See Minkowitz, UN Prohibition of Psychiatric Commitment: Review and Analysis, <http://www.madinamerica.com/2013/10/un-leaves-no-doubt-end-mental-health-detention/> (accessed October 15, 2013) for further information.

⁴¹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture, supra* note 1, ¶ 58; Special Rapporteur on Torture, *Interim Report, supra* note 7, ¶ 44; G.A. Res. 46/119, annex (1991), U.N. Doc. A/RES/46/119 (Dec. 17, 1991).

⁴² See Special Rapporteur on Torture, *Interim Report, supra* note 7, ¶ 65; Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture, supra* note 1, ¶ 69.

⁴³ *Id.*

cle 1 of the Convention against Torture, notwithstanding claims of 'good intentions' by medical professionals."⁴⁴

Méndez specifically calls into question the case of *Herczegfalvy v. Austria*, in which the European Court adopted the doctrine of medical necessity and held that force-feeding, force-drugging with neuroleptics, and handcuffing of the person to a "security bed" could be justified as "medically necessary" and in keeping with psychiatric practice at the time.⁴⁵ The *Herczegfalvy* case is emblematic of a disturbing callousness towards the subjective experience of persons with disabilities that characterizes the medical model of disability, which is not merely a faulty theoretical construct, but an assertion of unequal power relations.

Rejection of the medical necessity doctrine is supported by the standard articulated by the mandate in 2008 to distinguish between "fully justified" medical treatments and those that are unjustified and therefore "may constitute torture and ill-treatment." The standard contains three main elements: intrusive and irreversible nature of the medical treatments; the treatments' lack of a therapeutic purpose or their aim to correct or alleviate a disability; and enforcement or administration without the free and informed consent of the person concerned. Significantly, this standard treats the aim of correcting or alleviating a disability as being suspect in the same way as lack of a therapeutic purpose.

The Special Rapporteur omits the aim of correcting or alleviating a disability from his discussion in paragraph 32 of the report but restores this element of the standard in his statement to the Council. It may be appropriate to classify forced psychiatric interventions as a subset of non-therapeutic forced medical interventions; as the Special Rapporteur notes, in many instances of abuse in the healthcare context, "the explicit or implicit aim of inflicting punishment, or the objective of intimidation, often exist alongside ostensibly therapeutic aims."⁴⁶ Nevertheless, an important point is missed unless the standard is appreciated in its entirety. The aim of correcting or alleviating a disability is the primary reason nonconsensual psychiatric interventions against persons with psychosocial disabilities are discriminatory in nature,⁴⁷ irrespective of whether the treatment is considered therapeutic by medical professionals. It is also discriminatory because of the failure to apply standards that recognize forced psychiatric interventions as torture and ill-treatment when performed on non-disabled individuals, to persons with disabilities.⁴⁸

Psychiatric interventions can be considered non-therapeutic in another sense, similarly to abortion and sterilization, which are considered non-therapeutic when aimed at preventing or ending a pregnancy.⁴⁹ While such services may be necessary to the health and well-being of the individual who desires and freely consents to them, they do not treat any pathology. Similarly, a person who seeks help for psychic pain or distress must be provided with desired services that are experienced

⁴⁴ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 32.

⁴⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 34.

⁴⁶ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 22.; *see also* Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶ 63; Tina Minkowitz, *The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions*, 34 SYRACUSE J. INT'L L. & COM. 2 (2007) [hereinafter *Nonconsensual Psychiatric Interventions*].

⁴⁷ *See* Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 32.

⁴⁸ *See, e.g.*, Concluding Observations of the Committee against Torture, Turkmenistan, ¶ 17 U.N. Doc. CAT/C/TKM/CO/1, June 15, 2011. *See also* Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 119, Commission on Human Rights, U.N. Doc. E/CN.4/1986/15 (Feb. 19, 1986) (stating as a general principle that administration of neuroleptic drugs is a form of physical torture).

⁴⁹ *See* Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶¶ 40, 47.

as necessary to the person's health and well-being, without resorting to misleading metaphors that characterize such distress as a disease entity.⁵⁰

2. Legal Capacity

The right to enjoy legal capacity, guaranteed to persons with disabilities on an equal basis with others in CRPD Article 12,⁵¹ is necessary to safeguard free and informed consent as a means of protecting persons with disabilities against intrusive, irreversible and harmful medical interventions, amounting to torture and ill-treatment.⁵² With legal capacity, we are recognized as persons with subjectivity and voice; without it, human beings are reduced to mere objects in the eyes of the law and can be abused with impunity.

The Special Rapporteur addresses legal capacity and informed consent as a guiding principle and acknowledges that the CRPD changes the normative framework relating to legal capacity as a matter of international law.⁵³ He adopts the standards that free and informed consent in the mental health context must be "of the person concerned"⁵⁴ and that legal provisions allowing the authorization of confinement or compulsory treatment by guardians and substitute decision-makers must be revised.⁵⁵ He recommends that States "invest in and offer marginalized individuals a wide range of voluntary supports that enable them to exercise their legal capacity and that fully respect their individual autonomy, will and preferences."⁵⁶

Yet the discussion of legal capacity in paragraph 27 and later in paragraph 66 raises some questions that warrant further exploration in light of the underlying values and jurisprudence of the Committee on the Rights of Persons with Disabilities.

Paragraph 27 is coherent if it is read as describing first the law prior to the CRPD, and then a statement of the CRPD requirements. The paragraph begins, "In all legal systems, capacity is a condition assigned to agents that exercise free will and choice and whose actions are attributed legal effects. Capacity is a rebuttable presumption; therefore, 'incapacity' has to be proven before a person can be designated as incapable of making decisions." While this is an accurate description

⁵⁰ Joanna Moncrieff, *The Myth of the Chemical Cure: The Politics of Psychiatric Drug Treatment*, presentation at UNE Center for Global Humanities, available at <http://www.youtube.com/watch?v=IV1S5zw096U>.

⁵¹ Convention on the Rights of Persons with Disabilities, *supra* note 34, at art. 12 ("1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests. 5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.")

⁵² See Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶¶ 30, 65; Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶ 50.

⁵³ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 27-30.

⁵⁴ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(d).

⁵⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 85(e).

⁵⁶ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 85(f).

of legal capacity prior to the CRPD, it is incorrect under the CRPD to characterize capacity as a “rebuttable presumption.”

The paragraph continues, “Once a determination of incapacity is made, the person’s expressed choices cease to be treated meaningfully,” and goes on to describe the normative shift made by the CRPD:

One of the core principles of the Convention on the Rights of Persons with Disabilities is “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (art. 3 (a)). The Committee on the Rights of Persons with Disabilities has interpreted the core requirement of article 12 to be the replacement of substituted decision-making regimes by supported decision-making, which respects the person’s autonomy, will and preferences.⁵⁷

The normative shift made by the CRPD has implications for the concept of legal capacity that were not drawn out by the Special Rapporteur. The Committee on the Rights of Persons with Disabilities holds that a supported decision-making system must include “recognition of all persons’ legal capacity and right to exercise it”⁵⁸ and must be “in full conformity with article 12 of the Convention, including with respect to the individual’s right, on their own, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work, and to choose their place of residence.”⁵⁹

In this framework, the status of legal capacity is assigned to all persons, and it includes all rights (and responsibilities) associated with that status. The presumption of capacity is not rebuttable, there is no determination of incapacity, and every person’s expressed choices are treated as meaningful. Rather than treating difficulties in exercising legal capacity as a legal matter warranting restriction of the individual’s exercise of legal capacity—which adds legal obstacles to the practical difficulties faced by the individual—such difficulties are treated as a practical matter to be met with support and accommodation.⁶⁰

The obligation to treat all persons’ expressed choices as meaningful is particularly significant in the context of health care. The Special Rapporteur recognizes that “fully respecting each person’s legal capacity is a first step in the prevention of torture and ill-treatment”⁶¹ and that “the intimate link between forced medical interventions based on discrimination and the deprivation of legal

⁵⁷ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 27; see Concluding Observations on Spain, *supra* note 21.

⁵⁸ Concluding Observations on China, *supra* note 21, ¶ 22. Additional elements of a supported decision-making system include “accommodations and support where necessary to exercise legal capacity;” “regulations to ensure that support respects the person’s autonomy, will and preferences and establishment of feedback mechanisms to ensure that support is meeting the person’s needs;” and “arrangements for the promotion and establishment of supported decision-making.” *Id.*

⁵⁹ Committee on the Rights of Persons with Disabilities, Concluding Observations on Hungary, *supra* note 21, ¶ 26; see also Committee on the Rights of Persons with Disabilities, Observations on Paraguay, *supra* note 22, ¶ 30.

⁶⁰ Concluding Observations on China, *supra* note 21, ¶ 32(b). CRPD Articles 2, 5 and 13 set out a definition of reasonable accommodation and the duty to provide accommodation generally and in the context of access to justice, which is closely related to the exercise of legal capacity. The duty to provide access to support for the exercise of legal capacity is found in Article 12(3). Convention on the Rights of Persons with Disabilities, *supra* note 34, at art. 2, 3, 12, 13; see also Tina Minkowitz, *Norms and Implementation of CRPD Article 12*, (Sept. 18, 2010), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2037452 [hereinafter Norms and Implementation].

⁶¹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, at 15.

capacity has been emphasized both by the Committee on the Rights of Persons with Disabilities and the previous Special Rapporteur on the question of torture.⁶²

In paragraph 66, the Special Rapporteur says:

As earlier stated by the mandate, criteria that determine the grounds upon which treatment can be administered in the absence of free and informed consent should be clarified in the law, and no distinction between persons with or without disabilities should be made. Only in a life-threatening emergency in which there is no disagreement regarding absence of legal capacity may a health-care provider proceed without informed consent to perform a life-saving procedure. From this perspective, several of the 1991 Principles may require reconsideration as running counter to the provisions of the Convention on the Rights of Persons with Disabilities (A/63/175, para. 44).⁶³

The mandate's 2008 report recommended that States "issue clear and unambiguous guidelines in line with the Convention [on the Rights of Persons with Disabilities] on what is meant by 'free and informed consent',"⁶⁴ and did not address any situation in which treatment may be administered without such consent. Nevertheless, the Special Rapporteur raises that question here and answers it with a narrow proposal, limiting treatment without consent to life-saving procedures performed in a life-threatening emergency, "in which there is no disagreement regarding the absence of legal capacity." The criterion "absence of legal capacity" is problematic under the CRPD and should not be used. (In addition, it is ambiguous as to whether "no disagreement" refers to third-party observers only or if it means that a person's objection will prevail over others who agree that she or he is incapable.) As stated above, the CRPD does away with incapacity determinations and treats a person's expressed choices as meaningful. Even in a life-threatening emergency, free and informed consent of the person concerned is the rule to be followed; however, if the person is expressing no choice, there should be a default assumption in favor of preserving life.

Guidance is then needed as to when a life-threatening emergency exists and what measures qualify as life-saving procedures, which should be performed by default if the person's choice legitimately cannot be discerned. This cannot be the case for psychiatric interventions that have the purpose and effect of altering consciousness and behavior; such interventions are never life-saving in an immediate sense of preventing an otherwise imminent death. Psychosocial crises, while they may include risky behavior or destructive acts, are not life-threatening emergencies that, construed narrowly, justify emergency attention from health-care providers. The kind of support needed in such crises, including suicidal acts or acts of self-harm, is open-ended and focuses on the person and not the act.⁶⁵ These are acts of a person and not mere symptoms of a health condition; to treat them as the latter disrespects the right to legal capacity and negates an individual's personhood and agency.

When a person has attempted suicide or engaged in self-harm of a life-threatening nature, and is accepting or not refusing medical attention, life-saving procedures should be promptly undertaken. It should be noted that advocates often report cruel treatment of individuals who have self-harmed or attempted suicide; they are denied treatment for their injuries or denied pain relief.

⁶² Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶ 50; Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 30.

⁶³ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 66 (internal citations omitted).

⁶⁴ Special Rapporteur on Torture, *Interim Report*, *supra* note 7, ¶ 74.

⁶⁵ See Shery Mead, IPS: A Personal Retrospective, available at: http://www.intentionalpeersupport.org/documents/personal%20story.2%20_1_.pdf; see also David Webb, *Thinking About Suicide: Contemplating and COMPREHENDING THE URGE TO DIE* (2010).

Such actions also clearly constitute torture or ill-treatment. Attention of the same quality as in other circumstances must be provided, and if the individuals are perceived as persons with psychosocial disabilities, failure to do so constitutes discrimination based on disability.⁶⁶

3. Reparations

The duty to provide remedy and reparation to victims of nonconsensual psychiatric interventions,⁶⁷ which is set out in this report for the first time by any human rights mechanism,⁶⁸ is deeply gratifying to survivors. Survivors have lived with grief and losses that are not acknowledged by those around them, and expression of these deep and often buried emotions is violently suppressed when it is labeled as “symptomatic” of mental illness and “treated” with more forced interventions. Many survivors live with a constant fear that the violations will be repeated, and they often are. The prospect of individual and collective reparation is significant, even if it is a long way from being realized.

The right to reparation derives from the right to a remedy for violations, which is prescribed in Article 14 of the Convention against Torture and in other instruments. In 2006, the United Nations adopted “Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law [Basic Guidelines].”⁶⁹ The Guidelines include five forms of reparation: restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition.⁷⁰ States have an obligation to provide reparation for “acts or omissions which can be attributed to the State and constitute gross violations of international human rights law or serious violations of international humanitarian law.”⁷¹

In 2012, the Committee against Torture addressed the scope of States’ obligations under CAT Article 14. The Committee clarified that the Article applies to acts of ill-treatment as well as torture and recognized the Basic Guidelines as an outline of the “elements of full redress,” including the five forms of reparation.⁷²

Victimized persons have an active role to play in the redress process⁷³ and are entitled to be treated sensitively to prevent re-victimization and stigmatization.⁷⁴ In addition, persons who are marginalized and made vulnerable on the basis of identities including “mental or other disability” are entitled to rules of evidence and procedure that ensure their testimony is given equal weight with other testimony and that “prevent the introduction of discriminatory evidence and harassment of victims and witnesses.”⁷⁵

In adopting reparation measures, States need to work closely with survivors of nonconsensual psychiatric interventions and their representative organizations.⁷⁶ Survivors’ voices need to pre-

⁶⁶ See Convention on the Rights of Persons with Disabilities, *supra* note 34, at art. 25.

⁶⁷ See also Tina Minkowitz, *Forced psychiatric interventions: Right to Remedy and Reparation*, OPEN MIND, at 14 (January & February 2012); Tina Minkowitz, *Reparations: It is Conceivable*, MAD IN AMERICA (Dec. 3, 2012), <http://www.madinamerica.com/2012/12/reparations-it-is-conceivable/>.

⁶⁸ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 84.

⁶⁹ G.A. Res. 60/147, U.N. Doc. A/RES/60/147 (Mar. 21, 2006) [hereinafter Basic Guidelines].

⁷⁰ *Id.* ¶¶ 18-23.

⁷¹ *Id.* ¶ 15.

⁷² General Comment 3, *supra* note 17, ¶ 6.

⁷³ General Comment 3, *supra* note 17, ¶ 4.

⁷⁴ General Comment 3, *supra* note 17, ¶ 33.

⁷⁵ General Comment 3, *supra* note 17, ¶ 31-33.

⁷⁶ See also Convention on the Rights of Persons with Disabilities, *supra* note 34, at art. 4(3).

dominate in collaborative efforts, and their leadership needs to be respected when identifying violations and devising appropriate remedies. The diverse ways that survivors communicate about the harm done to them, the difficulty that they may experience in telling their stories, and their choices about public disclosure, need to be fully honored. Such diversity needs to be appreciated in its own right, on its own terms, and not reduced to a stereotype of “psychosocial disability.” Furthermore, survivors’ choices regarding language used to describe themselves and their experiences need to be respected.

The repeal of inconsistent legal provisions is among the measures required to guarantee non-repetition of violations.⁷⁷ This applies both to provisions that directly facilitate acts of torture and ill-treatment and to laws that marginalize a group of persons, making them vulnerable to serious violations.⁷⁸ As the Committee said, the amendment of relevant laws may be needed to “transform social relations that may be the underlying causes of violence.”⁷⁹

The reparations framework thus supplies another foundation for the obligation to repeal all legal provisions that authorize mental health detention and nonconsensual interventions, including those based on substitute consent following a determination of incapacity. Complementary reforms must also be undertaken in line with the CRPD to ensure full legal capacity and eliminate legal barriers and discrimination facing persons with psychosocial disabilities in aspects of life such as political participation (voting and standing for election), family and relationships (sexuality, marriage and parenting), legal proceedings (participation as a party or witness), finances, free and informed consent in health care, and freedom to choose one’s residence. In addition, the legal framework should ensure that civil remedies are available to victims of nonconsensual psychiatric interventions and detention and that these violations also constitute offenses under the criminal law.⁸⁰

Beyond legal reform, there is a need for considerable change with regard to services offered and programs available to meet diverse needs that may be expressed by persons with psychosocial disabilities. Such services and supports must be provided in community settings and must not resemble institutional care; they must respect the autonomy, choices, dignity and privacy of the person concerned; and they must include a wide range of options, with an emphasis on non-medical alternatives including peer support and personal assistance. Resources must be shifted to make these changes effective.⁸¹

Individual survivors, or their chosen family in the case of victims who did not survive, are entitled to reparation for the harm they personally suffered.⁸² Processes should be designed to facilitate the exercise of this right by all those who are eligible, i.e. all those who have been victimized by nonconsensual psychiatric interventions and detention. These processes should be easy to access and should include proactive outreach and presumptive eligibility for basic redress such as immediate restoration of liberty and legal capacity if currently deprived; immediate cessation of any nonconsensual interventions; compensation; expunction of any records of an individual’s mental

⁷⁷ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 84; Basic Guidelines, *supra* note 69, ¶ 23(h).

⁷⁸ Basic Guidelines, *supra* note 69, ¶ 23(h).

⁷⁹ General Comment 3, *supra* note 17, ¶ 18.

⁸⁰ Committee against Torture, General Comment No. 2, *Implementation of Article 2 by States Parties*, ¶¶ 6-7, U.N. Doc. CAT/C/GC/2 (Nov. 23, 2007) [hereinafter General Comment 2]; General Comment 3, *supra* note 17, ¶ 19.

⁸¹ Concluding Observations on China, *supra* note 21, ¶ 26; Committee on the Rights of Persons with Disabilities, Concluding Observations on Hungary, *supra* note 21, ¶ 35.

⁸² General Comment 3, *supra* note 17, ¶ 6; Basic Guidelines, *supra* note 69, ¶ 8-23.

health condition or history of psychiatric detention or nonconsensual interventions (such records should first be returned to the individuals concerned without cost to them to facilitate their pursuit of remedies); and pro bono legal assistance to pursue civil judgments against the perpetrators and initiate criminal complaints. Individuals should be given the opportunity to identify particular losses caused by nonconsensual psychiatric interventions and detention and to identify remedies that would be meaningful to them, including dignified assistance to renew a career path, return to school, or to secure decent housing. Assistance in discontinuing the use of psychiatric drugs, understanding and addressing the effects of withdrawal from those drugs, and connecting with alternatives to medical model services should be made widely available.

A group of survivor leaders based in Europe has called for a public apology from governments and professional psychiatric bodies, to be negotiated by user/survivor organizations at regional and global levels, as evidence of good faith to initiate a “truth and reconciliation” process.⁸³ Such negotiations would be accompanied by a demand for reparation, to include:

- Provision of services defined by service users based on collective knowledge and expertise and service user/survivor controlled research.
- Early intervention in first break/psychosis which is non-medical and non-stigmatising and based on existing work such as the original non-medical Soteria model and service user-led crisis houses. Finland currently has services offering a non-medicalised approach which is having good rates of success.
- Financial help for peer support and self management.
- Education and training in individually chosen + valued skills.
- Legal status for advance directives, advance statements, living wills, fully negotiated care and treatment plans.
- Repeal of all forced treatment legislation that discriminates against people using mental health services and is out of line with CRPD.⁸⁴

This initiative, which was started in 2010, offers a concrete proposal that can be taken up by professional psychiatric bodies and governments as a step towards compliance with international human rights norms and implementation of the Special Rapporteur’s recommendations.

4. Stigmatized Identities

The report identifies “stigmatized identities” as one of its transversal themes. However, only sex, gender, sexual orientation and gender identity are mentioned, disregarding disability in that context.⁸⁵ This is unfortunate because it is a missed opportunity to underscore the liberatory meaning of the standard adopted by the 2008 mandate, which identified nonconsensual medical interventions “aimed at correcting or alleviating a disability” as torture or ill-treatment. This standard was first advanced by the World Network of Users and Survivors of Psychiatry in order to articulate the right to be free from nonconsensual psychiatric interventions within the disability rights framework.⁸⁶ It affirms the principle that the physical and mental integrity of persons with disabil-

⁸³ *Truth and Reconciliation in Psychiatry (TRIP)*, RECOVERY IN SIGHT, <http://www.recoveryin-sight.com/truth-reconciliation-in-psychiatry-trip-petition-site/>.

⁸⁴ *Id.*

⁸⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶¶ 36-38.

⁸⁶ *Contribution by World Network of Users and Survivors of Psychiatry*, UNITED NATIONS (Dec. 30-31, 2003 & Jan. 3, 2004), <http://www.un.org/esa/socdev/enable/rights/wgcontrib-wnusp.htm>; Tina Minkowitz, *Advocacy*

ities as such deserves equal protection with that of others and directly counters the medical-model view that stigmatizes disability as being a condition of defect. The Special Rapporteur correctly notes that non-consensual psychiatric interventions are acts of discrimination against persons with psychosocial disabilities⁸⁷ and includes persons with disabilities generally in the category of marginalized groups whose rights are addressed in Section E of the report (without differentiating as to types of disability and without cross-referencing to the section on psychosocial disability).⁸⁸ Psychosocial disability has often been segregated conceptually from other disability issues, and from other groups that face discrimination and bigotry. Addressing psychosocial disability within a framework of “stigmatized identities” would be helpful to make known the essential unity of discrimination and acknowledge the positive framing of identity by persons with psychosocial disabilities themselves. This should be noted for future reference.

Looking Ahead

The norms and principles underlying the instant report, along with those of the Convention on the Rights of Persons with Disabilities, have relevance for ongoing standard-setting processes of the United Nations and regional bodies. This includes the development by the Human Rights Committee of a General Comment on liberty and security of the person,⁸⁹ and the development of instruments on the rights of older persons by the United Nations and the Organization of American States.⁹⁰ In addition, the United Nations is revising the Standard Minimum Rules for the Treatment of Prisoners,⁹¹ a document that was adopted in 1955 before the existence of the core human rights treaties.⁹² The Special Rapporteur on Torture has announced plans for his next thematic report to address the Standard Minimum Rules.⁹³ These processes directly affect the rights of persons with psychosocial disabilities and need to be harmonized with the CRPD, particularly with respect to abolition of forced psychiatric interventions and psychiatric detention.

1. Rights of Older Persons

Older persons face a high likelihood of deprivation of legal capacity, institutionalization, and forced psychiatric interventions, and in the vast majority of cases, these violations are based not only on age but also on perceived disability.⁹⁴ Age discrimination within the disability sector has

*Note: Forced Interventions Meet International Definition of Torture Standards, available at http://www.chrusp.org//media/AA/AG/chrusp-biz/downloads/29591/supplementary_paper_on_article_11.doc; Minkowitz, Nonconsensual Psychiatric Interventions, *supra* note 46.*

⁸⁷ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture, supra* note 1, ¶ 32.

⁸⁸ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture, supra* note 1, ¶ 80.

⁸⁹ Human Rights Committee, General Comment No. 35, *Article 9 Liberty and Security of Person*, U.N. Doc. CCPR/C/107/R.3 (Jan. 28, 2013).

⁹⁰ See *The Open-Ended Working Group on Ageing*, UN OFFICE OF THE HIGH COMMISSIONER ON HUMAN RIGHTS, <http://social.un.org/ageing-working-group/index.shtml> (last visited Sept. 29, 2013); *Committee on Juridical and Political Affairs*, ORGANIZATION OF AMERICAN STATES, <http://www.oas.org/consejo/cajp/personas%20mayores.asp> (last visited Sept. 29, 2013).

⁹¹ Standard Minimum Rules for the Treatment of Prisoners, E.S.C. Res. 663 C (XXIV), (Aug. 30, 1955), available at <http://www.ohchr.org/Documents/ProfessionalInterest/treatmentprisoners.pdf>.

⁹² See UNITED NATIONS OFFICE ON DRUGS AND CRIME, <http://www.unodc.org/unodc/en/justice-and-prison-reform/ieg-standards.html> (last visited Oct. 9, 2013).

⁹³ ANTI-TORTURE INITIATIVE, <http://antitorture.org/sm/> (last visited Sept. 29, 2013).

⁹⁴ See *Relevance to Older Persons of the Convention on the Rights of Persons with Disabilities*, WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY & CENTER FOR THE HUMAN RIGHTS OF USERS AND SURVIVORS OF PSYCHIATRY, <http://wgwnusp2013.files.wordpress.com/2013/04/human-rights-and-older-persons-wnusp-and-chrusp-2012.pdf> (last visited Sept. 23, 2013).

meant that older persons, particularly those with age-related impairments, have not been fully involved in implementation of the CRPD. Disability discrimination in the aging sector has created a double standard where the promotion of “active, healthy aging” guarantees equal rights and opportunities for older persons who are relatively free from impairments, but institutionalization and guardianship are planned for those who are deemed ineligible to live independently and manage their own affairs. Persons diagnosed with dementia are almost always institutionalized in locked wards and drugged without their free and informed consent. The CRPD, in particular Articles 12, 14, and 19, applies with full force to older persons in these situations, and the support model, both for living independently in the community and for exercising legal capacity, needs to be implemented and made available to all older persons who desire such assistance.

The Special Rapporteur's recommendation for an absolute ban on nonconsensual administration of mind-altering drugs applies without any exception to older persons, including those with dementia. The institutionalization of older persons is generally based on assessments made by health care personnel or caregivers that disregard the individual's right to free and informed consent. This should be added to the set of practices that constitute ill-treatment or torture in the health care setting. Just as in the case of detention on mental health grounds, such institutionalization must be abolished entirely;⁹⁵ procedural safeguards only shift a portion of the responsibility from health care personnel to courts, without remedying the underlying violation.⁹⁶

Older persons are commonly deprived of equal access to community resources and to basic needs such as food, water and housing. The perception that older persons' needs are a drain on society persists throughout public discourse and should be explicitly rejected when drafting new instruments. As the Special Rapporteur has said, arguments based on lack of adequate resources cannot justify the deprivation of civil rights such as freedom from torture and ill-treatment, including non-consensual medical interventions.⁹⁷ This also applies to legal capacity, freedom from arbitrary detention, liberty of movement, and the freedom to choose one's residence. The Committee on the Rights of Persons with Disabilities has found an obligation to shift resources where necessary to eliminate discrimination under both Article 14 on liberty and security of the person and Article 19 on the right to live in the community.⁹⁸

The working group drafting the OAS treaty has incorporated language from Article 12 as the standard for legal capacity and provisions guaranteeing older persons the right to exercise free and informed consent.⁹⁹ However, there remains an emphasis on “long-term care services,” which is equivalent to institutionalization, and a provision for procedural safeguards that appears to grant care providers authority to make the final decision regarding placement in such institutions. There is no guarantee either of the right to be free from discriminatory detention or of the right to live in the community with choices equal to others and to receive needed support, as required by CRPD Articles 14 and 19.¹⁰⁰ Further work is needed to ensure that the CRPD standards are not lowered

⁹⁵ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(d).

⁹⁶ See Tina Minkowitz, *Why Mental Health Laws Contravene the CRPD—An Application of Article 14 with Implications for the Obligations of States Parties*, (Sept. 16, 2011), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1928600.

⁹⁷ See Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(b).

⁹⁸ Concluding Observations on China, *supra* note 21, ¶ 26; Committee on the Rights of Persons with Disabilities, Concluding Observations on Hungary, *supra* note 21, ¶¶ 34-35.

⁹⁹ Working Group on the Protection of Human Rights of Older Persons, *Articles Considered at Meeting Held on May 2, 2013*, OEA/Ser.G, CAJP/JT/DHPM-37-12 add. 16, at art. 10, 32 (May 13, 2013) [hereinafter OAS draft treaty].

¹⁰⁰ *Id.* at art. 11, 33-34.

with respect to older persons both in the OAS treaty and in the creation of a new UN instrument. These instruments should be human rights-based, should include a transversal principle of non-discrimination that is applied in each article, and should be grounded in the lived experience of the diverse sector of older persons.

2. Standard Minimum Rules on the Treatment of Prisoners¹⁰¹

The Standard Minimum Rules fail to mention the right to free and informed consent in health care, including with respect to mental health services. Rule 33 allows restraint to be imposed “on medical grounds.” Rule 82 requires the removal of some persons with psychosocial disabilities from prison to psychiatric institutions and for others to be placed under medical supervision.¹⁰² These provisions (and the failure to address free and informed consent), contrary to the recommendations of the instant report, violate the requirements of the CRPD and facilitate acts of torture and ill-treatment, particularly the use of restraint as a medical intervention against persons with disabilities, psychiatric detention, and the nonconsensual administration of mind-altering-drugs.¹⁰³

The Outcome Document from the most recent meeting in December 2012 reflects an agreement that health care personnel in prison settings have a duty to “respect the principle of informed consent in the doctor-patient relationship and the autonomy of patients with regard to their own health.”¹⁰⁴ However, nothing is said with regard to Rule 33, and only cosmetic changes are proposed to the “outdated language” in Rules 82 and 83. Furthermore, in discussing the “protection and special needs of vulnerable groups deprived of their liberty,” a distinction is made between “persons with disabilities” and “persons with mental health-care needs.” Such a distinction is improper because the CRPD applies to all persons who express a need for mental health-care or who are perceived as such by others. Failure to use the proper terminology “persons with psychosocial disabilities” and to incorporate this sector into the same rights-based framework as other persons with disabilities will create confusion as to the applicable standards and, in particular, encourage a reversion to the MI Principles, which have been thoroughly discredited in light of the CRPD. It should be noted that the United Nations Office on Drugs and Crime, which is secretariat to the SMR revision process, issued separate guidelines on the treatment of prisoners with disabilities and on the treatment of prisoners with mental health care needs.¹⁰⁵

CRPD Article 14(2) states, “If persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with inter-

¹⁰¹ This section has been incorporated with specific recommendations into a submission to the Special Rapporteur on Torture. SUBMISSION TO THE SPECIAL RAPPORTEUR ON TORTURE REGARDING THE STANDARD MINIMUM RULES ON THE TREATMENT OF PRISONERS, WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY & CENTER OF HUMAN RIGHTS OF USERS AND SURVIVORS OF PSYCHIATRY, available at <https://dk-media.s3.amazonaws.com/AA/AG/chrup-biz/downloads/282901/WNUSPSMR070713.pdf>.

¹⁰² Standard Minimum Rules for the Treatment of Prisoners, *supra* note 91, at art. 82 (“(1) Persons who are found to be insane shall not be detained in prisons and arrangements shall be made to remove them to mental institutions as soon as possible. (2) Prisoners who suffer from other mental diseases or abnormalities shall be observed and treated in specialized institutions under medical management. (3) During their stay in a prison, such prisoners shall be placed under the special supervision of a medical officer. (4) The medical or psychiatric service of the penal institutions shall provide for the psychiatric treatment of all other prisoners who are in need of such treatment.”)

¹⁰³ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture, supra* note 1, ¶¶ 85(e), 89.

¹⁰⁴ Report on the meeting of the Expert Group on the Standard Minimum Rules for the Treatment of Prisoners held in Buenos Aires from 11 to 13 December 2012, ¶ 9(e), U.N. Doc. UNODC/CCPCJ/EG.6/2012/4 (Dec. 27, 2012).

¹⁰⁵ UNITED NATIONS OFFICE ON DRUGS AND CRIME, HANDBOOK ON PRISONERS WITH SPECIAL NEEDS, available at <http://www.unodc.org/documents/justice-and-prison-reform/Prisoners-with-special-needs.pdf>.

national human rights law and shall be treated in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation." Removal to a psychiatric facility or segregation from the general population in a psychiatric unit within the prison amounts to a deprivation of liberty beyond the lawfully imposed sanction for a criminal offense or other reason unrelated to disability. Such detention, under medical supervision and subject to medical judgment as to discharge or release, is deprivation of liberty based on disability and prohibited under CRPD Article 14(1)(b). CRPD Article 19 is also pertinent; the right to live in the community applies *mutatis mutandis* to the context of detention so that detainees who are persons with disabilities have the right to be housed in the general population and to be provided with support and accommodation that meets their expressed needs. Detainees who are persons with disabilities have a right to be eligible for all programs and services available to other detainees, such as work and education, and such services must be made accessible to them and offer reasonable accommodation.

CRPD Article 12 has implications for criminal liability because legal capacity entails responsibility for one's acts and choices. As stated by OHCHR:

In the area of criminal law, recognition of the legal capacity of persons with disabilities requires abolishing a defense based on the negation of criminal responsibility because of the existence of a mental or intellectual disability.¹⁰⁶ Instead disability-neutral doctrines on the subjective element of the crime should be applied, which take into consideration the situation of the individual defendant. Procedural accommodations both during the pre-trial and trial phase of the proceedings might be required in accordance with article 13 of the Convention, and implementing norms must be adopted.¹⁰⁷

The Committee on the Rights of Persons with Disabilities holds under Article 13 that penal sanctions applicable to persons with psychosocial or intellectual disabilities must be subject to the same guarantees and have the same conditions as any other person, providing for reasonable accommodation and procedural accommodation.¹⁰⁸

Rule 82(1) contravenes these standards when it refers to "prisoners who are found to be insane" and prescribes their removal to psychiatric institutions. While the Rules cover only the treatment of prisoners once detained and not permissible grounds or procedures related to detention, they must be harmonized with existing standards in human rights treaties, including the CRPD.

The Rules should be harmonized with the recommendations of the instant report, as well as the jurisprudence of the Committee on the Rights of Persons with Disabilities. This should include: to ensure, in all mental health services provided to prisoners or detainees, the free and informed consent of the person concerned; to ban nonconsensual medical interventions against prisoners or detainees with disabilities, including the use of restraint, solitary confinement, or nonconsensual administration of electroshock, psychosurgery or mind-altering drugs such as electroshock;¹⁰⁹ to ensure that both penal sanctions and the conditions under which they are imposed are the same for

¹⁰⁶ Often referred to as "insanity defense" [internal footnote within original document].

¹⁰⁷ U.N. High Commissioner for Human Rights, OHCHR Study, *supra* note 31, ¶ 47 (internal citation retained).

¹⁰⁸ Committee on the Rights of Persons with Disabilities, Observations on Paraguay, *supra* note 21, ¶ 32. This standard is a welcome advance over an earlier recommendation that had countenanced the imposition of distinct security measures on persons with disabilities who had been declared "unimputable" with respect to criminal liability. See Committee on the Rights of Persons with Disabilities, Observations on Argentina, *supra* note 24, ¶ 26.

¹⁰⁹ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(b).

persons with disabilities as for others, along with provision of reasonable accommodation;¹¹⁰ and to ensure that prisoners with disabilities have the same rights and opportunities as all other prisoners, including eligibility for work, education, release, and being housed in the general population.¹¹¹ All provisions pertaining to prisoners with disabilities must be understood to include those with psychosocial disabilities;¹¹² prisoners with psychosocial disabilities must not be singled out for differential treatment; and all prisoners must be protected against discrimination based on an actual or perceived disability.¹¹³ Mental health services in prison and detention should emphasize peer support, trauma-informed approaches, and other alternatives to the medical model of mental health, and all relevant personnel should be trained accordingly.¹¹⁴ Conflict-resolution mechanisms, including disciplinary mechanisms, should be reviewed and reformed to eliminate any discrimination based on disability.

Conclusion

The report of Special Rapporteur on Torture Juan E. Méndez on torture in the context of health care is both an advance in the jurisprudence regarding the abolition of disability-based medical torture and ill-treatment and a welcome occasion for discussion and clarification of related norms and principles. His statement to the Human Rights Council, which clarified an inconsistency in the report and made other minor corrections, was especially welcomed by persons with disabilities and human rights defenders and should be further publicized. Such a milestone reminds us, unfortunately, of the huge gap in implementation that persists due to severe discrimination and that leaves large numbers of persons with psychosocial disabilities in situations amounting to torture and ill-treatment—in particular, detention and institutionalization in mental health settings and nonconsensual interventions both in institutions and in the community. It is to be hoped that the instant report, along with the statement to the Council, will be promoted and that all countries will be urged to promptly comply with its recommendations.

¹¹⁰ Committee on the Rights of Persons with Disabilities, *Observations on Paraguay*, *supra* note 22, ¶ 32; U.N. High Commissioner for Human Rights, *OHCHR Study*, *supra* note 31, ¶ 47.

¹¹¹ Convention on the Rights of Persons with Disabilities, *supra* note 34, at art. 5, 14, 19, 24, 27.

¹¹² *Id.* at art. 1.

¹¹³ Report on Spain, *supra* note 21, ¶ 20.

¹¹⁴ Special Rapporteur on Torture, *Report of the Special Rapporteur on Torture*, *supra* note 1, ¶ 89(c).

The Role of Global Psychiatry in Advancing Human Rights

OLIVER LEWIS*

Abstract

This paper examines the role of human rights in psychiatry and the responsibilities of mental health professionals under international human rights law. The Movement for Global Mental Health is described, and some critiques of the Movement by social psychologists and transcultural psychiatrists are offered. Global psychiatry and the Movement are examined from the perspective of international human rights law, and the following recommendations are offered. First, human rights rhetoric should not be used to legitimize forced psychiatric treatment and other human rights violations, and the harm that psychiatry has and continues to cause in the name of therapy, care, and science should be acknowledged. Second, global psychiatry should adopt a more balanced approach to the use of psychiatric medication, including the choices to not take or to stop taking them. Third, there should be accountability for human rights violations. Survivors of psychiatric injustices should have access to a process of restorative justice that gives them an opportunity to be heard. And fourth, mental health professionals should align their mission to treat within the human right to live in the community. In doing so they should offer choices and services that prevent segregation and isolation. The article concludes by noting that world psychiatry is in crisis and needs a new direction. A fresh approach that rejects the dogmatic, institutional, and biomedical approach of the past is needed, and the Global Movement for Mental Health—more holistic, interdisciplinary, and empirically-based than mainstream global psychiatry—is in an ideal leadership position. While mental health professionals are part of the human rights problem, the article concludes that they are also a part of the solution.

Introduction

The porousness of the human rights vocabulary means that the interventions and exercises of state authority it legitimates are more likely to track political interests than its own emancipatory agenda.¹

This paper seeks to contribute to the discourse on the role of human rights in psychiatry and the responsibilities of mental health professionals under international human rights law. It begins by outlining the Movement for Global Mental Health, which will be referred to as “the Movement”. It then lays the contours of critique that has thus far come from social psychology and transcultural

*Oliver Lewis is Executive Director of the Mental Disability Advocacy Center, an international human rights organization. He is a Visiting Professor at the Legal Studies Department of Central European University and as a non-practising member of the Bar of England and Wales, is an Associate Member of Doughty Street Chambers, London. Contact: olewis@mdac.info.

¹ DAVID KENNEDY, *THE DARK SIDES OF VIRTUE: REASSESSING INTERNATIONAL HUMANITARIANISM* (2004).

psychiatry. Using the lens of international human rights, it analyses statements about human rights made by key spokespeople of the Movement and leaders of the World Psychiatric Association. The focus of this paper is human rights, rather than the terrains of public health or development, which both interact with human rights.

Four recommendations are offered throughout the paper. The first is that those who seek to speak for the Movement should stop using the rubric of human rights to legitimize forced psychiatric treatment. The right to reject medical treatment is located within the right to health, which also establishes the State obligation to make mental health care accessible and available, linking with the priority goal of the Movement. It is also located outside the right to health, namely in the right to be free from torture, inhuman and degrading treatment or punishment, the right to physical and mental integrity, and the right to be free from exploitation, violence and abuse. Aligned to this, the second recommendation is that the Movement should take a more nuanced approach to psychiatric medications, and accept that, given that they do not work for everyone and may have serious adverse effects, the focus on medication should be altered. Thirdly, the Movement should take measures towards accountability for human rights violations. Some mental health professionals carry out or acquiesce in such violations, often with impunity, with good intentions in the name of therapy and best interests. The movement should speak out robustly against historic abuses, and establish a forward-looking process of accountability based on the values of restorative justice. Fourthly, the Movement should start advocating for the right to live in the community, a concept that is encompassed within, but is not synonymous with, community psychiatry.

What is the Movement for Global Mental Health?

The Movement was launched in 2007 in the medical journal *The Lancet*, which published six pieces about various aspects of mental health from around the world. A year later, the Movement's leaders clarified in a shorter piece in the *Lancet* that the Movement is "not an organisation. It has no constitution, no office, no board of governors, and no budgets. Anybody and any organisation can join the movement; all that is required is support for the specific goals of scaling up services for and protecting the human rights of people living with mental disorders."² The stated twin goals are: (1) to scale up services for people living with psychosocial disability,³ and (2) protecting their human rights.

The Movement is based on four premises that are, from a human rights point of view, important to get out in the open. In doing so I take no position as to their validity.

The first premise is that there are lots of people in the world who other people think have something called a mental illness. Every year, up to 30% of the population worldwide has some form of "mental disorder," and globally 32% of all years lived with disability are due to "neuropsychiatric conditions."⁴ These disorders and conditions are taken to be something to be prevented from occurring, and treated if they do occur. Poverty, low education, and food insecurity have been iden-

² Vikram Patel et al., *The Lancet's Series on Global Mental Health: 1 Year On*, 372 *THE LANCET*, 1354-1357 (2008).

³ I avoid the medical term "mental disorders" in this paper, preferring the term "people with psychosocial disabilities", which is the term used by the relevant global membership NGOs, the UN Committee on the Rights of Persons with Disabilities, the UN High Commissioner for Human Rights and others.

⁴ Lancet Global Mental Health Group, *Scale Up Services for Mental Disorders: A Call for Actions*, 370 *THE LANCET* 1241-1252 (2007); WORLD HEALTH ORGANIZATION [WHO], *WHO RESOURCE BOOK ON MENTAL HEALTH, HUMAN RIGHTS AND LEGISLATION* (2005).

tified as key causal factors which means that the disorders and conditions strike unequally: they are highest in economically marginalized populations, the least educated, women, and youth.⁵

The second premise is that few of these people have access to treatment for mental illness. The difference between the high numbers of people with diagnosable mental disorders and the low numbers of them getting western-style biomedical treatment is called the treatment gap. In low and middle income countries, between 75% and 90% of people with mental illness reportedly do not receive medical treatment.⁶ In 2004, mental disorders accounted for 13% of the global burden of disease, which is defined as premature death combined with years lived with disability, yet some countries spend less than 1% of their health budgets on mental health.⁷ There are numerous statistics about how few psychiatrists there are in low and middle-income countries compared to richer countries.

The Movement's third premise is that mental illness can be treated. A common mantra in global public health is that there is "no health without mental health." Mental illnesses are treated on par with physical ones, which enables the literature to draw parallels between access to psychiatric medications and medication, for example, for epilepsy or HIV/AIDS. This allows comparisons to be drawn in terms of advocacy strategies to achieve the fourth premise—access to mental health treatments should be scaled up so that more people with mental illness get treated. This is both a moral and an economic claim. A simple utilitarian approach motivates those who have resources (skills, technology, money) to help the maximum number of people in the greatest need. The economic argument is that people with mental illness are poor, out of work, and a burden on families and on the economy.

The advocacy messages at the 2007 launch of the movement hides disagreements within health, social science, and public policy about the nature and size of the challenge, how we talk about the challenge, and the methodology we use to address it. The movement's choice of biomedicine was, as social psychologists have observed, "a necessary first step in establishing a broad-based global awareness of the issue" one which is a "prelude to the development of a more complex social approach." It is true that a complex and diluted message would likely not convince governments and attract donors, so for strategic messaging a "one-size-fits-all approach" was chosen.⁸

Critiques of the Movement

Introducing the WHO's 2001 annual report, which for the first time focused on mental health, its then Director General said that the "WHO has one, and only one option—to ensure that ours will be the last generation that allows shame and stigma to rule over science and reason."⁹ This raises the question whether western psychiatric treatments of perceived mental disorders are founded upon science and reason. The field of transcultural psychiatry has been asking this question for a generation. HBM Murphy was one of the founders of cross-cultural psychiatry. In 1977 he pointed out that, "the failure of psychiatry as a practice to listen carefully and thoughtfully to the voices of

⁵ Crick Lund et al., *Poverty and Mental Disorders: Breaking the Cycle in Low-Income and Middle-Income Countries*, 378 THE LANCET 1502-1514 (2011).

⁶ Shekhar Saxena et al., *Resources for Mental Health: Scarcity, Inequity, and Inefficiency*, 370 THE LANCET 878-898 (2007); Vikram Patel et al., *A Renewed Agenda for Global Mental Health*, 378 THE LANCET 1441-1442 (2011).

⁷ WHO, RESOURCE BOOK ON MENTAL HEALTH, HUMAN RIGHTS AND LEGISLATION, SUPRA NOTE 4.

⁸ Catherine Campbell & Rochelle Burgess, *The Role of Communities in Advancing the Goals of the Movement for Global Mental Health*, 49(3-4) TRANSCULTURAL PSYCHIATRY 379, 379-395 (2012).

⁹ WORLD HEALTH ORGANIZATION, THE WORLD HEALTH REPORT: 2001 MENTAL HEALTH: NEW UNDERSTANDING, NEW HOPE (2001).

patients before moving to classifying them according to a set of necessarily objectifying and simplifying diagnostic criteria."¹⁰

Is the Movement the latest incarnation of this biomedical globalization? Even though it is well-intentioned, it is misconceived as it uses western products, technologies and approaches which are not subject to universal consensus in the west, and exports them to poor parts of the world. That's the view of consultant psychiatrist Derek Summerfield, perhaps the Movement's most strident critic.¹¹

His view is that to claim that one in four people suffer [sic] from a mental health disorder [sic] is disease-mongering. He points to a study in the States that interviewed average people and concluded that 46% of them met American Psychiatric Association criteria for at least one mental disorder (and often more than one) over a lifetime. This cannot possibly be true, Summerfield argues. Psychiatry tends to convert human pain, misery and madness into technical and standardized terms which it then universalizes and creates expert-led interventions. He notes how this line of thinking is rather profitable for pharmaceutical companies too.

Like their colonial forefathers with a Bible in one hand and gun in the other, western psychiatrists are now flying to developing countries with a DSM in one hand and Haloperidol-loaded syringe in the other. That image may overstate the link between the powers of the colonizers and that of western doctors and the pharmaceutical industry. Even in low and middle-income countries, a biomedical approach may well be part of the treatment package that a person may choose. The criticism of the Movement from social psychologists and from transcultural psychiatrists is that the Movement pedals a culturally-defined response whereas the diversity of people seeking help with their problems requires an equally diversified response. What then is the human rights critique?

What Does the Movement Say About Human Rights?

Before offering an analysis based on a human rights approach, I would like to outline statements about human rights made by the Movement and its key spokespeople.

First, let us look at the six *Lancet* papers that were the Movement's launch-pad in 2007. Paper 1 is entitled "No health without mental health" and contains no reference to human rights.¹² Paper 2, on resources for mental health, says that laws should be in place "for protection of the basic human and civil rights of people with mental disorders, especially those in receipt of involuntary treatment."¹³ It is a bad thing, the paper says, that 78% of countries in the world lack mental health laws and that 16% of the laws that do exist were enacted before 1960. This view illustrates the misleading and dangerous tendency by the Movement to conflate human rights implementation with the existence of mental health laws.

Paper 3 is on treatment and prevention and contains the occasional reference to human rights.¹⁴ Services for people with schizophrenia are apparently most effective when they are organized to

¹⁰ Leslie Schwarz, *An Unruly Coming of Age: The Benefits of Discomfort for Global Mental Health*, 49(3-4) *TRANSCULTURAL PSYCHIATRY* 531-538 (2012).

¹¹ Derek Summerfield, *Afterword: Against "Global Mental Health,"* 49(3-4) *TRANSCULTURAL PSYCHIATRY* 519-530 (2012).

¹² Martin Prince et al., *No Health Without Mental Health*, 370 *THE LANCET* 859-877 (2007).

¹³ Saxena et al., *supra* note 6.

¹⁴ Vikram Patel et al., *Treatment and Prevention of Mental Disorders in Low-Income and Middle-Income Countries*, 370 *THE LANCET* 991-1005 (2007).

ensure a number of elements, including human rights promotion. But the paper does not tell us what human rights these human rights-promoting services should promote.

Paper 4 on mental health systems recommends that care in the community should respect human rights, and paper 5 on barriers to service reform contains one reference to human rights, embedded in a quotation from a leader of a user/survivor NGO in Zambia.¹⁵

Paper 6 sets out the global call for scaling up, observing that “present mental health services are largely centralised, with inadequate human rights protection and weak links with community mental health and general-health services.”¹⁶ It does not explain what human rights protection means or how it is currently inadequate. It sets out a range of recommendations to various “stakeholders.” Governments of low and middle-income countries are requested to “[p]romote adoption and implementation of national mental health legislation in accordance with international human-rights instruments.” Human rights groups should “[m]onitor and protect the human rights of the mentally ill” and “[a]dvocate for the rights of people with severe mental disorders—especially those living in mental hospitals—and for mechanisms to protect those rights.” And UN agencies should “[a]dvocate for an improved national mental health system that provides effective interventions and human rights protection.” Health professionals are listed as another stakeholder group. The paper makes no human rights recommendations to them.

It goes on to list 11 indicators to achieve the desired scaling-up of services. Protecting human rights of people with mental disorder comes in at number ten. The authors propose an indicator to measure whether this has been achieved, namely the “[p]resence of a national body that monitors and protects the human rights of people with mental disorders, and issues reports at least every year.” The existence of a body is an easy process indicator to measure, but one that tells us nothing about how human rights are being protected, respected, and fulfilled.

In summary, the 2007 series contains a few references to the phrase “human rights,” but this is nowhere explained, is equated with legislation, is dislocated from mental health practice, is placed at tenth spot in eleven priorities, and even then is treated in a mechanistic and tick-box way. Four years later, in 2011, the Movement had another series in *The Lancet*. There were again six papers. I was drafted in to co-author a paper entitled “Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis.”¹⁷ The editorial to the special edition cited this human rights paper (number 6 out of 6!), emphasizing that adherence to human rights and working with communities are key actions to overcome stigma and discrimination. It said this:

*First and foremost, the issue of the human rights of people with mental health problems should be placed at the foreground of global health—the abuse of even basic entitlements, such as freedom and the denial of the right to care, constitute a global emergency on a par with the worst human rights scandals in the history of global health.*¹⁸

That is a change in tone compared with four years before. The question is whether this strident approach has trickled out beyond the pages of *The Lancet*? A major international conference was organized in March 2013 at the Royal Society of Medicine in London. There, presentations by some

¹⁵ K.S. Jacob et al., *Mental Health Systems in Countries: Where Are We Now?*, 370 THE LANCET 1061-1077 (2007); BENEDETTO SARACENO ET AL., *Barriers to Improvement of Mental Health Services in Low-Income and Middle-Income Countries*, 370 THE LANCET 1164-74 (2007).

¹⁶ Lancet Global Mental Health Group, *Scale Up Services for Mental Disorders: A Call for Actions*, 370 THE LANCET 1241-1252 (2007).

¹⁷ Natalie Drew et al., *Human Rights Violations of People With Mental and Psychosocial Disabilities: An Unresolved Global Crisis*, 378 THE LANCET 1664-1675 (2011).

¹⁸ Vikram Patel et al., *A Renewed Agenda for Global Mental Health*, 378 THE LANCET 1441-1442 (2011).

leaders of world psychiatry readily acknowledged the need to protect human rights. One or two presentations listed human rights on the last PowerPoint slide which referenced the Universal Declaration on Human Rights, and the 2006 UN Convention on the Rights of Persons with Disabilities without saying anything about content. In other presentations, human rights appeared as one of several cross-cutting issues which need to be taken into account. For example: “universal health coverage, human rights, evidence-based practice, life course approach, multi-sectoral approach, empowerment for people with mental disorders” all need to be considered.¹⁹ In other words, human rights are part of a list, rather than presented as an operational framework within which all of the other listed elements can be placed.

These are somewhat benign utterances about human rights. Different examples come from some other speeches and papers. I will do this by layering my own interpretation at the outset, so as to be clear about how I am decoding the sometimes quite cryptic messages.

Four Concerns

This section contains four concerns, which can be read as recommendations to mental health professionals, especially those in the progressive global Movement. The first is to cease and resist deploying and manipulating human rights rhetoric to legitimize human rights violations, and forced psychiatric treatment in particular. Secondly, mental health professionals could usefully take a more nuanced approach to psychiatric medication, acknowledging that there are all sorts of legitimate reasons why people choose not to take them, and choose to come off them. The third concern is aimed to move forward by looking back. It is to publicly acknowledge the harm that psychiatry has caused and continues to cause in the name of therapy, care, and science. I suggest that global psychiatry should speak out against injustices, and that it should establish a process of accountability that gives survivors of psychiatric injustice an opportunity to be heard. Fourthly, mental health professionals could usefully align their mission to fit within the broader human right to live in the community, with choices and services so as to prevent segregation and isolation.

1. Using Human Rights Rhetoric to Legitimize Human Rights Violations

There is some evidence that the Movement takes rights to be the notion of *being a nice doctor*. For others, human rights are more threatening because rights concern distribution of power and status. Psychiatrists wield immense power over the individual, and have significant status in policy circles and the media. Rights are used as a way of navigating our way through competing claims. But in psychiatry the conflict is in-built, because in most jurisdictions in the world, a psychiatrist has the direct legal power to override someone's refusal of treatment and the indirect influence to determine deprivation of legal capacity, place of residence, access to bank account, marriage and so on. Psychiatry makes the claim for access for treatment for people with mental illness, sometimes couching this in right to health and non-discrimination terms. Patients sometimes have a competing claim to bodily and mental integrity, freedom from torture and other forms of ill-treatment, and to freedom from abuse and exploitation: patients have the right to disagree with their doctor. Injecting the language and practice of human rights has the unfortunate side effect of heightening the sense of conflict, but it provides a vocabulary at least for all parties to use.

¹⁹ Shekhar Saxena, International Action on Mental Health, Plenary Paper Delivered at the Royal Society of Medicine Conference: The World in Denial? Global Mental Health Matters (Mar. 26, 2013).

a. Paperwork is Not Consent

The leading guidance for doctors providing mental health services is the World Health Organization guidelines called mhGAP.²⁰ The document says that the psychiatrist should “[e]nsure that the person understands the proposed treatment and provides free and informed consent to treatment.” But it contains no guidance about what these terms mean, or what the medic should do if consent is not given. There’s no discussion of autonomy, or preferences or choices. The assumption is that mental illness in all circumstances clouds a person’s decision-making faculties so much that their opinion becomes worthless and the person needs to be treated using evidence-based biomedical approach.

The UN Convention on the Rights of Persons with Disabilities includes within its scope the rights of people with psycho-social (mental health) disabilities (this is the term used by the global movement itself, and the UN Committee on the Rights of Persons with Disabilities).²¹ The Convention sets out that that disability shall in no case justify detention and that treatment should be given on the basis of free and informed consent.²² What these statements mean is open to interpretation, and there are serious calls now being made that this means the end of mental health legislation, so that the law does not allow a doctor to override a patient’s refusal of mental health treatment.²³

In March 2013, Juan Méndez, the UN Special Rapporteur on Torture issued his annual report to the UN Human Rights Council. The report focused on torture in healthcare settings. The report reiterates that even when psychiatric treatment is given with “good intentions,” because of the “discriminatory character of forced psychiatric interventions” it can satisfy the requirements of Article 1 of the UN Convention against Torture, meaning that psychiatric treatment can be torture.

In his report, Juan Méndez states:

It is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions. The environment of patient powerlessness and abusive treatment of persons with disabilities in which restraint and seclusion is used can lead to other non-consensual treatment, such as forced medication and electro-shock procedures.

Developments in human rights standard-setting are intended to have a direct effect on the day-to-day practice of professionals like psychiatrists, psychiatric nurses, and social workers. Yet instead of engaging with the human rights discourse, representatives of the Movement have tended to posit treatment as a value-neutral humanitarian objective, framing its success in maximal quantitative roll-out.

This is not surprising, because doctors impulsively want to treat. The Hippocratic oath, or its modern day equivalent, the Declaration of Geneva, sets out how for a doctor, “the health and life of my patient will be my first consideration.” Health and being kept alive trump all other consid-

²⁰ WORLD HEALTH ORGANIZATION, MHGAP INTERVENTION GUIDE: FOR MENTAL, NEUROLOGICAL AND SUBSTANCE USE DISORDERS IN NON-SPECIALIZED HEALTH SETTINGS (2010).

²¹ Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. Doc. A/Res/61/106 (Dec. 13, 2006).

²² *Id.* art. 14, 25(d).

²³ U.N. Comm. on the Rts. of Pers. with Disabilities, *Concluding Observations: Spain*, para. 36, U.N. Doc. CRPD/C/ESP/CO/1 (2011); U.N. Comm. on the Rts. of Pers. with Disabilities, *Concluding Observations: Peru*, para. 28, U.N. Doc. CRPD/C/PER/CO/1 (2012); U.N. Comm. on the Rts. of Pers. with Disabilities, *Concluding Observations: Australia*, para. 32, U.N. Doc. CRPD/C/AUS/CO/1 (2013).

erations. But for the patient, her autonomy and privacy may be more important than the doctor's account of her health. There seems to be no consensus within the Movement that this position is open to review, and given the power in policy reform which medical practitioners hold (compared to mental health service users), until there is a firm view, bottom-up reform at the grassroots level is unlikely to happen. This may explain why much of the advocacy is focused on a top-down approach, in which if a law is changed, medical practitioners will not have a choice as to conform with it or not.

b. The Dark Side of the Dark Side

Human rights are embedded socially, focus on human frailties and irregularities, are qualitative, political, conflicting, gritty and downright dirty. This leads some health practitioners to retract to the scientific comfort of the health domain without attempting to engage in the complexities presented by human rights. They sometimes then deploy the language of human rights to justify a perspective which itself does not accord with human rights standards. Let me give some examples. Norman Sartorius (a senior psychiatrist, and former director of the World Health Organization's Division of Mental Health) gave a keynote address to the Royal Society of Medicine conference in March 2013, entitled "Recognising mental health human rights—the way forward."²⁴ One of the PowerPoint slides was entitled, "The dark side," and Professor Sartorius argued that human rights are flawed *per se*. He described the 2013 report on torture in healthcare settings of Juan Méndez, the UN Special Rapporteur of Torture, as an "obstacle to care," justifying his view by giving an example of a patient with dementia who will die if the doctor does not intervene. The Méndez report does not suggest anything of the sort. Whether Professor Sartorius has misread the paper, not read the paper, or is deliberately manipulating it for the purpose of promoting an agenda is unclear. In response to a question by me about this, Professor Sartorius said that his opinion about the report was that it will be "thrown out" by mental health professionals.

Many psychiatrists have joined discussions with human rights and mental health service users. Everyone is welcome to help clarify the as yet under-explored terrain of *how* to implement the UN Convention on the Rights of Persons with Disabilities. Article 14 of the treaty states that, "in no cases shall disability justify detention." What would a world free of psychiatric coercion look like? How should cases be handled where a person is deemed to lack capacity to consent? What does capacity to consent actually mean? Is the notion of capacity itself a discriminatory one? How can we rethink the status quo so as to respect self-determination? How can supports or advance directives be put in place to help someone exercise their will and preferences? What sort of safeguards should be constructed to guard against exploitative substitute decision-making? These are all live questions being debated so as to find human rights-based solutions which are feasible in practice.

In his speech, Professor Sartorius made the point that "advocates for the human rights of the mentally ill neglect to highlight the importance of fulfilling human duties which contribute to self-stigmatisation." There are various possible interpretations of this coded message. One could be that a person deemed 'mad' (by others) should be more 'normal' (as defined by others). Or perhaps that there is an obligation to take psychiatric medication in pursuit of normalcy. Another could be that people in the global south should be grateful for the unsolicited assistance of well-meaning outsiders. What unites these possible interpretations is intolerance of diversity.

²⁴ Norman Sartorius, *Recognising Mental Health Human Rights—The Way Forward, Plenary Paper Delivered at the Royal Society of Medicine Conference: The World in Denial?* Global Mental Health Matters (Mar. 27, 2013) <http://www.rsmvideos.com/videoPlayer/?vid=370>.

Professor Sartorius is of course correct that rights impose duties. But these duties are imposed upon States. Duties on non-State actors are filtered through State interventions, so that person A's duty not to kill person B can be traced to human rights because the State has a duty under international law to protect the right to life of everyone within its territory, including, through the force of the criminal law, preventing individuals from doing so. Is it not true to say that an individual has duties under human rights law to refrain from murder? Under criminal law, yes; but not under human rights law. It is difficult to think of a way in which one could argue that human rights law obliges an individual to behave nicely or appropriately. And by extension, human rights law does not place any sort of obligation on a person to agree with their doctor, or receive mental health treatment when someone else thinks it is necessary. Ethical preferences do not always find solid ground in human rights law.

The reason many people with mental health problems seek help with their mental health is to alleviate unpleasant symptoms. Choice about which options to select or reject is at the core of the claim by many users of mental health services worldwide. The notion that there is a utopia of normalcy/sanity exemplifies a medical model of disability focused on fixing the individual rather than offering a range of supports. For this model to work, it must contain a mechanism to allow a doctor to allow the choices a person makes about the sort of person she wants to be and the sort of ways she wants to live her life. A social model of disability rejects this approach, as does international human rights law. One does not need to read very far into the UN Convention on the Rights of Persons with Disabilities to find in Article 3 the principle of "[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity."²⁵

c. Hierarchy

The last of Professor Sartorius's ideas is to have a document setting out a hierarchy of rights. He asserts that rights cannot be implemented at the same time. He proposes the right to life as number one priority. If a person's life is in danger, he says, the person should get the mental health treatment that will save his life, "not voting rights, which is something which comes later. There is a certain thing which you can do now and must do now."²⁶ This statement is not only empirically untrue, but runs counter to established notions of interdependence of human rights provisions. It goes without saying that human right A can be implemented at the same time as human right B. The right to vote can and must be provided immediately. Equally, the right to be free from torture can and must be provided immediately. Coordination across government is necessary to ensure spread and avoid duplication, but human rights is not a linear list. Policy-makers are not supposed to check one human rights box before proceeding to implement the next one. Furthermore, the right to political participation for many people with psycho-social disabilities and intellectual disabilities who have been denied that right, has an instrumental and expressive value. Not only is participation in a democracy one of the easiest rights to implement, it is one of the most fundamental in reversing the political invisibility of people historically invalidated by law and politics.

Norman Sartorius is not the only psychiatric leader calling for prioritization. Writing in the *Lancet* in 2011, the immediate past president of the WPA, Italian professor of psychiatry Mario Maj also suggested a list. "The first indisputable right of a person with a mental disorder" is quite a surprise. It is not the right to life. It is not the right to liberty and security, to food, water, shelter,

²⁵ Convention on the Rights of Persons with Disabilities, *supra* note 21, art. 3.

²⁶ Sartorius, *supra* note 24.

or housing. It is not the right to be free from abuse and neglect. "The first indisputable right of a person with a mental disorder is to find in the public health system a professional who is able to understand the nature of that disorder."²⁷

"A second unquestionable right of a person with a mental disorder is to receive an intervention for that disorder that accords with available research evidence, within the limitations of the local context." It is also a right for the "disorder" to be "managed in a setting that is decent, humane, and non-abusive." A fourth right is for the person with a "mental disorder" to have "a full affective and social life."

The "most important right" for a group of people is an empirical claim that can be tested. One can ask the people concerned. Yet these statements cite no research evidence. Dr Maj says that his view is "unquestionable." He erects a Perspex screen between himself and other views. As president of the World Psychiatric Association he speaks a truth that cannot be questioned. His views also perpetuate an old-fashioned and debunked medical model of disability where the disordered mind (or brain?) is a machine that needs to be fixed. Mending the mind is not only a medical goal, but a pre-requisite to "a full affective and social life." As noted above, this worldview offends well-established notions of human rights, namely respect for diversity (which includes a right not to be 'normal', however defined), autonomy and the right to make one's own decisions.

The World Psychiatric Association's views on human rights are deeply concerning. For example, the Association's position on unmodified electro-convulsive therapy (given on a patient who is awake, without anaesthesia and without muscle relaxant) is that it is actually acceptable form of medical treatment.²⁸ The World Psychiatric Association has understood and ignored the fact that authoritative human rights bodies (including the European Committee for the Prevention of Torture—a body which includes psychiatrists and other doctors as members) consider unmodified ECT as torture and ill-treatment which can never be justified.²⁹

The WPA's flagship human rights initiative a prize awarded on a biennial basis. The last document adopted by WPA on anything related to the human rights is the "Madrid Declaration on Ethical Standards of Psychiatric Practice."³⁰ It was written in 1996 and revised in 1999, 2002, and 2011. The document is very far from what one might expect, namely a statement urging global psychiatric practice to comply with international human rights standards.

The Declaration states that, "[e]thical practice is based on the psychiatrist's individual sense of responsibility to the patient and judgment in determining what is correct and appropriate conduct." In this way the Declaration is the antithesis of accountability to the patient. It continues: "[e]xternal standards and influences such as professional codes of conduct, the study of ethics, or the rule of law by themselves will not guarantee the ethical practice of medicine." Nothing should get in the way of the patient's "right" to receive best treatment possible.

In a section entitled "Protection of the rights of psychiatrists," the Declaration states that, "psychiatrists ought to have the right to [...institute] effective treatment and management protocols in accordance to best practices and evidence-based medicine." The right, according to the Declaration,

²⁷ Mario Maj, *The Rights of People With Mental Disorders: WPA Perspective*, 378 THE LANCET 1534-1535 (2011).

²⁸ Mohammed T. Abou-Saleh & George Christodoulou, *The WPA Position Statement on the Ethics of the Use of Unmodified Electroconvulsive Therapy*, 20(1) THE ARAB J. OF PSYCHIATRY 57-65 (2009).

²⁹ Eur. Comm. for the Prevention of Torture, Inhuman and Degrading Treatment or Punishment [CPT], CPT Standards, CPT/Inf/E (2002).

³⁰ World Psychiatric Association [WPA], *Madrid Declaration on Ethical Standards for Psychiatric Practice* (approved by the General Assembly of the WPA in Madrid, Spain on Aug. 25, 1996).

is the psychiatrist's, and the nature of the right is to institute treatment. It is a very creative use of the word "right."

d. Summary

For some leaders of world psychiatry, human rights boil down to imposing treatment whether the patient likes it or not. There is an idiosyncratic and intolerant view that is challenged by firmly established notions of human rights. Those who speak on behalf of the Global Movement for Mental Health would be well advised to distance themselves from those who seek to use rhetoric of human rights to legitimize forced treatment, which can amount to torture, inhuman and degrading treatment and punishment.

2. A Nuanced Approach to Medication

The way in which treatment is given needs to be rethought, and so do the treatments themselves. Psychiatrist Derek Summerfield warns against focusing on the narrow Western biomedical aspects of patients' lives and on diagnostic categories, because the result will be that community mental health "collapses down to prescribing a pill." The Movement has sometimes grossly exaggerated the benefits of medication. An example is the one of the PowerPoint slides in the March 2013 conference showing two pictures. On the left was a man chained to a hospital bed. On the right was the same man working in a field. The caption on the left was "before treatment" and on the right "after treatment." Medication may indeed have enabled the person to function better and to work in a field. But pills do not unlock padlocks; people do. The contrary is also true, pills are used as chemical chains.

Anthropologist Ursula Read has observed that the Movement has "glossed over the limitations of psychotropic drugs, particularly antipsychotics, and the ambivalent attitudes they provoke in those who take them." Surely that is true. We know that there are high rates of noncompliance also in higher-income countries where medications also have side effects, and this is one of the primary reasons people stop taking their medications.³¹ Read points out from her research in Ghana that a person's symptoms return when medication is discontinued, and that this poses a challenge to the perceived efficacy of the treatment. This causes patients to turn to traditional healers for help, which may be a good thing, depending on what that treatment is.

In low and middle-income countries, older drugs like Chlorpromazine or Haloperidol are very commonly used. These drugs were synthesized in the early 1950s and played a part in deinstitutionalization in North America and Western Europe. The downside is that these drugs make people fat, lazy, drowsy, and weak. They can cause skin irritations. They can make people's tongues swell, causing speech impairments.

In Ghana, Ursula Read found that people thought hospital medicine was effective only in the short term, because of its sedating effect on troublesome behavior such as talking too much, wandering, sleeplessness, and aggression.³² Inducing sleep is good, but medication can make the person sleep all day. Making people weak and exhausted renders them without the energy to do any meaningful work: this is a big problem in low and middle-income countries, Read observes,

³¹ PETER LEHMANN PUBL'G, *COMING OFF PSYCHIATRIC DRUGS: SUCCESSFUL WITHDRAWAL FROM NEUROLEPTICS, ANTIDEPRESSANTS, LITHIUM, CARBAMAZEPINE AND TRANQUILIZERS* (PETER LEHMANN, ED. 2004).

³² Ursula Read, "I Want the One that Will Heal Me Completely so It Won't Come Back Again": *The Limits of Antipsychotic Medication in Rural Ghana*, 49(3-4) *TRANSCULTURAL PSYCHIATRY* 438-460 (2012).

because it prevents people from a means to a livelihood. In an effort to cure the mental illness, medication can induce the very caricature of a shuffling and dribbling madman. The effect of drugs is troubling.

The conditions in which they are given are also troubling. Medications are often given by way of injections on admission, because laws allow this to happen and it is convenient for staff. My own observations in psychiatric hospitals in both India and Moldova in 2013 are that this is a violent process. The patient is restrained by nurses onto a bed in front of other patients, given injections and/or ECT ignoring the person's refusal.

Mental health services currently on offer are often not attractive. As Read points out, "if psychiatric services are to be promoted as the best possible treatment for mental illness, then they must provide the highest standard of care which requires not just investment but ongoing training, monitoring, and accountability, not an easy task where staff are often demoralised and patient numbers overwhelming."³³ My observation is that mental health services that are violent and abusive actually contribute to the treatment gap: people understandably avoid these types of services.

Medication is not a panacea. They have side effects, do not help with family and social relations, and are given in a coercive manner and abusive environments, authorized by mental health laws promoted by the World Health Organization. The Movement would be well advised to approach the issue of treatment for mental health problems in a more nuanced way.

3. Accountability for Human Rights Violations

The World Psychiatric Association's former president Mario Maj acknowledges that people with mental health problems, "have been and are neglected or abused in public mental hospitals and in a range of private institutions, and sometimes also in community facilities or in their home."³⁴ The use of the passive voice introduces fuzziness in causation: who did what and why? The statement "Some psychiatrists cause harm to people" is as uncontroversial as "Some police officers cause harm to people."

There are two ways in which the Movement could make progress on accountability. First, as Amartya Sen says, "Silence is a powerful enemy of social justice."³⁵ The Movement should speak out against human rights violations. It needs to start naming these abuses as torture where that word is justified. If the World Psychiatric Association is not willing to demand that psychiatric associations regulate and discipline their members properly, those representing the more progressive Movement should step up to the mark. Any democratic society needs doctors to behave ethically and lawfully. Mechanisms to enforce standards need to be effective and they need to be used. The Movement could call for state-paid independent advocacy to prevent abuses and represent people when abuses take place. The Movement could work with bar associations to ensure that people with mental health diagnoses can access justice on an equal basis with others.

Second, the Movement could usefully borrow from restorative justice some guiding principles on how to establish a process of accountability that focuses on the harm done and engages those most involved. The process should give survivors of psychiatric injustice an opportunity to tell their stories, be listened to, and be asked about what needs to be done to prevent future human rights violations. This could be carried out within a framework of values that "include the need to

³³ *Id.*

³⁴ Maj, *supra* note 27.

³⁵ AMARTYA SEN, *THE IDEA OF JUSTICE* (2009).

heal the hurts that have been felt.”³⁶ Words can be more powerful than pills. Used in a smart way, words can demonstrate human rights readiness.

Many psychiatrists do wonderful work and are human rights champions. But there are others who have harmed people and acquiesced in human rights abuses. They have enjoyed immunity from punishment and prosecution, shielded by unjust laws and malfunctioning redress mechanisms. Recognition of wrongs is introspective and painful, but the wrongs carried out in the name of medicine demand such humility and thought, whatever the level of awkwardness may be.

4. The Right to Live in the Community

Professor Vikram Patel is one of the Movement’s leading figures and is playing a hugely important role advocating care—including pharmacology—and also psychological and social interventions. He talks about the need to respect autonomy and dignity, about efforts to reduce social exclusion and discrimination, and about addressing situational factors impacting on mental health like poverty and war. Patel takes the view that the models used in the north and west—large number of psychiatrists, ample psychiatric beds, second generation medication, psychological treatments and so on, “have no chance of addressing the huge treatment gaps in [low and middle-income countries].”³⁷ He rejects the view that mental health professionals can solve the global mental health treatment gap. Instead, he suggests turning attention instead to tapping into the inherent resources of existing communities.

This is much more closely aligned to human rights principles. Community living with supports is no longer a favorable policy development but an internationally recognized right in Article 19 of the UN Convention on the Rights of Persons with Disabilities. The provision sets out the right to choose where and with whom to live, to access a range of community support services, and to access community services and facilities for the general population, all with a view to prevent all forms of segregation or isolation.

This right is broader than decentralization of mental health services. The medical community could engage with the independent living community so that they can learn about the nature of this right to live in the community, what it means for their patients, and what role they have in implementing the right. Psychiatrists can then contribute back so that people with disabilities can benefit from their wisdom and insight. In other words, the Movement could make a bridge between the public health and disability rights worlds. Aligning themselves with disability means rethinking views such as “I can cure mental illness therefore it is not a disability” or “disabilities are long-term and therefore short-term mental illnesses are not disabilities” (all views which I have heard many medical people say). These views are increasingly desperate attempts to stop their patients having the benefits of rights given to people with disabilities—rights which are indeed intended to rebalance psychiatric power and influence.

The Movement defines the word community narrowly to mean “the patient and their families, and lay health workers linked to primary health care facilities.”³⁸ Social psychologists Cathy Cambell and Rochell Burgess at the London School of Economics have pointed out how the Movement focuses on human vulnerability rather than resilience with the everyday challenges of life. They and others suggest that instead of quantitative symptom checklists that currently domi-

³⁶ JOHN BRAITHWAITE, *RESTORATIVE JUSTICE AND RESPONSIVE REGULATION VII* (2002).

³⁷ Vikram Patel, *Global Mental Health: From Science to Action*, 20(1) *HARV. REV. PSYCHIATRY* 6-12 (2012).

³⁸ Campbell, *supra* note 8.

nate research and practice, people would be better served by participatory research and interventions focused on understanding how people cope, and how their wider communities might best be supported to facilitate their coping.

A focus on communities is gaining ground within psychiatry too. Recently in the *British Journal of Psychiatry*, social psychiatrists Stefan Priebe, Tom Burns, and Tom Craig have noted the lack of any useful research advances or treatment modalities within the last 30 years. Observing that “community care has been established, with services that work in the community, but rarely with the community,” they call for a “social paradigm” of mental health that “requires research to study what happens between people rather than what is wrong with an individual wholly detached from a social context.”³⁹

These social capital models snuggle up close to a paradigm grounded in human rights principles. Developing meanings of community, finding out how we can tap into it, discovering how its supportive potential can be unleashed so as to give effect to human rights standards: these are important tasks for further interdisciplinary scholarship.

Conclusion

World psychiatry is in crisis. Neuroscience and cognitive and social psychology—neither of which are tools in the psychiatrist’s toolbox—seem to hold out more promise than pharmacology. At the same time the disability rights movement is coming of age. It (mostly) fully embraces within its membership people with psychosocial disabilities and recognizes their claims under international disability law. It is entirely understandable why some people with psychosocial disabilities refuse to be labelled as having a disability. Identity politics aside, international law is now clear that the entitlements that those labelled with mental illness are asserting are indeed claims of human rights and of the rule of law.

Human rights violations have been documented across the globe, and it is clear that mental health professionals are part of the problem. They are also part of the solution. The solution is not only to scale-up access to treatments, but to recognise human rights violations for what they are, and to establish accountability mechanisms through professional bodies, criminal courts and processes of restorative justice. The silence on accountability is a stain on leaders of global psychiatry that renders their pronouncements increasingly irrelevant and diminishes their credibility in politics, law and medicine alike.

Equally, so strongly are lawyers grounded in their own prejudices that it has taken too long for mainstream human rights actors such as the mandate of the UN Special Rapporteur on Torture, or the European Court of Human Rights, to take seriously the autonomy and equality claims of people with psychosocial disabilities. But they are beginning to do so now.

Against this backdrop, it is therefore no surprise that the World Psychiatric Association is running scared. In 2010, the WPA’s in-house journal *World Psychiatry* ran a series of articles about the future of psychiatry as a profession. The titles of some of these pieces speak for themselves: “Psychiatry is alive and well,” “Psychiatry and the psychiatrists have a great future,” “The golden years of psychiatry are in the future,” and “Psychiatrists shall prevail.” The apex article was written by the then WPA president and was entitled, “Are psychiatrists an endangered species?” (The

³⁹ Stefan Priebe, Tom Burns & Tom Craig, *The future of academic psychiatry may be social*, 202 THE BRIT. J. OF PSYCHIATRY 1-2 (2013).

answer, upon reading the article, is no). Not one of these articles contains the word “rights” or “consent.”

World psychiatry needs a new direction. A fresh approach should reject the dogmatic, institutional, and biomedical approach of the past. The Global Movement for Mental Health is in many ways more holistic, interdisciplinary, and empirically-based than mainstream global psychiatry. The Movement has made significant inroads in embracing an evidence-based approach, a significant contribution to the ethical rolling out of effective treatments: a better idea than leaving treatment to the sole discretion of the doctor. The Movement is to be credited for linking up with NGOs such as BasicNeeds, which adopts a livelihood, wellbeing, and a community-based approach. It is, however, open to the critique that adopting a one-size-fits-all pill for each corner of the globe is intuitively and empirically problematic.

Psychiatry’s flirtatious relationship to human rights is unhelpful, because like the best of flirts, one doesn’t quite know how to react. Global mental health leaders should renounce those who deploy the rhetoric of human rights to legitimize human rights violations. They should join the discourse on consent to treatment rather than ignoring or rejecting it out of hand. The human rights project is strengthened by a diversity of voices and perspectives. The voices must now focus on implementation of human rights standards, rather than denying that these standards exist.

The human rights project is of course broader than a critique of western psychiatry. Mental health professionals do not bear the burden of implementing human rights alone. If we want to instil an acceptance for difference and a celebration of diversity, we need to work with the youngest possible people. How else can we reasonably expect doctors to change when the only interaction with people with mental health issues they have is in medical school? Exposure to difference can only happen if all children—whatever their labels—are educated in the same setting, from the youngest age. Education, the CRPD says, is supposed to develop people’s “personality, talents and creativity,” and by doing so all children will realize that the talents and needs of others may be different to their own.⁴⁰ The obligation on governments is to “ensure an inclusive education system at all levels,” which is directed at nothing less than enabling people “to participate effectively in a free society.”

This paper began with a quotation by David Kennedy who pointed out that human rights can be jettisoned by the politics of power and legitimation. A human rights framework does not provide all the policy answers, but it offers a vision of diversity and acceptance, of autonomy and support. Mental health professionals have had unfettered power over individuals in many countries and with the balance of power now shifting, they need to re-evaluate their positions. The period leading up to the CRPD’s adoption in 2006 was an opportune time to discuss the sort of principles which should underpin human rights standards in the disability and mental health fields. Given that the treaty now exists, it is the responsibility of all service providers to engage in a discourse about how these established principles can be transformed into policy and practice.

⁴⁰ Convention on the Rights of Persons with Disabilities, *supra* note 21, art. 24.

Torture in Health Care Settings: Urgent Issues and Challenging Questions

YUVAL GINBAR & JAMES WELSH*

Abstract

This paper presents comments stimulated by the publication of the report in 2013 of the Special Rapporteur on torture concerning torture and ill treatment in health care settings. It focuses on issues arising with respect to the rights of persons with psychosocial and intellectual disabilities, and decision making in situations when free and informed consent is difficult to obtain, and urgent or otherwise crucial interventions may need to be taken to preserve life, physical integrity, and personal security. The paper welcomes the debate stimulated by the Special Rapporteur's report and, notwithstanding some points of variation, argues that increased attention to the treatment of persons in healthcare facilities is highly merited.

Introduction

The report of the Special Rapporteur on Torture on abuses in health-care settings that may amount to torture or other cruel, inhuman or degrading treatment or punishment (other ill-treatment) is an important contribution to the understanding of torture as a risk and a reality in health-care settings.¹ His report follows other ground-breaking work on the same theme.² In this paper, we comment on some of the issues raised in the Special Rapporteur's report and point to questions we believe require further analysis.

We welcome the clear overall message that comes out of the Special Rapporteur's report, namely that the human right to freedom from torture and other ill-treatment, and the legal framework set up to protect it, extend and are applicable to health care settings; and that abuse in such settings should be countered with the full force of that legal framework.

In this context it is important to emphasize that for this framework to apply effectively to the broad range of abuses that occur, in healthcare settings as elsewhere, the scope of the protection against torture and other ill-treatment must itself be viewed broadly. In our view, the Special

* Yuval Ginbar PhD, Legal Adviser; James Welsh PhD, Research/Adviser, Amnesty International, 1 Easton Street, London WC1X 0DW, UK, (yginbar@amnesty.org).

¹ Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, *2013 Report*, U.N. Doc. A/HRC/22/53 (2013) (by Juan Mendez), http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

² Mental Disability Rights Int'l, *Torment Not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities* (2007); Human Rights Watch, *Abusing Patients: Health Providers' Complicity in Torture and Cruel, Inhuman or Degrading Treatment* (2010), http://www.hrw.org/sites/default/files/related_material/patients_0.pdf; Open Society Foundations, *Government Accountability for Torture and Ill-Treatment in Health Settings* (2011), <http://www.opensocietyfoundations.org/sites/default/files/accountability-torture-health-20110511.pdf>.

Rapporteur's report seems often to set a high "entrance threshold" of cruel, inhuman or degrading treatment or punishment—in fact setting it at the same level of severity as that of torture. Thus, para. 39 states, *inter alia*, that "[m]edical care that causes severe suffering for no justifiable reason can be considered cruel, inhuman or degrading treatment or punishment."³ We are concerned that this appears to narrow the protection that the torture/ill-treatment legal framework can offer, confining it to extreme cases and excluding from its remit ill-treatment that must be prohibited even if may not cause "severe" pain or suffering. Instead, we recommend that the Special Rapporteur adopts the broader view of this prohibition, for instance, as explained within the U.N. Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment,⁴ namely that "[T]he term 'cruel, inhuman or degrading treatment or punishment' should be interpreted so as to extend the widest possible protection against abuses."⁵

At the same time, the torture/other ill-treatment legal framework must be applied carefully and precisely, taking into account that the human rights of persons, other than those being treated, may be involved. This requires maintaining openness to the possibility that other legal frameworks for the protection of human rights may at times be better equipped to address certain issues within healthcare settings. It also requires considering the far-reaching legal consequences of a finding of any ill-treatment, particularly torture, in cases where law and professional regulations are being followed. Whereas international law obviously prohibits torture and ill-treatment absolutely and in all circumstances, we are concerned that framing positions on certain measures which are not inherently torturous in absolute terms would not serve the rights of persons with disabilities; nor would linking such sweeping positions to the prohibition on torture and other ill-treatment encourage observance of that prohibition, which is indeed absolute.

In this paper, we outline our main concerns arising from our reading of the Special Rapporteur's report, focusing mostly on the way it addresses issues relating to the treatment of persons with intellectual or psychosocial disabilities in health-care settings. We do not comment on wider questions about disability—nor do we address larger, underlying issues relating to the validity of psychiatry, psychiatric treatment and related diagnostic schema.

1. Are "Psychosocial Disability" and "Mental Disorder" Different Descriptions of the Same Phenomena?

Psychosocial disability is a term introduced by the World Network of Users and Survivors of Psychiatry during the drafting of the Convention of the Rights of Persons with Disabilities and subsequently advocated as their terminology of choice.

WNUSP developed language to refer to persons with psychiatric disabilities that moved away from the medical model of individual pathology. We described ourselves as persons with psychosocial disabilities. The word psychosocial refers to the interaction between psychological and social/cultural components of our disability. The psychological component refers to ways of thinking and processing our experiences and our perception of the world around us. The social/cultural component refers to societal and cultural limits

³ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2013 Report, U.N. Doc. A/HRC/22/53 paras. 20, 54, 64, 69 (2013) (by Juan Mendez), *See also* paras. 20, 54, 64, 69.

⁴ U.N. Body of Principles for the Protection of All Persons Under Any Form of Detention or Imprisonment, U.N. G.A. 43/173 (1988).

⁵ *Id.*, at Principle 7.

for behavior that interact with those psychological differences/madness as well as the stigma that the society attaches to labeling us as disabled.⁶

A publication of the Australian National Mental Health Consumer and Carer Forum⁷ offers this summary of the term that links it with underlying mental disorders:

The term 'psychosocial disability'...has not been widely used in the Australian community. It is a term preferred by mental health consumers and carers to describe living with a disability that is associated with a severe mental health condition. As with other disabilities, a psychosocial disability associated with a mental health condition is the result of the complex interactions between limitations in activity (related to impairments associated with usually severe mental health conditions) and the environment in which people live. As with other disabilities, not all people with a mental health condition will experience a psychosocial disability. Many will go on to lead fulfilling and productive lives with little support.

In addition to psychosocial disability as defined above, a related area of human rights concern is intellectual disability (known in some regions as “learning disability” or similar). Intellectual disability differs from psychosocial disability in that it arises from an incomplete developmental process during early life or as a result of trauma later in life. It defines conditions marked by an individual’s diminished intellectual and adaptive capacities.

Mental health professionals and the media tend to use terms such as “mental illness,” “mental health condition,” or “mental disorder,” to describe patterns of thinking and behavior that differ significantly from the norm and are believed to constitute a diagnosable medical condition. In previous times the notion of “mental illness” was regarded as a progressive and non-stigmatizing description of people who might otherwise have been regarded as affected by moral failings or divine punishment and subject to exclusion and harsh treatment. However, this term (and the wider “medical model”) is now regarded by some as stigmatizing and medicalizing of a person’s behavior, identity, and self-perception, though it is still widely used both in day-to-day language and in the law.⁸ While the two terms—psychosocial disability and mental disorder⁹—appear to describe similar phenomena, they are not entirely interchangeable: there are short term disorders that may not be consistent with the notion of disability referred to in the Convention on the Rights of Persons with Disabilities (Art. 1) since they do not meet its “long term...impairments” criterion. There are also disorders that arise from an organic event in the body—there may be psychosocial outcomes, but the “medical model” is relevant in understanding, diagnosing, and providing care for the disorder. It is possible that in the foreseeable future social analysts, disability groups, and human rights bodies will increasingly use the term “psychosocial disability” while health professionals, governments, and courts will continue to refer to mental illness/disorder/impairment.

⁶ WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY [WNUSP], IMPLEMENTATION MANUAL FOR THE U.N. CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2008), available at <http://www.un.org/disabilities/documents/COP/WNUSP%20CRPD%20Manual.doc>.

⁷ National Mental Health Consumer & Carer Forum, *Unravelling Psychosocial Disability, A Position Statement by the National Mental Health Consumer & Carer Forum on Psychosocial Disability Associated with Mental Health Conditions* (2011).

⁸ For example, the term “mental retardation,” now widely discarded, unfortunately remains in international diagnostic manuals, see World Health Org., *International Statistical Classification of Diseases and Related Health Problems*, F70-79 (2010).

⁹ World Health Org., *WHO Resource Book on Mental Health, Human Rights and Legislation* 21 (2005) (We use the term “disorder” in the manner defined by WHO as “a clinically recognisable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions” but not “social deviance or conflict alone.”).

There may also be terminology linking both audiences, such as “mental and psychosocial disabilities.”¹⁰ For the moment, it seems likely that disability and medical language will co-exist though often addressing substantially different audiences. We will use the term “psychosocial disability” in this paper, but will occasionally refer, alongside it, to “mental disorder,” as we hold the view that at times greater clarity is achieved by describing certain conditions in medical terms.

2. Who Cares for Those Whose Needs Arise from Psychosocial Disability or Mental Disorder?

Many people who experience serious psychosocial and intellectual disabilities receive little more than abuse and harassment despite having significant need of support. This is particularly the case where special services for this population are non-existent or under-developed and where official, as well as social, attitudes are discriminatory and stigmatizing. Where help is available, carers range from family members, religious or charitable bodies, local doctors and nurses, self help groups, community services through to specialist mental health workers. Globally, only a fraction of those with psychosocial or intellectual disabilities see effective community services or professional staff such as social workers, psychologists, or medical doctors specializing in psychiatry. A number of writers have identified lack of access to physical and mental care as, variously, matters of social justice,¹¹ inequity,¹² and a “failure of humanity.”¹³ While some critics of psychiatry are concerned by the medicalization of disability and, more generally, pathologization of normal life experiences or mild problems, others point to the lack of adequate support and services for people with intellectual or psychosocial disabilities, and particularly the failure to respect and protect their human rights. This was neatly summarized by the editors of Public Library of Science Medicine journal:

*Among all the conditions in the world of health, mental health occupies a unique and paradoxical place. On the one hand is over-treatment and over-medicalization of mental health issues... On the other hand exists profound under-recognition of the suffering and breadth of mental health issues affecting millions of people across geographies.*¹⁴

While the discussion engendered by the Special Rapporteur's report is focused on the first half of this “paradox” we should not lose sight of the widespread suffering that is not currently being effectively addressed in many parts of the world.

3. When do Harmful Acts in Healthcare Constitute Torture or Other Ill-Treatment?

There can be little doubt that many of the experiences described in the report of the SRT may often involve significant or severe pain or suffering. Ill-treatment of drug users, by holding them involuntarily and subjecting them to “painful withdrawal from drug dependence without medical assistance, administration of unknown or experimental medications, State-sanctioned beatings,

¹⁰ Natalie Drew et al., *Human Rights Violations of People With Mental and Psychosocial Disabilities: An Unresolved Global Crisis*, 378 LANCET 1664-75 (2011).

¹¹ Ezra Susser & Michaeline Bresnahan, GLOBAL MENTAL HEALTH AND SOCIAL JUSTICE, IN MENTAL HEALTH AND HUMAN RIGHTS: VISION, PRAXIS AND COURAGE 195-205 (M Dudley et al., 2012).

¹² Jonathan K. Burns, *Mental Health And Inequity: A Human Rights Approach To Inequality, Discrimination, and Mental Disability*, 11 HEALTH AND HUMAN RIGHTS 19-31 (2009).

¹³ Arthur Kleinman, *Global Mental Health: A Failure of Humanity*, 374 LANCET 603-604 (2009).

¹⁴ PLOS Medicine Editors, *The Paradox of Mental Health: Over-Treatment and Under-Recognition*, PLOS MEDICINE (2013), 10(5): e1001456. DOI:10.1371/JOURNAL.PMED.1001456.

caning or whipping, forced labor, sexual abuse and intentional humiliation”¹⁵ is clearly within the remits of Articles 1 and 16 of the Convention against Torture (“CAT”), Article 7 of the International Covenant on Civil and Political Rights (“ICCPR”) and other international treaties and standards.

Similarly, other medical practices also conflict with medical ethics. These include:

*[I]nvoluntary sterilization; denial of legally available health services such as abortion and post-abortion care; forced abortions and sterilizations; female genital mutilation; violations of medical secrecy and confidentiality in health-care settings, such as denunciations of women by medical personnel when evidence of illegal abortion is found; and the practice of attempting to obtain confessions as a condition of potentially life-saving medical treatment after abortion.*¹⁶

These may either constitute torture or other ill-treatment directly, or else illustrate a lack of due diligence by government in the protection of women and girls from abuse.¹⁷

Whether acts of these types will constitute cruel, inhuman or degrading treatment or punishment—or torture—will depend on the circumstances, in particular whether or not the acts were done intentionally and for a purpose such as those listed in Article 1(1) of the Convention against Torture (or for any reason based on discrimination), as well as the severity of the pain or suffering inflicted by the act. In assessing “severity”, the victim’s mental as well as physical suffering must be considered, taking into account his or her individual experience.

Other healthcare settings discussed in the report—hospitals in which pain control is required, but not supplied and involuntary placement of persons with psychosocial disabilities or mental disorders in psychiatric or other institutions—raise further questions. Clearly both are areas where human rights, including the right to freedom from torture and other ill-treatment, can be (and in fact are) placed under considerable threat.¹⁸ However, both issues may also raise complex questions, including as to when they would involve human rights violations and when they would not, as will be discussed below. The report of the Special Rapporteur acknowledges for instance that not all denial of pain control can be regarded as cruel, inhuman or degrading treatment, or punishment, though it could be so, among other things “when the State is, or should be, aware of the suffering, including when no appropriate treatment was offered; and when the Government failed to take all reasonable steps to protect individuals’ physical and mental integrity.”¹⁹ This implicitly recognizes the inevitability of decisions by healthcare staff being constrained by available resources, and that it is often not staff on the ground but senior managers up to Ministerial level who are responsible—and therefore accountable—for the availability of such medication. Measures to control the use of addictive drugs may also be taken by doctors in the exercise of their clinical judgment. Again they must be held accountable for their decisions but limitations placed on pain control medication

¹⁵ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2013 Report, U.N. Doc. A/HRC/22/53 para. 41 (2013) (by Juan Mendez).

¹⁶ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2013 Report, U.N. Doc. A/HRC/22/53 para. 46 (2013) (by Juan Mendez).

¹⁷ Amnesty Int’l, *Colombia: ‘This Is What We Demand, Justice!’: Impunity for Sexual Violence Against Women in Colombia’s Armed Conflict*, AMR 23/018/2011 (2011); Amnesty Int’l, *Rape And Sexual Violence: Human Rights Law and Standards in the International Criminal Court*, IOR 53/001/2011 (2011); Amnesty Int’l, *Realizing Sexual And Reproductive Rights: A Human Rights Framework*, ACT 35/006/2012 (2012).

¹⁸ Human Rights Watch, *Global State of Pain Treatment: Access to Palliative Care as a Human Right*, (2011); U.N. Office of the High Comm’r on Human Rights, *Expert Seminar on Freedom from Torture and Ill Treatment and Persons with Disabilities* (2007), <http://www2.ohchr.org/english/issues/disability/docs/torture/seminartorturereportfinal.doc>.

¹⁹ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2013 Report, U.N. Doc. A/HRC/22/53 para. 54 (2013) (by Juan Mendez).

may reflect honest, professional decisions made by those who prescribe and use the drugs to treat patients.²⁰

Ill-thought-out drug policies instituted by governments must also be regarded as contributing to problems relating to the supply of opioids and other controlled medicines. The role of domestic laws in circumscribing behavior of healthcare professionals and thus placing limits on clinical freedoms can be challenged on ethical grounds, but breaches of the law by doctors (such as illegal supply of drugs even with good intentions) may nevertheless lead to prosecutions—a variation of dual loyalties.

In the case of emergency medical care at the scene of an accident or an improvised medical intervention (such as in the case of a woman who unexpectedly undergoes a painful birth) it may not be feasible to adequately control the pain, in which case the question of whether or not uncontrolled pain amounts to torture or other ill-treatment would not arise. Conversely, the denial of pain control when it is (or should be) available is both unethical and in breach of right to highest attainable health standards. Where there is official involvement, deliberate withholding of available palliative care recommended by best practice would constitute ill-treatment or even torture.²¹ Factors such as availability of enough drugs to provide all those who need the care, availability of trained staff, and matters of clinical judgment as to priority, are all appropriate considerations bearing on whether any individual receives the palliative medication they need. Jurisprudence on the human rights aspects of these issues is yet to be developed.

Despite the adoption of the Optional Protocol to the Convention against Torture (“OPCAT”), which extends to “any place under its jurisdiction and control where persons are or may be deprived of their liberty”²² the development of monitoring of social care homes and mental institutions (both of which may have voluntary as well as involuntary residents) has lagged behind. And interviewing inmates of such institutions is not without challenges. The possible vulnerability of persons in institutions is well captured in the ITHACA²³ Toolkit, a guide developed to monitor human rights and health care in mental health and social care institutions:

Some people in such institutions have profound disabilities and . . . would find it difficult to communicate [to external monitors] any human rights violations they are suffering. In addition, institutions are often far removed from urban centers and there are few visitors, no means of communicating with the outside world, no groups providing an advocacy service, and no State-funded lawyers to take up allegations of human rights violations.²⁴

²⁰ World Health Org., *Ensuring Balance in National Policies on Controlled Substances: Guidance for Availability and Accessibility of Controlled Medicines*, (2011); American Academy of Pain Medicine, the American Pain Society & the American Society of Addiction Medicine [AAPM et al.], *Public Policy Statement on the Rights and Responsibilities of Healthcare Professionals in the Use of Opioids for the Treatment of Pain: A consensus document from the American Academy of Pain Medicine, the American Pain Society, and the American Society of Addiction Medicine* (2004), <http://tinyurl.com/jwg9okg>.

²¹ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2009 Report, U.N. Doc. A/HRC/10/44 para. 72 (2009) (by Manfred Nowak).

²² Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Dec. 18, 2002, G.A. Res. A/RES/57/199 Art. 3 (entered into force June 22, 2006).

²³ ITHACA stands for “Institutional Treatment, Human Rights and Care Assessment.” See ITHACA Project Group, *ITHACA Toolkit for Monitoring Human Rights and General Health Care in Mental Health and Social Care Institutions* 5 (2010).

²⁴ ITHACA Project Group, *ITHACA Toolkit for Monitoring Human Rights and General Health Care in Mental Health and Social Care Institutions* 5 (2010).

This has been the situation documented by NGOs examining the human rights situation in a number of social care homes in Europe—the use of terms such as “abandoned” and “out of sight” in the report titles underlines this.²⁵

4. Is Involuntary Psychiatric Treatment Inherently a Form of Torture or Other Ill-Treatment?

This question is posed in response to claims that psychiatry, at least when used to treat patients involuntarily, is indeed, *eo ipso*, a form of torture or other ill-treatment and not just that it can be *abused* so as to constitute either, as was the case, for example, where psychiatry was a governmental tool of political repression.²⁶

A number of reports and advocacy positions state that involuntary psychiatric treatment either constitutes, or might constitute, torture or other ill-treatment. The Special Rapporteur’s report states unequivocally that “involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.”²⁷

In our view this position needs refinement. Arguably, all forms of medical practice are open to abuse, but we believe that currently no form of science-led, ethically applied, and professionally regulated medicine should be viewed as *inherently and categorically* constituting torture or other ill-treatment. This does not automatically change, even when treatment is involuntary, as long as such treatment is applied within the very narrow confines and subject to extensive safeguards and oversight as outlined below. Nevertheless, the potential for abuses of psychiatry constituting torture or other ill-treatment has been known for many years. Bloch and Reddaway,²⁸ writing of Soviet psychiatric abuse in the 1970s, suggested some reasons why psychiatry was amenable to use for political purposes: “psychiatry’s boundaries are exceedingly blurred and ill-defined; little agreement exists on the criteria for defining mental illness; the mentally ill are often used as scapegoats for society’s fears; and the psychiatrist commonly faces a dual loyalty [to patient and to institution].”

Arguably these observations remain valid though politically motivated abuse of psychiatry is not common. However, abuses perpetrated without any apparent political motivation are evident. The involuntary application of neuroleptic medication to manage residents of nursing homes,²⁹ or

²⁵ Mental Disability Rights Int’l, *Abandoned and Disappeared: Mexico’s Segregation and Abuse of Children and Adults with Disabilities* (2010); Mental Disability Advoc. Ctr., *Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia* (2010).

²⁶ Amnesty Int’l, *Prisoners of Conscience in the USSR: Their Treatment and Conditions* (1980).

²⁷ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, 2013 Report, U.N. Doc. A/HRC/22/53 para. 64 (2013) (by Juan Mendez); cf. *Submission By The European Network Of (Ex-) Users and Survivors of Psychiatry, International Disability Alliance, Mental Disability Advocacy Center, and the World Network of Users and Survivors of Psychiatry to the UN Special Rapporteur on Torture on his Upcoming Thematic Paper on Torture in the Context of Healthcare*, World Network of Users and Survivors of Psychiatry paras. 17, 28 (2012), http://www.wnusp.net/documents/2012/2012_11_06_TortureInHealthcare_submission.doc. (stating that “[f]orced commitment and treatment in health care facilities are forms of torture and ill-treatment” and “[f]orced psychiatric interventions are not only a violation of the CRPD, but are also forms of torture and ill-treatment.”)

²⁸ SIDNEY BLOCH & PETER REDDWAY, *RUSSIA’S POLITICAL HOSPITALS* (1977).

²⁹ *Antipsychotic Drugs Called Hazardous for the Elderly*, N.Y. Times, May 9, 2011, <http://www.nytimes.com/2011/05/10/health/policy/10drug.html>.

to facilitate capital punishment,³⁰ and the use of unmodified electroconvulsive therapy (“ECT”),³¹ all breach good practice guidelines and the human rights of those affected, including the right to freedom from torture and other ill-treatment. The World Health Organization (“WHO”)³² recommends a requirement of informed consent for the use of ECT, which should include the use of anesthesia and muscle relaxants—so-called modified ECT. WHO calls for an end to the use of unmodified ECT, for use to be based on informed consent and for legislation against the use of ECT for juveniles.³³ Others argue for a complete ban on ECT in all circumstances³⁴ though this procedure remains in use in many countries.

With regard to psychosocial disabilities or mental disorders, there have been challenges to the tenets of psychiatry for many years including by the so-called anti-psychiatrist movement of the 1960s (articulated by critical psychiatrists of different hues,³⁵ and in subsequent decades by a range of critics including user and self-help groups.)³⁶ Professional debate about the most appropriate response to psychosocial disabilities, including the role of diagnosis, continues.³⁷ Other stake holders—support organizations, mental health care professionals, professional bodies, etc.—have adopted a range of positions on mental health care, professional ethics, and human rights.³⁸

Conditions considered as mental disorders are multiple, and range from those that appear to have no clear physical origin through to changes in thought, or behavior, arising from physical changes in the body, such as hormonal changes, disease, or injury. Conditions such as autism remain to be fully understood. A social understanding of some forms of “mental disorder” as a disability is characterized by the existence of an impediment or form of behavior that, in conjunction with negative reactions and/or neglect from society “disables” the person. It is this latter factor—discrimination, prejudice and inadequate investment in facilities and support—that has given rise to demands that states guarantee “reasonable accommodation” of the person’s disability-related needs. Earlier in this century, these demands were defined and codified into an international legal term, within the U.N. Convention on the Rights of Persons with Disabilities.³⁹

To stress the obvious, good health is better than bad health. The right to the highest attainable standard of physical and mental health, as articulated in article 12 of the ICESCR, is interpreted in the relevant general comment in terms of states’ obligations to respect, protect and fulfill this

³⁰ Howard V. Zonana, *Competency to be Executed and Forced Medication: Singleton V. Norris*, 31 J. OF THE AM. ACAD. OF PSYCHIATRY AND THE L. 372-6 (2003).

³¹ Human Rights Watch, *“Like a Death Sentence”: Abuses Against Persons With Mental Disabilities in Ghana*, (2012), <http://www.hrw.org/sites/default/files/reports/ghana1012webwcover.pdf>.

³² World Health Org., *WHO Resource Book on Mental Health, Human Rights and Legislation* at 64 (2005).

³³ “There are no indications for the use of ECT on minors, and hence this should be prohibited through legislation.” (World Health Organization, 2005 at 64.)

³⁴ PsychOut: A Conference for Organizing Resistance Against Psychiatry, Toronto, Can., 2010, *Electroshock Must Be Banned Now: Strategies of Resistance* (by Don Weitz), http://www.oise.utoronto.ca/psychout/panels/weitz_paper.pdf.

³⁵ RONALD D. LAING, *THE DIVIDED SELF* (1965); *PSYCHIATRY AND ANTI-PSYCHIATRY* (D COOPER ED., 1967); THOMAS SZASZ, *THE MYTH OF MENTAL ILLNESS* (1961).

³⁶ See e.g., the World Network of Users and Survivors of Psychiatry (www.wnusp.net).

³⁷ Felicity Callard et al., *Debate: Has Psychiatric Diagnosis Labeled Rather Than Enabled Patients?*, 347 BRITISH MED. J. (2013).

³⁸ See e.g., the World Psychiatric Association www.wpanet.org; World Federation for Mental Health www.wfmh.com; Movement for Global Mental Health <http://www.globalmentalhealth.org/>; International Association for Suicide Prevention <http://www.iasp.info/>.

³⁹ Convention on the Rights of Persons with Disabilities [CRPD], U.N. G.A. Res. 61/106 at Art. 2 (December 13, 2006) (entered into force May 3, 2008); Peter Bartlett, *The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law*, 75 THE MODERN L. REV. 752-778 (2012).

right and little attention is given to the right to reject healthcare.⁴⁰ Nevertheless there is a widely-held view, which we share, and is enshrined in medical ethics,⁴¹ and international human rights law, (most recently the CRPD⁴²) that people have a right to refuse or to withdraw from treatment even if is intended, or indeed guaranteed, to improve their health. Obtaining informed consent to treatment, care, or participation in medical research (“experimentation”) is essential, and enshrined in medical ethics,⁴³ in international principles⁴⁴ and in domestic legislation. The Special Rapporteur on the right to health has also underscored the importance of informed consent, noting the inadequacy of the Mental Illness Principles⁴⁵ to protect the right to consent and that “decisions to administer treatment without consent are often driven by inappropriate considerations [arising from] ignorance or stigma surrounding mental disabilities, and expediency or indifference on the part of staff.”⁴⁶

Nevertheless, the paragraph above has to be read with the recognition that many, or most countries, have legislation that provides for modifying procedures relating to consent where the individual being offered treatment is regarded as lacking capacity to make informed decisions. While such legislation is often problematic (see below), this does not necessarily mean that the principle at its core is unacceptable.

There are already elaborate procedures in many countries which attempt to facilitate clinically necessary interventions in the face of non-consent arising from lack of, or loss of, capacity for a variety of reasons (see below) while ensuring respect for the rights of the affected individual.

However, current laws and practices throughout the world often involve plenary guardianship regimes that deprive persons with intellectual or psychosocial disabilities of their human right to be recognized as persons before the law.⁴⁷ In its Concluding Observations on states parties’ reports, the Committee on the Rights of Persons with Disabilities (“CRPD Committee”) has, since its establishment, consistently expressed concerns about states maintaining systems of legal guardianship

⁴⁰ Committee on Economic, Social and Cultural Rights [CESCR], *General Comment 14*, UN Doc. E/C.12/2000/4 (2000).

⁴¹ World Medical Assc., *Declaration of Lisbon on the Rights of the Patient* (1981), <http://www.wma.net/en/30publications/10policies/14/>

⁴² Convention on the Rights of Persons with Disabilities [CRPD], U.N. G.A. Res. 61/106 (December 13, 2006) (entered into force May 3, 2008).

⁴³ World Medical Assc., *Declaration of Helsinki—Ethical Principles for Medical Research Involving Human Subjects* (1964), <http://www.wma.net/en/30publications/10policies/b3/>.

⁴⁴ International Covenant on Civil and Political Rights [ICCPR], G.A. Res. 2200A (XXI), at Art. 7 (Dec. 16 1966), <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx>; U.S. Government Printing Office, *Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10*, Vol. 2, 181–2 (1949).

⁴⁵ Protection of Persons with Mental Illness and the Improvement of Mental Health Care [Mental Illness Principles], G.A. Res. 46/119 (Dec. 17, 1991), <http://www.ohchr.org/EN/ProfessionalInterest/Pages/PersonsWithMentalIllness.aspx>.

⁴⁶ Special Rapporteur On The Right Of Everyone To The Enjoyment Of The Highest Attainable Standard Of Physical And Mental Health, *2005 Report*, U.N. Doc. E/CN.4/2005/51 para. 89 (2005) (by Paul Hunt).

⁴⁷ International Covenant on Civil and Political Rights [ICCPR], G.A. Res. 2200A (XXI) at Art. 16 (Dec. 16 1966), <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx>; Convention on the Rights of Persons with Disabilities [CRPD], U.N. G.A. Res. 61/106 at Art. 12 (December 13, 2006) (entered into force May 3, 2008).

for persons with intellectual and psychosocial disabilities, and has recommended that they replace substitute decision-making by supported decision-making,⁴⁸ in the exercise of legal capacity.⁴⁹

Nevertheless, while the Committee is clearly opposed to guardianship regimes, it has so far (as of August 2013) refrained from interpreting Article 12 of the CRPD as dictating, categorically, that under no circumstances whatsoever may the decision-making of persons with disabilities ever be taken over by others. We believe that adopting such a sweeping position would be excessive and unwarranted, not least because it would set disabled persons apart from the non-disabled and thus be discriminatory, which the CRPD itself does not allow. This is specifically true in health care settings: “informed consent”, while having absolute aspects (e.g. right to give or withhold consent to participation in research or to accept a particular medical procedure), is not a one-size-fits-all categorical imperative and in practice, as Henry Beecher has famously contended, often “[c]onsent in any fully informed sense may not be obtainable.”⁵⁰ This is not to undermine the centrality of informed consent, but rather to acknowledge that it cannot always be obtained in circumstances where humanity, compassion and urgency require action.

Loss of capacity to make decisions, when decisions must be made in order to avoid irreparable harm, severe suffering or death, may occur in a wide variety of situations, and while they may constitute a small minority of the cases, they nevertheless cannot be set aside or ignored, let alone denied. Such situations may be acute—among them injury, complications during/post operations or childbirth, loss of consciousness, the influence of drugs (including alcohol) and more; or they may be chronic—including where individuals are suffering from advanced dementia, are comatose, in persistent vegetative states or are reaching the end of their lives. The loss of capacity for decision-making by persons with intellectual and psychosocial disabilities and other mental disorders, including as a short-term or long-term effect of their disability/disorder, may occur (again—in a minority of cases but not a negligible minority) in both acute and chronic situations. An individual in any of these situations, be they disabled or non-disabled, may be or become incapable of understanding the choices he or she faces, of making such choices or of communicating decisions on his/her choices to others. The fact that informed consent at times cannot be obtained due to communication problems rather than to the person’s clear opposition to the treatment further militates against placing an absolute requirement for informed consent from the affected person where delayed treatment could have serious consequences—and *a fortiori*, against all non-consensual treatment being automatically linked to the absolute prohibition on torture and other ill-treatment.

In sum, these situations are almost invariably difficult and complex, and to our mind require solutions that take into account a variety of aspects and indeed rights. We support in the strongest way the principle of informed consent but suggest that individuals, both disabled and non-disabled, are not always in the position to give it and a variety of measures, including legislation, are needed to address this.

⁴⁸ Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making*, 19 HUMAN RIGHTS BRIEF 10 (2012) (“Supported decision making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life”); LEGAL CAPACITY AND SUPPORTED DECISION-MAKING, U.N. ENABLE (2013), <http://www.un.org/disabilities/default.asp?id=242>.

⁴⁹ Report of the Committee on the Rights of Persons with Disabilities (2011-12), U.N. Doc. A/68/55, Annex II, (A) Tunisia, ¶¶22-23; (B), Spain, ¶¶33-4; (C), Peru, ¶¶24-5; C(D), Argentina, ¶¶19-20, China, ¶¶21-2, Hungary, ¶¶25-6; Concluding observations on the initial report of Paraguay, U.N. Doc. CRPD/C/PRY/CO/1 at ¶¶29-30 (2013).

⁵⁰ Henry K. Beecher, ETHICS AND CLINICAL RESEARCH, in BIOETHICS: AN ANTHOLOGY 506 (Kuhse & Singer eds., 2006).

Thus the Council of Europe's Commissioner on Human Rights, while opposing (like the CRPD Committee) depriving persons with disabilities of their legal capacity, nevertheless stated that:

[T]here will be situations of communication difficulties despite genuine efforts to support the individual. In such cases it may be necessary to resort to "best interests" reasoning—seeking to find out what the person would have wanted, if communication had worked.⁵¹

In our view this approach, which combines practicality, sensitivity, and non-discrimination—since it applies both to disabled and non-disabled persons—and advocates individual solutions to individual situations, better reflects human right values and principles than the blanket imposition of a single solution—obtaining informed consent of the individual concerned—which in any case may not always be achievable in practice.

However, in our view, no one must fall within the narrow exceptions to the "informed consent" rule automatically, due solely to the fact that they are disabled; rather, this can only be determined on the basis of the specific circumstances of the specific individual.⁵²

More generally, non-consensual treatment can only take place once it is clear that either urgency (in acute situations), or the exhaustion of efforts at direct or supported decision-making by the individual concerned leave supporters and carers with little or no other choice if they are to prevent serious harm or suffering from befalling that individual. Such treatment must be limited to the minimum necessary in the circumstances, if it is of longer duration, it must be subjected to frequent review, including access to judicial oversight. In particular, whenever such treatment involves individuals being placed in closed settings without their consent, this must be considered a deprivation of liberty, therefore subjected to the full safeguards established under human right treaties, such as Article 9 of the ICCPR.⁵³

Lastly, as soon as a person regains his or her capacity to make decisions, directly or with support, that power must return to him or her. On no account should a determination that a person has regained this capacity be conditioned on him or her being "cured" of their disability as such.

We believe that there are serious problems associated with classifying as torture acts whose sole intention is to treat a suffering patient, and whose sole purpose is his or her enhanced well-being and improved health, and where any resultant pain or suffering is considered an undesired and unwelcome side effect which doctors seek to minimize, indeed to avoid altogether where possible.⁵⁴ Such acts may at times involve serious misconceptions, mistakes and negligence, which result in unnecessary and avoidable pain and suffering, and may in turn, in certain circumstances, fall within the remit of cruel, inhuman or degrading treatment; however, we believe it would be wrong to place them in the same category as acts where the victim's severe pain or suffering is the cho-

⁵¹ Thomas Hammarberg, *Comment: Persons With Intellectual and Psycho-Social Disabilities Must Not Be Deprived of their Individual Rights*, THE COUNCIL OF EUROPE COMMISSIONER ON HUMAN RIGHTS (FEB. 20, 2012), http://commissioner.cws.coe.int/tiki-view_blog_post.php?postId=207.

⁵² See e.g., NHS Education for Scotland, *Think Capacity. Think Consent* (2012) (noting that "Capacity to consent must always be assessed and incapacity should never be presumed because a person has a particular health condition or disability").

⁵³ Cf. Council of Europe, Commissioner For Human Rights, *Who Gets to Decide? Right to Legal Capacity for Persons With Intellectual and Psychosocial Disabilities* 6 (2012).

⁵⁴ The European Court of Human Rights has stated that "A measure which is of therapeutic necessity from the point of view of established principles of medicine cannot in principle be regarded as inhuman and degrading" (see *Herczegfalvy v. Austria*, 10533/83 Eur. Ct. H.R. 244 para. 82 (1992); *Nevmerzhitsky v. Ukraine*, 54825/00 Eur. Ct. H.R. 210 at para. 94 (2005)). The Court's rulings on force feeding in these two cases suggest that although therapeutic necessity may be a relevant factor in the Court's view, the manner in which procedures are carried out can indeed be material for a finding of torture.

sen, desired means to the torturer's ends. The "good intentions" of carers criticized in the Special Rapporteur's report⁵⁵ cannot of course excuse acts of incompetence or callousness, but good intentions certainly are a marker of a different purpose from that usually manifested by torturers.

The Special Rapporteur, following his predecessor, argues that "the discriminatory character of forced psychiatric interventions, when committed against persons with psychosocial disabilities, satisfies both intent and purpose required under the Article 1 of the Convention against Torture, notwithstanding claims of 'good intentions' by medical professionals."⁵⁶ We believe that, with torture being, not only a serious human rights violation, but also an internationally recognized and universally prosecutable crime, it may be more helpful to establish in each case whether or not specific acts did indeed satisfy these requirements.⁵⁷

Forced psychiatric interventions may in certain cases indeed be motivated by discriminatory attitudes towards persons with mental disorders or psychosocial or intellectual disabilities, giving rise to the possibility that they would constitute torture or other ill-treatment. However, as noted, in other cases such interventions are carried out either in situations of dire emergency or else they follow extensive consultations which focus on the specific condition and circumstances of the individual concerned, including serious efforts to obtain informed consent, and limited to treatment that is perceived as being in the best interest of that person not only by professionals, but also by the person's decision-making supporters and loved ones—and where non-intervention could result in serious harm or irreparable damage to the person concerned or else risk harm to others.⁵⁸ We believe that to brand such acts of intervention as torture without even considering the specific circumstances of individual cases, is not conducive to principled and effective protection against torture and other ill-treatment.

5. Should There Be an Absolute Ban on Restraints and Seclusion?

Amnesty International has worked for decades against unlawful use of restraints⁵⁹ and isolation of prisoners.⁶⁰ However, here too we are concerned that placing an absolute, sweeping ban when it comes to persons with disabilities, and linking it to the absolute prohibition on torture and other ill-treatment, is neither desirable nor practicable. An absolute ban may entail compromising the rights of other persons and allowing, indeed forcing, states into failing in their duty to exercise due diligence in protecting human rights from abuses by non-state actors⁶¹ without necessarily serving the interests of the persons concerned.

⁵⁵ At paras. 32, 61.

⁵⁶ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, *2013 Report*, U.N. Doc. A/HRC/22/53 para. 32 (2013) (by Juan Mendez).

⁵⁷ It should be noted that under the definition in Art. 1(1) of the Convention against Torture, discrimination is not a purpose but rather an alternative to purpose, as indicated by the use of "or" separating these alternate requirements.

⁵⁸ In some cases, domestic courts have set standards of accountability that require staff to intervene in cases of risky behavior including suicide attempts.

⁵⁹ Amnesty Int'l, *Report on Torture*, ACT 40/001/1973 (1973); Amnesty Int'l, *Pakistan: Medical Concern: Cruel, Inhuman or Degrading Treatment: Use of Fetters*, London ASA 33/020/1995 (1995); Amnesty Int'l, *Republic of Cameroon: Make Human Rights a Reality*, AFR 17/001/2013 (2013).

⁶⁰ Amnesty Int'l, *USA: The Edge of Endurance: Prison Conditions in California's Security Housing Units*, AMR 51/060/2012 (2012).

⁶¹ See e.g., Committee On The Elimination Of Discrimination Against Women, *General Recommendation 19*, UN Doc. HRI\GEN\1\Rev.1 para. 9 (1994); Committee on Economic, Social and Cultural Rights [CESCR], *General Comment No. 16*, UN Doc. E/C.12/2005/4 para. 7(2005); Committee Against Torture [CAT], *General Comment No. 2*, UN Doc. CAT/C/GC/2 para.18 (2008).

Policies of restraining and secluding persons with disabilities for prolonged periods, and using inhumane means, are widely recognized as unacceptable as much from professional as from human rights viewpoints.⁶² We, therefore, support placing wide-ranging constraints on their use. However, while safeguards within international standards governing the use of restraints (for instance Articles 33-4 of the Standard Minimum Rules for the Treatment of Prisoners)⁶³ need strengthening, restraints may also, in certain circumstances, be used for legitimate reasons, including against persons deprived of liberty—such as for preventing a person from harming others or self. In these circumstances only humane instruments may be used, for the shortest period of time necessary, and under constant supervision, and with accountability mechanisms in place; however, banning them in all circumstances may expose other persons—including those who are themselves vulnerable and helpless—to harm.

Therefore a call for an “absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities,” that “should apply in all places of deprivation of liberty, including in psychiatric and social care institutions”⁶⁴ is more restrictive than measures applied to other detainees, and goes beyond existing human rights standards and practice. The Committee for the Prevention of Torture in Europe (“CPT”), for example, notes that “instruments of physical restraint shall only very rarely be justified” and, where used, “should be removed at the earliest possible opportunity. They should never be applied, or their application prolonged, as a punishment.”⁶⁵ The same is true about seclusion for extremely short durations—indeed as a measure of restraint—against persons who are behaving violently, allowing time for them to calm down or bring others to safety. It is an extreme measure, which may be used only in the direst of situations, but an absolute ban could leave the authorities with little or no means of protecting those towards whom they have a duty of care.

If people with psychological or intellectual disabilities are to be treated as persons with equal rights, which, obviously, we advocate, they cannot have the freedom to harm others any more than non-disabled persons can. Measures to ensure that persons with such disabilities do not cause harm should certainly be adapted to their particular needs and (where present) vulnerabilities, but the authorities, including in health-care settings, must nevertheless have at their disposal means of protection against all persons behaving violently.⁶⁶

Recommendations

The report of the Special Rapporteur rightly shines a light on some areas where human rights violations, at times involving torture and other cruel, inhuman or degrading treatment or punishment, occur within health-care settings, and for this reason is very welcome.

⁶² American Psychiatric Nurses Association [APNA], *Position Statement on the Use of Seclusion and Restraint* (2007), http://www.apna.org/files/public/APNA_SR_Position_Statement_Final.pdf.

⁶³ U.N. Office of the High Comm’r on Human Rights, *Standard Minimum Rules for the Treatment of Prisoners*, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/TreatmentOfPrisoners.aspx>.

⁶⁴ Special Rapporteur on Torture And Other Cruel, Inhuman Or Degrading Treatment Or Punishment, *2013 Report*, U.N. Doc. A/HRC/22/53 para. 63 (2013) (by Juan Mendez).

⁶⁵ European Committee for the Prevention of Torture and Inhuman or Degrading Treatment [CPT], *CPT Standards*, CPT/Inf/E (2002) 1–Rev. 2011 at 44 para 4. (2002).

⁶⁶ The link between psychosocial disability and violence is regularly over-played in the media. As one observer pointed out “most people who are violent are not mentally ill, and most people who are mentally ill are not violent” (Richard A. Friedman, *Violence And Mental Illness—How Strong Is The Link?*, 355 NEW ENGLAND J. OF MED. 2064-2066 (2006)). Nevertheless (and obviously), persons with intellectual or psychosocial disabilities may become violent for reasons unrelated to their disability.

However, care must be taken both in defining and delineating the human rights involved in health-care settings—and the corresponding duties of states, and in applying the legal framework of protection against torture and other ill-treatment to these settings.

We all agree that human right violations and abuses, including torture and other ill-treatment, are a significant issue within health-care settings. Persons with disabilities, in particular intellectual and psychosocial disabilities, often bear the brunt of these violations; it is crucial for all of us to continue the struggle against these violations.

Legal Capacity, Informed Consent and Stigmatized Identities: Reform and Remedy Efforts in Central and Eastern Europe

CLAUDE CAHN*

Abstract

The paper draws on the author's experience in efforts aimed at securing legal remedy for victims of human rights abuses in the health sector in Central and Eastern Europe, as well as on the author's work to reform on a human rights basis health systems in post-Communist contexts. It examines in particular several aspects of these questions: (1) current state-of-play of efforts to reform the system of guardianship and incapacity in the Republic of Moldova; (2) efforts to secure remedy for victims of coercive sterilization in the Czech and Slovak Republics, as well as in Hungary; and (3) emergent issues in this area as concerns health and human rights. The first part examines two particular scenarios in detail: (a) the treatment of persons with psycho-social disorders in the Republic of Moldova, concentrating on the issues of mistreatment in institutionalization; and (b) the coercive sterilization of Romani women in Czechoslovakia and its successor states. The second part explores the use of coercive sterilization on stigmatized groups in the region from Soviet times to date. It concentrates in particular on the practice and effect on Romani women, and it also discusses other vulnerable persons and groups. The paper ends by discussing emerging issues in the region concerning health and Human Rights, covering the legalization of the practice of birth at home; opposition to vaccination; and issues relating to the coercive treatment of people with TB and drug addiction and alcoholism in the region.

Introduction

In his February 2013 report to the United Nations Human Rights Council,¹ UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, examined in particular abusive practices reported in the health sector and reflected upon their relation to the ban on torture as set out under international law. In studying these questions, Special Rapporteur Méndez set out three categories of “interpretive and guiding principles”, according to which he reviewed the problem of torture and related acts in the health sector: (1) legal

*Human Rights Adviser, United Nations Moldova and Office of the United Nations High Commissioner for Human Rights (OHCHR): ccahn@ohchr.org, claude.cahn@one.un.org. The author has over twenty years of experience working on human rights issues in Central and Eastern Europe.

¹ A/HRC/22/53.

capacity and informed consent; (2) powerlessness and the doctrine of “medical necessity”; and (3) stigmatized identities.

This paper draws on the author’s participation in efforts to secure legal remedies for victims of human rights abuses in the health sectors of Central and Eastern Europe and on his work to reform healthcare systems in post-Communist contexts from a human rights perspective. The current paper examines in particular, (1) the current state-of-play of efforts to reform the system of guardianship and incapacity in the Republic of Moldova; (2) efforts to secure remedy for victims of coercive sterilization in the Czech and Slovak Republics and in Hungary; and (3) emergent issues in this area as concerns health and human rights. The paper examines issues facing two particularly stigmatized groups in the region: Roma on the one hand, and persons with psychosocial disabilities on the other. The paper concludes with reflections as to next steps required to address the challenges posed by torture and related abuses in the health sector.

Background

Richard Ashby Wilson has recently challenged legal anthropologists to “venture into the central sites of the international legal order, so as to complement recent studies of international law’s impact upon human rights struggles outside North America and Western Europe.”² Under Communism, Central and Eastern European states developed highly advanced systems of health care, extending access to all or most of the population. At the same time, certain aspects of these systems were highly troubling in terms of human rights. Psychiatry, for instance, was applied as a tool against all forms of deviance, including political dissent. These systems have been in crisis for several decades due to problematic resourcing exclusion from developments in mainstream medical literature and other reasons. The present article draws on the author’s work to support the effective exercise of fundamental rights in the health sectors of Central and Eastern Europe. Two particular issues are examined in detail: the treatment of persons with psycho-social disorders in the Republic of Moldova, and the coercive sterilization of Romani women in Czechoslovakia and its successor states. These two cases are seen as as exemplary. Through the prism of examining them, efforts are made to explore in detail some aspects of the issues identified in Special Rapporteur Méndez’s 2013 report. Thereafter, a summary of some emergent issues in health and human rights is presented, with a view to drawing tentative conclusions in this area.

The Right to Equal Legal Capacity: Efforts to Reform the System of Guardianship and Incapacity in the Republic of Moldova

Guardianship (“tutelă” or “opekunstvo”), as provided for and applied under the Moldovan Civil Code, similar to many countries of the region, removes a person’s legal personhood and places it with another person or institution named as the “guardian.”³ People placed under guard-

² Wilson, Richard Ashby, “Tyrannosaurus Lex: The Anthropology of Human Rights and Transnational Law”, in in Goodale, Mark and Merry, Sally Engle (eds.), *The Practice of Human Rights: Tracking Law between the Global and the Local*, Cambridge: Cambridge University Press, 2007, p.343.

³ Civil Code of the Republic of Moldova (Law No. 1107 of 06.06.2002) provides for the deprivation of the capacity to exercise rights (a component part of the legal capacity) if the person, due to a mental disorder (mental illness or mental deficiency), cannot understand or control his/her actions. Thus, as a result of Article 24 of the Civil Code, guardianship is assigned to people with intellectual and psychosocial disabilities who are declared incapacitated. As provided by Civil Code Article 33, the guardian is the legal representative of the person declared incapacitated, and concludes all necessary legal documents on behalf of this person and in his or her interest, without being mandated by the person concerned to do so.

ianship are frequently in or on the way to being placed in institutions, and there is a direct link between institutionalization measures and guardianship measures. Institutionalization is often life-long. Even when not institutionalized, persons placed under guardianship or otherwise declared “incapacitated” are deprived, pursuant to a court orders, of their right to engage in even basic socio-legal relationships. This can affect their ability to marry, divorce, conclude a work contract, own property, claim social benefits, consent to medical treatment and even—the ultimate paradox—to have standing to appeal a guardianship order before courts. Several thousand people in the Republic of Moldova and hundreds of thousands of people throughout Europe are currently under guardianship.⁴

Guardianship arrangements are centuries old. They were streamlined and hardened in the atmosphere of scientific positivism dominating the Soviet Union and are directly linked to the policy and practice of excluding persons with mental or intellectual disabilities—as well as other persons perceived to be “deviant”—entirely from the body politic.

The logic underlying these arrangements has been invalidated by the entry-into-force in 2007 of the Convention on the Rights of Persons with Disabilities (CRPD). CRPD Article 12, which has been described as “the roots from which all of the other rights of the Convention grow,” sets out *inter alia* that persons with disabilities have the right to recognition everywhere as persons before the law, and that States Parties shall take appropriate measures to provide access for persons with disabilities to the support they may require in exercising their legal capacity. The clarification in international law of a guarantee that any protection measures for persons with mental or intellectual disabilities ought to explicitly follow the rights, will, and preferences of the person concerned throws a sharp light on the institution of guardianship, and calls it fundamentally into question. The European Court of Human Rights has followed these developments, increasingly reading equal legal capacity requirements into the provisions of the European Convention on Human Rights and, in a row of recent cases, finding Council of Europe Member States to be in violation of the Convention.⁵

The Republic of Moldova has had an open discussion on reforming the guardianship system to comply with the requirements of international law, and in particular CRPD Article 12, since an inter-ministerial working group was formed to examine the issue in late 2011. The work of the group has to date focused on designing a new draft law which would set out modalities for supported decision-making arrangements to replace the current substituted decision-making arrangements, and on making necessary amendments to the Civil Code, Family Code, and other laws that are evidently in conflict with CRPD Article 12. The work of this group received significant impetus in the period of 2011–2013 as a result of missions to Moldova by Gábor Gombos, Tina Minkowicz and Amita Dhanda—all directly involved in the drafting of the CRPD Convention—as well as by UN Special Rapporteur on Disability Shuaib Chalklen. A growing portion of the national-level policy and lawmaking community, as well as Moldovan civil society, are engaged in examining these questions and their reform implications.

⁴ The Budapest-based Mental Disability Advocacy Centre estimates that there are between one million and two million people in guardianship throughout the Council of Europe region (email communication, 27 June 2013, on file with the author).

⁵ See for example *Alajos Kiss v. Hungary*, *Lashin v. Russia*, *Salontaji-Drobnjak v. Serbia*, *Shtukaturv v. Russia*, *Stanev v. Bulgaria*. The Court has in particular read these issues into the European Convention Article 8 right to private and family life.

In support of this work, in February 2013, the UN Office of the High Commissioner for Human Rights (OHCHR) published a study of the impact of the guardianship system in Moldova in light of the CRPD requirements, which was coordinated by a prominent Moldovan sociologist.⁶ The study examines how persons in the system—both professionals involved in guardianship as well as persons placed under guardianship—perceive guardianship. The guiding assumption of the study was that—rightly or wrongly—guardianship is conceived of in principle as a protection measure. The study in particular aimed to assess whether the guardianship system is actually functioning as a protection measure, and whether it is perceived as such.

The OHCHR study reveals a number of issues. Firstly, it transpires that in the Republic of Moldova, those working within the system believe that guardianship is generally used for abusive purposes, most commonly in order to seize the property of the person concerned and isolate people perceived as “dangerous” or problematic in supervised settings. Authorities involved in guardianship and guardians themselves frequently do not understand their obligations to facilitate or enable the exercise of the trustee’s rights, but rather think of guardianship as the provision of habitual care. Few, if any, think the system is functioning effectively as a system of protection of the rights or interests of the persons concerned.

Secondly, the study revealed that Moldova has had quite a dramatic increase in recent years of persons placed under guardianship. At least one of the reasons for that appears to be a highly legalistic-formalistic interpretation of human rights requirements, according to which forcible institutionalization (hospitalization) should only take place after a person has had his or her legal capacity removed.

Thirdly, as is standard for most places applying guardianship or similar legal forms, persons placed under guardianship are in practice almost completely excluded from the proceedings that place them under guardianship and are denied review of such decisions. In nearly all cases, once placed under guardianship, a person cannot and will not be released from the measure—he or she will spend their life in a situation of life-long dependence. In Moldova there is also an intimate link between guardianship measures and long-term or life-long institutionalization and/or other measures intended to segregate persons with disabilities, particularly mental or intellectual disabilities.

In Moldova, as in other countries, the vulnerabilities magnified by the guardianship system are linked directly to the occurrence of very serious abuse, both inside and outside institutions. A range of issues falling in the continuum of guardianship and institutionalization have recently been highlighted in the recent reports of the Centre for Human Rights and the first report of the Ombudsperson for Psychiatry.⁷ Removing entirely the legal standing of a person leads to greater exposure to practices such as forced medication, physical abuse including sexual abuse, arbitrary detention, the near total deprivation of privacy, and arbitrary removal of property, among others.

The Republic of Moldova is no stranger to human rights concerns in the area of psychiatry and in the treatment of persons with disabilities more broadly. In 2007, in the case of *David v. Moldova*, the European Court of Human Rights held that Moldova violated Article 5 of the European

⁶ Ciocan, Ludmila, “The System of Guardianship in Practice in the Republic of Moldova: Human Rights and Vulnerability of Persons Declared Incapacitated: A study carried out with a view to supporting reforms to implement the right to equal legal capacity as set out under Article 12 of the Convention on the Rights of Persons with Disabilities”, United Nations High Commissioner for Human Rights (OHCHR), Chisinau, 2013.

⁷ Doina Ioana Straisteanu, Institutional Ombudsman of Psychiatric Hospitals, “REPORT ON THE OBSERVANCE OF PATIENTS’ RIGHTS IN THE PSYCHIATRIC HOSPITALS OF THE REPUBLIC OF MOLDOVA, April-September 2012”, October 2012.

Convention, which guarantees the right to liberty and security of person, as a result of the forced detention of Mr. David, who had been targeted for involuntary psychiatric detention measures on a number of occasions due to, among other things, his perceived political dissident.⁸ In 2009, the Court held that Moldova violated the right to fair trial in Article 6 in connection with the summary firing of a woman who had lost the use of her hands as a result of work in a carpet factory.⁹ Most recently, the Court has potentially eroded to some extent the doctrine of medical necessity, when it found Moldova in violation of Article 3 of the European Convention, which prohibits torture and related forms of ill-treatment, as well as several other of the Convention's provisions, in a case involving forced psychiatric medication.¹⁰

At issue then are violations of a number of fundamental human rights set out in the CRPD Convention, going well beyond CRPD Article 12. Indeed, the threatened forms of human rights violations extend across the range of the core international human rights treaties, and include the ban on torture and inhuman or degrading treatment, the ban on arbitrary detention, the right to private and family life, the right to free and informed consent with respect to any intervention in the health field, the right to marry and found a family, the right to work, the right to social security, the right to live in the community, and a host of other established fundamental legal rights.

Efforts to Secure Effective Remedy for Romani Women Coercively Sterilized in the Czech and Slovak Republics, as well as in Hungary

Human rights issues in health care systems have also arisen where abusive systems are only partially reformed and abuses are insufficiently challenged. Similar to persons with psychosocial disabilities, the Roma—a highly stigmatized ethnic group in Europe—are exposed to abuses as a result of a very high degree of antipathy toward them.¹¹ Romani women and girls are particularly exposed to abuse. Healthcare systems have been part of a wider pattern of systematic discrimination and abuse of Roma in Europe in recent decades. Their autonomy, will, and preferences are frequently overridden by health care providers as a result of their status as a “stigmatized identity” in Méndez’s sense.

From the early 1970s, under the influence of resurgent eugenics considerations under Communism, doctors in Czechoslovakia systematically coercively sterilized Romani women, with considerable support from policy-makers and national structures, and with extensive assistance from social workers. These practices were an early and continuing part of human rights concerns raised by the Czechoslovak dissident group Charter 77.¹² Sterilization became actively promoted

⁸ David v. Moldova, judgment of 27 November 2007.

⁹ Panzari v. Moldova, judgment of 29 September 2009.

¹⁰ Gorobet v. Moldova, judgment of 11 October 2011.

¹¹ The Romani and related ethnic groups are a diverse set of peoples and communities living in Europe, the Americas and parts of Africa, related to similar groups in the Middle East and Central Asia. Roma are believed descended from groups of people who left India approximately 1000 years ago and arrived in Europe in successive waves beginning in or around the 14th century. Soon after their arrival in Europe Roma were excluded in Western Europe, and periodically subjected to raw persecution. In the Ottoman Empire, Roma occupied a low status, even when of the privileged Muslim community. Roma were enslaved in the Romanian principalities. From the beginning of the modern state, significant efforts were periodically undertaken—with mixed success—to assimilate Roma forcibly. Roma were targeted for genocide during World War II. The period since 1989 has seen a renewal of active anti-Romani antipathy throughout the continent. Tens of thousands of Roma were ethnically cleansed from Kosovo in the period 1999-present. Outbreaks of anti-Romani racism have plagued every European society without exception.

¹² “The consent of Gypsy women to sterilization is obtained by certain suspicious means. In some areas the sterilization of Gypsy women is carried out as a planned administrative program and the success of employees

in Czechoslovakia in particular—although not exclusively—among the Roma through a number of measures, including a series of social benefits apparently introduced in the 1970s.¹³ A one-time grant for undergoing sterilization surgery is set out in a 1973 internal act of the Ministry of Labour and Social Affairs of the Czech Socialist Republic.¹⁴ It was later included in social security regulations.¹⁵ Communist policy at its heart regarded the Roma as an “unhealthy population” with impermissibly high birth rates.¹⁶

Immediately following the fall of Communism, the new democratizing government endeavoured to end these practices. Policies explicitly targeting the Roma for sterilization were struck down in 1990, and a prosecutorial investigation was initiated. The latter resulted in no prosecutions. Discourses on the necessity of sterilizing Roma however persisted throughout the 1990s.

In fact, sterilization practices continued in post-Communism in both the Czech Republic and Slovakia, being undertaken by doctors, hospitals and social workers. In the early 2000s, as a result of the work of civil society organisations, patterns and practices of collusion among doctors and social workers were revealed in which Romani women were sterilized, in the standard case during or shortly after a second caesarean birth. The range of situations involved: (i) cases in which consent had reportedly not been provided at all, in either oral or written form, prior to the operation; (ii) cases in which consent was secured during delivery or shortly before delivery, during advanced stages of labor, i.e. in circumstances in which the mother is in great pain and/or under intense stress; (iii) cases in which consent appears to have been provided (a) on a mistaken understanding of terminology used, (b) after the provision of apparently manipulative information and/or (c) absent explanations of consequences and/or possible side effects of sterilization, or adequate information on alternative methods of contraception; (iv) cases in which officials put pressure on Romani women to undergo sterilization, including through the use of financial incentives or threats to withhold social benefits; (v) cases in which explicit racial motive appears to have played a role during doctor-patient consultations.

is judged by the number of Gypsy women an employee has been able to talk into sterilization. Under such circumstances it is impossible to be objective about such a program. Often, in order to get consent for sterilization, the authorities offer financial reward. In this way, sterilization is becoming one of the instruments of the majority against the minority aimed at preventing childbirth in a particular ethnic minority... The authorities view the solution of the Gypsy ‘problem’ in the elimination of this minority and its integration with the majority.” (Charter ‘77, “Document 23” concerning “Situation of the Gypsies in Czechoslovakia”, 13 December 1978, signed by Vaclav Havel and Dr. Ladislav Hejdanek, as provided in Commission on Security and Cooperation in Europe, Congress of the United States, “Human Rights in Czechoslovakia: The Documents of Charter ‘77: 1977–1982”, Washington, D.C., July 1982, pp. 158-168).

¹³ For an excellent summary of Communist-era policies and practices concerning Roma in Czechoslovakia, see Vera Sokolova, *Cultural Politics of Ethnicity: Discourses on Roma in Communist Czechoslovakia*, Stuttgart: Ibidem Verlag, 2008.

¹⁴ Ref. No. IV/1-8750-13.9.1973/7. Reforms undertaken in the wake of the events of 1968 in Czechoslovakia, seen as at least in part driven by Slovak dissatisfaction in the highly centralized Czechoslovak state, turned the Czech and Slovak Socialist Republics respectively into independent lawmaking entities, within an overall Socialist Federal structure.

¹⁵ For example, Act No. 121/1975 Coll. on Social Security, Czech National Council Act No. 129/1975 Coll. on the Mandate of the Czech Socialist Republic Bodies in Social Security and the implementing decree of the Ministry of Labour and Social Affairs of the Czech Socialist Republic No. 130/1975 Coll. to both acts, including instructions from the Ministry of Labour and Social Affairs of the Czech Socialist Republic issued for the same purpose.

¹⁶ Arne Mann, “The Development of the Romany Family”, available at <http://www.radaeuropy.sk/?1494> (accessed 20 March 2009).

In 2004, the Czech Public Defender of Rights (“Ombudsman”) initiated investigation into these practices. A typical case from that investigation is the case of Mrs. A.H., sterilized in 1995 at the hospital in Havířov:

The record of the birth testifies to heightened initiative by social workers beyond the expressions by Mrs. A.H. In the birth record, the following appears: “For reasons of the inadaptability of the family and on the basis of the agreement of the department of gynaecology, social workers and both members of the couple, the birth will be carried out by caesarean section with the implementation of sterilization measures. It is not possible to anticipate the implementation of sterilization measures through laparoscopic surgery following spontaneous birth, because Mrs. A.H. is not willing to undergo these measures as she has repeatedly indicated in the past.”¹⁷

“Inadaptable” persons or families is a code-word for the Roma in the Czech Republic, and a frequent part of public debate about the Roma. In some cases, one of the reasons given for the sterilization is the ethnicity of the person concerned. In the case of Mrs. J.T. for example: “[o]n the reverse side of the request is provided among other things as a social reason for the measure the fact that Mrs. J.T. is Romani.”¹⁸

The Czech Ombudsman issued his “Final Statement of the Public Defender of Rights in the Matter of Sterilizations Performed in Contravention of the Law and Proposed Remedial Measures”¹⁹ on 23 December 2005, concluding that the public and policy-makers in the Czech Republic needed to come to terms with the fact that patterns and practices of coercive sterilization of Romani women continued to take place, a state of affairs the Ombudsman described as “intolerable”: “[t]he Public Defender of Rights is certain that accepting this unpleasant reality is the only way to bring about a catharsis”.²⁰ In finding that this standard of consent was not provided in the given cases, the Ombudsman noted that “[f]rom a legal perspective the unlawful nature of the sterilizations lies in the fact that consent, that was without error and fully free in the human rights sense, was not given to the interventions. This conclusion applies to all cases without exception.”²¹

Romani women have been particularly targeted for these measures. However, they are not the only people who have been harmed by these practices. Although there are some cases involving men, the overwhelming majority of those sterilized have been women. Romani women, older women, women with disabilities or other health conditions, and women with multiple caesarean section births are particularly exposed to these harms. In November 2009, then-Czech Ombudsman Motejl, speaking in the wake of an official expression of regret by the Czech government for coercive sterilization practices undertaken during Communism and after Communism,²² stated that he believed there were as many as 90,000 women in the territory of the former Czechoslovakia who had been coercively sterilized.²³

The European Court of Human Rights has begun ruling on cases concerning the coercive sterilization of Romani women. The first of these cases reached the Court in the mid-2000s after exhaust-

¹⁷ Sp. zn.: 3099/2004/VOP/PM et al., p.36.

¹⁸ Sp. zn., at.82.

¹⁹ JUDr. Otakar Motejl, Public Defender of Rights, “Final Statement of the Public Defender of Rights in the Matter of Sterilizations Performed in Contravention of the Law and Proposed Remedial Measures”, Brno, December 23, 2005 (Official Translation).

²⁰ *Id.*, at .3.

²¹ *Id.* at 73-76.

²² Czech Government Resolution No.1424, 23 November 2009.

²³ Lidové Noviny “Ministr Kocáb: Politování sterilizovaných žen je první faze” (“Minister Kocáb: Expression of Regret for Sterilizing Women is Only the First Step”), 24 November 2009.

ing domestic remedies. In November 2011, in *V.C. v. Slovakia*, the Court ruled on the first such case directly challenging the sterilization measures—a case concerning a Romani woman coercively sterilized in a hospital in eastern Slovakia in 2000—finding Slovakia in violation of the Article 3 prohibition on inhuman or degrading treatment, and of the Article 8 right to private and family life. The Court has subsequently issued several further rulings on Czech and Slovak coercive sterilization complaints. The United Nations Committee on the Elimination of Discrimination against Women (CEDAW) has adjudicated a case of coercive sterilization of a Romani woman from Hungary.²⁴ A number of other international review instances have also condemned these practices as infringing international human rights law.

Nevertheless, due to rigid approaches at national level, not more than a handful of the women concerned have received any form of due legal remedy for these harms. Courts and other authorities have avoided applying accountability measures in all but a handful of cases, and neither of the two governments concerned have adopted general remedy mechanisms, apparently fearing backlash from the public at large, and in any case sceptical that “Gypsies” constitute “deserving victims”.

Also, the underlying forces giving rise to the coercive sterilization of women have arguably not yet been extruded from medicine. There is now a considerably strengthened commitment to free and informed consent in health interventions generally, and in particular as concerns contraceptive sterilization. However, the forces driving pressure to sterilize arguably continue, with Ministry of Health regulations in a number of countries of the region specifying “medical indications” for sterilization. The Slovak regulation in this area, for example, was adopted on April 1, 2004 and includes an “Annex of Medical Indications for Sterilization,” dated October 31, 2003 with no fewer than 14 subsections—on matters ranging from “women’s kidney and urinary tract diseases” to “nervous system diseases” to “dermatological diseases” to “ocular diseases,” “hearing diseases in women and men” and, inevitably, given the logic of the premises behind the regulatory effort, “genetic indications.” The total list of “medical indications” (sic) for sterilization in the 2003 amended Regulation’s Annex runs to more than 130 individual conditions, although the total number of possible “medical indications” for sterilization is perhaps better stated as “infinite,” as a result of the inclusion, in some sections, of texts such as this one:

*Any diseases for which a specialist—cardiologist, angiologist—concludes that each pregnancy would be connected with severe threat to health and these diseases can not be cured with medication, by intervention or surgery in such a way that the women’s state of health is corrected or substantially favorably influenced.*²⁵

Finally, as noted above, the forces giving rise to these practices are by no means confined to Czechoslovakia and its successor states. Czechoslovakia and its successor states have had a particularly intense series of abusive practices in this area because of explicit policies targeting Roma. However, practices overriding the autonomous will of individuals to decide on the number and spacing of their children, as well as generally in the health sector, are region-wide. It appears that our efforts to redress these harms—or even to understand their scope and breadth—are as yet only in their infancy.

²⁴ CEDAW/C/36/D/4/2004.

²⁵ The Republic of Moldova has a similarly sweeping regulation and, perhaps not surprisingly, it was found in violation of the European Convention by the European Court of Human Rights in December 2012, in a coercive sterilization case (see *G.B. and R.B. v. Moldova*). The case does not concern a Romani woman.

Emergent Issues in the Region as Concerns Health and Human Rights

The two cases studies set out above are paradigm examples of forces and issues seen region-wide, in particular as concerns stigmatized identities and the right to free and informed consent in any intervention in the health sector. The field of health and healthcare is increasingly gaining attention in human rights circles. There are a number of reasons for this. Firstly, the health system is a primary locus of discipline—it may be among the first or most important sites for the inculcation of power relations and dynamics. Secondly, patterns and practices of human rights abuse have been particularly durable in the health sector, among other things as a result of the strong element of expertise acting as protection and impunity defense for human rights abusers in the health sector. As individuals increasingly endeavor to take control of decisions over their own lives, inevitably, abuses in the health system emerge and are challenged. A number of emerging human rights issues in the health systems of Central and Eastern Europe are summarized below, in no particular order.

In the recent period, a number of legal struggles are playing out over the issue of birth at home. In the Czech Republic, a number of claims have recently been filed at the European Court of Human Rights by women who were issued administrative fines for giving birth at home, or by midwives who were sanctioned by Czech authorities for assisting women in giving birth at home.²⁶ These cases are currently pending before the Court. In Bulgaria, women have recently succeeded in efforts to establish the right to give birth at home. In Hungary by contrast, Agnes Gerebes, a leading midwife and advocate for birth at home, has been the subject of high-profile criminal prosecution, at points involving her being led to and from court in hand and leg shackles.

A similar struggle is currently played out over the issue of vaccination. Vaccination is mandatory in a number of the countries of the region, and vaccination generally is only successful if a certain quantum—in some cases more than 90% of a given population—is vaccinated. There are however widespread views among the public-at-large that vaccination may be dangerous, and frequently parents have friends or acquaintances in their immediate circles who have had real or perceived medical problems, often very serious ones, after initial vaccination. As a result, many people now refuse vaccination for their children. Responses by authorities have included bans on enrolment in school, as well as threats of criminal prosecution for the willful spreading of disease. In Moldova, the Constitutional Court recently issued a divided opinion on a petition by the Ombuds institution, as to whether excluding children without vaccination from school was legal. Moldovan law includes no exemptions—medical or on grounds on conscience—for persons unable or unwilling to vaccinate.

The growth of concern at the return of tuberculosis, and in particular multi-drug-resistant (MDR) tuberculosis, has led to a growth of planned policy measures for coercive treatment of persons with TB. In some cases, the issue is concern over possible non-compliance by prisoners being released following the end of serving criminal sentences; thus, measures for continued confinement are envisioned once sentences are completed. In other cases, policy-makers have sought to plan and design detention facilities in TB wards for treatment-related detention. While forced medication is not regularly reported, in general the terminology of laws has been left sufficiently vague so as not to preclude actually compelling a person to ingest medication. The punitive and coercive visions of such schemes are strikingly at odds with TB treatment in its real, existing form. In reality, poor management of facilities, including problematic isolation and ventilation, means

²⁶ See for example *Dubská v. Czech Republic* (Application no. 28859/11), pending as of 5 July 2013.

that a leading threat of TB, and in particular MDR TB, is TB hospitals themselves. Also, a lack of beds in human rights-compliant TB facilities means that in fact, access to effective treatment of TB evidently remains a larger issue region-wide than treatment avoidance. In any case, reliance on coercion or the threat of coercion continues to reveal a major gap in frameworks for establishing free and informed consent based on competent, patient-centered information. It is the absence of such information that gives rise to the perceived need for coercive measures.

Coercion also remains a primary mode of treatment throughout the former Soviet Union for other “conditions” including drug addiction and alcoholism. In the separatist region of Transnistria (Republic of Moldova) for example, facilities existed for forced treatment for alcoholism. As part of a criminal sentence, persons convicted of drugs-related offenses may be required to ingest medicines to “cure” their addiction—including from cannabis. Refusal to ingest these medicines means that convicts are ineligible for ameliorations to their sentence, such as out-of-prison community work programs. Some of the medicines prescribed under the forced treatment regime have potentially serious side effects, more serious in fact than the effects of cannabis. In Russia, a range of problematic treatment for drug use or addiction measures exist a number of which potentially implicate the international law ban on torture. For instance, according to one study:

“[q]uestionable private drug treatment practices are widely advertised through mass media. Desperate for quality treatment drug users and their families informed about methods which promoters falsely allege have high success in treatment of drug addiction. Such methods may include therapy by flogging, handcuffing to beds for prolonged periods, and hypnotherapies to convince patients that drug use will be fatal (“coding”).”²⁷ The same report makes reference to “stereo toxic brain surgery” as a treatment of drug addiction in private clinics in Russia.²⁸

The medical community has found itself entangled with criminal justice in other areas of punishment as well. Although the chemical castration of pedophile sex offenders has generally been a practice in steady retreat in the Council of Europe space, not least because of European Court of Human Rights jurisprudence banning corporal punishment,²⁹ some countries have discussed reintroducing it, and some have in fact done so. On July 4, 2013, the Moldovan Constitutional Court struck down a 2012 law on chemical castration of pedophile sex offenders, following a petition by the Ombuds institution, as well as an opinion on the matter by the Council of Europe’s Venice Commission. Vexing review of the matter was the question of how the norm of free and informed consent could be respected if the measure was deemed treatment. Had the law not been struck down, Moldova’s 2005 patients’ rights act likely would have had to be amended.

The HIV/AIDS pandemic has received extensive attention in the international community. It is unusual among diseases to have a specific, dedicated UN agency like UNAIDS. In Moldova, two issues in particular have come to the fore as regards the human rights of persons living with HIV/AIDS: the right to privacy, confidentiality, and data protection on the one hand, and the ban on discrimination on the other. As to the former concern, 69% of persons living with HIV/AIDS reported

²⁷ Andrey Rylkov Foundation for Health and Social Justice in consultation with NGOs and experts involved in HIV/human rights in Russia and UNODC, “Report to the International Committee on Economic, Social and Cultural Rights on implementation by the Russian Federation of article 12 of the International Covenant on Economic, Social and Cultural Rights as it relates to access of people who inject drugs to drug treatment and HIV prevention, care and treatment programs”, 2011, p.8, at <http://www2.ohchr.org/english/bodies/cescr/cescrs46.htm> (accessed 4 July 2013).

²⁸ http://www.narkotiki.ru/internet_5242.html (accessed 4 July 2013)

²⁹ See for example *Tyrer v. United Kingdom*.

in 2011 that medical providers or other persons had violated patient confidentiality.³⁰ The problem is particularly pronounced in rural areas, and flows at least in part from the fact that epidemiological data includes personal information. Reforms in the latter area are underway, particularly as a result to 2012 amendments to Moldova's Law on HIV/AIDS. Discrimination, however, has been more difficult to address. A number of particularly clear cases currently before the courts concern the pre-textual refusal of prosthetic surgery, even where medical literature indicates that HIV status is not a contraindication to the surgery.

Discrimination also intrudes in the health field in questions concerning lesbian, gay, bisexual, and transsexual (LGBT) persons. Particularly prominent is the question of changes in documentation for people who have undergone gender adjustment procedures. Here again there is clear, settled European Court of Human Rights case law indicating that individuals have a right to have their documents altered to reflect gender adjustment procedures.³¹ In Moldova, however, high-level interventions in court proceedings have stopped the adjustment of personal documents. Church opposition to equality rights for LGBT persons and groups has driven high-level political limitations of these rights despite European and global moves to finally establish equality in these areas.

Finally, some of the human rights issues weighing on medicine in Central and Eastern Europe continue to call into question the depth of commitment to core human rights principles in the population at large. The question of whether all lives are equally protected is seen in particular in questions concerning spina bifida in Romania and Moldova, as well as likely in other countries of the region. Children born with spina bifida, a congenital condition, have a more than 80% chance of normal life expectancy if they receive very early on an operation inserting a rudimentary drain into their spinal column. The drain, or "shunt," costs not more than several hundred dollars, well within the means of the economies of the region. If they do not receive such an operation, in the majority of cases, their head fill with water, a condition known as hydrocephaly, and they will die horrible deaths during childhood. Failure to carry out the operation in a timely fashion is effectively a death sentence for the child. Tens of children annually in Romania and Moldova do not receive the operation in a timely manner, both due to unwillingness to make the shunt available to all children needing it and reportedly because of demands of up to 4000 EUR in informal payments (bribes).

Ján Jařab, regional representative for Europe of the United Nations Office of the High Commissioner for Human Rights, himself a doctor, has commented with respect to failure to treat spina bifida correctly: "This is not a fast death, but a slow and painful one—with an enormous head, blindness developing over months or years, and horrendous pain. It is probably the most torturous preventable death that exists."³² The failure to ensure that all children needing such operations receive them in a timely manner has led some experts to conclude that some people—children—are being left deliberately to die painful deaths, and thus that the right to life is not in fact genuinely established.³³

³⁰ Malcoci, Ludmila, *Statutul socio-economic al persoanelor cu HIV: studiu sociologic*, Soros Foundation Moldova, Chisinau, 2012, p.107.

³¹ See for example *Christine Goodwin v. United Kingdom*.

³² Email communication, 6 July 2013, on file with the author.

³³ Author communication with Adriana Tontsch, President, ARSBH (Association for Spina Bifida and Hydrocephalus in Romania), 14 June 2013, on file with the author.

Conclusions

Haunting at least some of these questions is the extent to which eugenics remains embedded in medicine, particularly in the countries of the former Communist block. Born in the United States, the eugenics movement lodged itself in European continental medicine and social policy in the 1920s and 1930s, and was most prominently officially established in Nazi Germany.³⁴ By 1945, circa 45% of the doctors in Germany were members of the National Socialist German Workers Party (NSDAP—Nazi Party).³⁵ According to Gisela Bock, the leading scholar in the field, almost 1% of the population between the ages 16-50 were sterilized during the Nazi period.³⁶ The Nordic countries and Switzerland also extensively adopted eugenics ideologies and associated coercive sterilization practices.³⁷

Eugenics were hugely influential in Central and Eastern Europe, falling as the region did within the German sphere-of-influence (including in the medical field), and being generally dependent on external forces for development.³⁸ Less clearly understood or mapped are the ways in which Communism preserved, transmitted or even amplified eugenics in medicine, social policy and law, even as eugenics and related ideologies were discredited and extirpated in the West, linked as they were with the Nazis.³⁹ In her remarkable study of the transmission of nationalism in Ceau escu's Romania, Katherine Verdery describes how national ideology was "built up in Romania throughout the communist period—and not just by the Party's recourse to it, but by intellectuals' continued elaboration of the national idea, which was also highly functional within Romania's socialist political economy."⁴⁰ Ultimately: "... the outcome in Romania was more than simply the discursive rupture of Marxism. It was the discursive constitution of a nationalism even more powerful than before."⁴¹ Thus, Communism in Romania produced an amplified version of the very nationalist ideology it claimed explicitly to have superseded. Verdery's insights are complemented by several works on eugenics in Romania, in particular that of Gail Kligman, which traces a near-continuous line from interwar Romania to the end of the Ceaușescu regime in the preoccupation with female fertility for the promotion and transmission of the Romanian nation.⁴² While Romania constituted an extreme example within the Communist world, differences between Romania and other coun-

³⁴ The author follows Bucur, who in turn follows Dikötter in using the term 'eugenics' to mean, broadly, 'not so much a clear set of scientific principles as a 'modern' way of talking about social problems in biologizing terms' (Dikötter, Frank, 'Race Culture: Recent Perspectives on the History of Eugenics', *American Historical Review* 103, No. 2, April 1998, p. 467, quoted in Bucur, Maria, *Eugenics and Modernization in Interwar Romania*, Pittsburgh: University of Pittsburgh Press, 2002, p. 5).

³⁵ Kater, Michael H., *Doctors under Hitler*, Chapel Hill and London: University of North Carolina Press, 1989.

³⁶ Bock, Gisela, *Zwangsterilisation im Nationalsozialismus. Studien zur Rassenpolitik und Frauenpolitik*, Opladen, 1986, pp. 230-238.

³⁷ For example, between 1935 and 1975, around 63,000 people were sterilized in Sweden, of which 93% were women. Around 40% were sterilized without any form of consent (Swedish Government report, *Steriliseringsfrågan i Sverige 1935–1975. Ekonomisk ersättning*, 1999, p. 2).

³⁸ See for example Bucur, Maria, *Eugenics and Modernization in Interwar Romania*, Pittsburgh: University of Pittsburgh Press, 2010.

³⁹ Some authors endeavour to identify continuities with Nazi ideologies also in the West. Whitman for example endeavours to trace a line between Nazi 'honour' and European 'dignity': 'seen in its proper perspective, 'dignity' as it is protected today, is the product of an evolution that partly took place during the fascist era'. (emphasis in the original) (Whitman, James Q., 'On Nazi 'Honour' and the New European 'Dignity'', in Joerges, Christian & Navraj Singh Ghaleigh (eds), *Darker Legacies of Law: The Shadow of National Socialism and Fascism over Europe and its Legal Traditions*, Oxford and Portland, Oregon, USA, 2003, p. 245).

⁴⁰ Katherine Verdery, *National Ideology Under Socialism: Identity and Cultural Politics in Ceau escu's Romania*, Berkeley: University of California Press, 1991, p. 4.

⁴¹ *Id.* at, 315.

⁴² See Gail Kligman, *The Politics of Duplicity: Controlling Reproduction in Ceau escu's Romania*, Berkeley: University of California Press, 1998.

tries of central and south-eastern Europe appear to be differences of degree, rather than of kind.⁴³ The Czech Ombudsman considered the role of eugenics on contemporary practices sufficiently significant to include 12-pages on “eugenically-oriented social systems” in his 2005 report on coercive sterilization practices in the Czech Republic.⁴⁴

Less contentious is the continuing influence of paternalism as an operative doctrine in the medicine of Central and Eastern Europe. Doctors in the region routinely and habitually take decisions on behalf of patients, viewing themselves as “Gods of science” and members of the public-at-large as incompetent in matters of medicine. Some doctors view denying the patient involvement in medical decisions as important from the idea of the cure, based on the idea that faith in the power of the doctor is itself a component of healing.⁴⁵ These practices are driven at least in part by some patients who indicate that they prefer not to know—and above all not to choose—in issues related to their healthcare. However, as anyone who has ever sought information from doctors in this region can attest, a far more powerful driver of bad practice in this area is doctors themselves, who can and often do react with diffidence or even vindictive fury to patients who ask questions or seek to receive information or make choices about their own care.

Another key factor is bad professional training. Similar to elsewhere, medical training in Central and Eastern Europe involves heavy components of indoctrination to the idea that the patient’s views, fears, and concerns are a distraction to the work of identifying and rectifying mechanical and biological problems related to the organism. In this view, the mindfulness of the patient is at best an irritating nuisance, and at worst an active obstacle, to the doctors’ work. Questions, inquiries, and the need to secure informed consent are, on this account, something like static which the doctor must try to isolate in the course of his (usually the doctor is a man) efforts to receive the clear signals required for sound medicine.

Such views discount the key role played by both the doctor and the individual in the empowerment or disempowerment of the person. The importance of fostering an environment in which the person is enabled to take decisions about her own treatment, health and body cannot be underestimated. Among our earliest contacts with power is the health system. The health system can be a force in the disciplining of the person and the extraction of her submission to arbitrary power. Or it can be an educator in the creation of free moral agents in democratic society. At stake, then, are matters that go far beyond medicine.

Reform in this area is thus ultimately one key litmus test for an inclusive society. In the case of stigmatized identities—the Roma and persons with mental disabilities or psycho-social disorders as discussed above—the issue at stake are whether legacies of removing persons perceived to be different, deviant or otherwise in need of support and assistance will finally be overcome, or whether such persons will continue to be forced excluded from public view and condemned to lives outside of society. In the case of the public-at-large, can health systems move forward to empower the person? Underpinning these considerations is the question of whether the original

⁴³ For similar transmissions of nationalism among intellectuals, see for example (from the Czechoslovak context) Jan Patočka’s *Co jsou eši?*. On the transmission of anti-Semitism under Communism in Hungary, see Kovács, András & Eszter Andor, ‘Zsidók a második világháború utáni Magyarországon’, in Szalai, Anna (ed.), *Hágár országa. A Magyar zsidóság—történelem, közösség, kultúra. Antall József Alapítvány/Kossuth Kiadó*, Budapest, 2009, pp. 278-283.

⁴⁴ JUDr. Otakar Motejl, Public Defender of Rights, ‘Final Statement of the Public Defender of Rights in the Matter of Sterilisations Performed in Contravention of the Law and Proposed Remedial Measures’, Brno, December 23, 2005 (Official Translation), pp. 59-72.

⁴⁵ One doctor at a conference on health and human rights in Hungary told the author publicly, “I went into medicine as a mission. If I had to treat the patient as an equal, I would go into another line of work.”

human rights vision will be realized: namely whether the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world, will be achieved in practice.

On the positive side, reform efforts are ongoing in a number of areas. Moldova's 2010 ratification of the Convention on the Rights of Persons with Disabilities (CRPD) has sparked an effort to replace systems of plenary guardianship with a new system of supported decision-making for persons with psychosocial disorders and others. It is hoped that this reform will come before Parliament during the second half of 2013. Similarly, there are continued efforts by the Czech Republic's Commissioner for Human Rights, jointly with civil society, to finally put in place a remedy mechanism for victims of coercive sterilization. More broadly, as evidenced by Special Rapporteur Méndez's 2013 report, there is ever-greater attention globally, including in Central and Eastern Europe, to human rights issues in health care systems. These reforms, while still in their infancy, have the potential to remake and renew the relationships of the person her peers, as well as to society-at-large. With some common efforts on the part of many, the future will likely have interesting positive developments in these areas.

Torture and Ill-Treatment Against African Persons with Psychosocial Disabilities In and Out of Health Care Settings

SHUAIB CHALKLEN*, HISAYO KATSUI**, MASA ANISIC***

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Abstract

This paper addresses the identified theme of this volume from the perspectives of persons with psychosocial disabilities in Africa who encounter torture and ill-treatment in and out of healthcare settings. Their lived experiences have been largely hidden due to multilayered discrimination and structural challenges including lack of mechanisms both for duty-bearers and rights-holders to investigate and prevent torture and ill-treatment experienced by persons with psychosocial disabilities. Inspired by the influential report of the Special Rapporteur Méndez, this paper presents realities of persons with psychosocial disabilities in Africa and existing national, regional, and international legal frameworks relevant to prevent torture. A lack of participation of persons with psychosocial disabilities is evident. An idea of establishing an African Disability Forum is introduced to show one of the ways forward towards equality that leaves no one behind including the most vulnerable people among us.

Introduction

The report of Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment particularly in healthcare settings is a warmly welcomed piece of work that has advanced the understanding on one of the most marginalized groups of people even among persons with disabilities, namely persons with psychosocial disabilities. Persons with disabilities, particularly those with psychosocial disabilities, are often excluded from mainstream discourse and

*Chalklen is current United Nations Special Rapporteur on Disability of the Commission for Social Development. chalklenshuaib68@gmail.com

**Katsui is Assistant to the Rapporteur and a senior researcher at Institute for Human Rights, Åbo Akademi University, Finland.

***Anisic is an intern to the Rapporteur and a PhD candidate at Sant'Anna School of Advanced Studies in Pisa, Italy.

practices of human rights. The Rapporteur, however, identifies persons with psychosocial disabilities as a significant group in his report to which attention should be paid. Furthermore, he calls upon all States to respect, protect, and fulfill human rights of persons with psychosocial disabilities in the healthcare settings that are often infringed. When not specifically mentioned, persons with disabilities tend to be forgotten as the Millennium Development Goals have unfortunately exempted. Therefore, the Rapporteur's report has a great impact on properly including persons with disabilities into the important discourse of torture and ill-treatment.

Moreover, the primary focus on States and their obligations is a relevant approach also for persons with psychosocial disabilities in Africa as more than half of the African States have ratified the United Nations Convention of the Rights of Persons with Disabilities (CRPD) and thus have legally committed to realization of their human rights. The CRPD also stipulates interpersonal relationships as an important aspect beyond state-citizen relationships. If torture and ill-treatment are left only to the States' responsibilities whose priorities are many and resources scarce, that would easily become low priority among them. Furthermore, mental health issues cannot be considered in isolation from other areas of development, such as education, employment, emergency responses, and human rights capacity building.¹ This article aims to make a contribution by shedding light on African persons with psychosocial disabilities, arguing that a wider approach beyond healthcare settings is relevant in the discourse of disability and human rights in Africa. Although Africa's population is extremely diverse, when it comes to the realities of persons with disabilities, particularly those with psychosocial disabilities, countries share some commonalities. We are careful not to generalize the African realities but try to tease out possible similar tendencies based on literature review as well as on vast empirical knowledge of the UN Special Rapporteur on Disability who was previously the chief executive officer of the Secretariat of the African Decade of Persons with Disabilities.

First, the article briefly explores realities of persons with psychosocial disabilities in Africa so as to locate their torture and ill-treatment in this specific context. Subsequently, implications of healthcare for persons with psychosocial disabilities in Africa are critically discussed. Second, this paper introduces national, regional, and international legal frameworks that are relevant to promote rights of persons with psychosocial disabilities in Africa in terms of prevention against torture. This part aims to explore existing legal possibilities as well as challenges for the rights of persons with psychosocial disabilities in Africa. Third and lastly, the article introduces the initiative of establishing an African Disability Forum as a way to engage African persons with psychosocial disabilities into African human rights discourse and beyond.

Health Care, Torture and Ill-treatment, and Persons with Psychosocial Disabilities in Africa

The World Health Organization estimates that 151 million people experience depression, and 26 million people are afflicted with schizophrenia.² It is estimated that one in four people globally experience a mental health condition in their lifetime.³ In low-income countries, depression represents almost as large a proportion as does malaria (3.2% versus 4.0% of the total disease), but the

¹ WORLD HEALTH ORGANIZATION [WHO], *Mental Health, Poverty and Development*, http://www.who.int/mental_health/policy/development/en/ (last visited on May 21, 2013).

² WORLD HEALTH ORGANIZATION [WHO], *MENTAL HEALTH AND DEVELOPMENT: TARGETING PEOPLE WITH MENTAL HEALTH CONDITIONS AS A VULNERABLE GROUP 2* (2010).

³ UNITED NATIONS & WORLD HEALTH ORGANIZATION [WHO], *MENTAL HEALTH AND DEVELOPMENT: INTEGRATING MENTAL HEALTH INTO ALL DEVELOPMENT EFFORTS INCLUDING MDGs 2* (2010).

funds invested for treatment and prevention of depression are only a very small fraction compared to those allotted to malaria.⁴ Treatment is only available to very few people, typically less than 10% of people with severe psychosocial disabilities in Africa.⁵ The statutory healthcare system tends to be fragile, particularly in the area of mental health. It is, however, worth noting that “treatment” often means “Western” medical treatment in these reports and not locally available traditional treatments. Some traditional beliefs and practices are harmful but should not undermine useful, traditional treatment.⁶ Robb claims that 80% or more of persons with psychosocial disability in Africa seek support outside the Western medical model in traditional healers or faith-based practices. She also points out that mental health care services are concentrated in the urban areas. The following Ghanaian statistics teases out part of the African realities that do not rely merely on “Western,” expensive medical care services. In Ghana, 2.8 million people are estimated to have psychosocial disabilities, of which 650,000 have severe psychosocial disabilities, whereas psychiatric nurses number 600, psychiatrists 12, and public psychiatric hospitals number only three.⁷ According to this report from Human Rights Watch, a psychiatric nurse visits a religious and traditional prayer camp with 100 persons with psychosocial disabilities only once a month and only for two hours, while private hospitals cost 150 USD per month, a cost beyond the reach of most Ghanaians, 40% of whom live on less than 2USD per day.⁸ Lack of accessibility to “Western” medical treatment is common in many African countries. For instance, in Kenya, there are only five psychiatrists, and only one in Malawi.⁹

As the primary structure for supporting African persons with psychosocial disabilities is family, accessibility and analysis only on medicalized Western treatment does not depict their realities.¹⁰ As many instances of tortures and ill-treatment against African persons with psychosocial disabilities take place outside of the healthcare settings to which they do not have access, widening the scope of a setting becomes a necessity. This is in line with the influential report of the Special Rapporteur Méndez who states, “the examples of torture and ill-treatment in health settings discussed likely represent a small fraction of this global problem.”¹¹

This example of multiplicity of “treatment” eloquently suggests that realities of torture and ill-treatment of persons with psychosocial disabilities in Africa have to be carefully elaborated on their own account and not merely from predominant Western theories and concepts including medical model of disability. Nevertheless, literature on this exact topic is limited in general, while literature written by African persons with psychosocial disabilities is extremely limited. Thus, the report of PANUSP written by Robb is of significant value because the author is an African person with a psychosocial disability and collected information on the realities of those in African coun-

⁴ WHO, TARGETING PEOPLE WITH MENTAL HEALTH CONDITIONS AS A VULNERABLE GROUP, *supra* note 2.

⁵ CHRISTIAN BLIND MISSION, *Psychosocial Disabilities*, <http://www.cbm.org/Psychosocial-disabilities-251912.php> (last visited on May 21, 2013).

⁶ ANNIE ROBB, TOWARDS STRENGTHENING THE RIGHTS OF PERSONS WITH PSYCHOSOCIAL DISABILITIES IN AFRICA 37 (2012).

⁷ HUMAN RIGHTS WATCH, “LIKE A DEATH SENTENCE”: ABUSE AGAINST PERSONS WITH MENTAL DISABILITIES IN GHANA 27 (2012).

⁸ *Id.* at 30, 53-54.

⁹ WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY [WNUSP], *Persons Living with Psychosocial Disabilities in Kenya* (2005) available at www.un.org/disabilities/documents/mental_disabilities_kenya.doc; MALAWI HUMAN RIGHTS COMMISSION, REPORT ON MONITORING OF MENTAL HEALTH HOSPITALS AND SELECTED OUTREACH FACILITIES IN MALAWI 28 (2012).

¹⁰ ROBB, *supra* note 6, at 29.

¹¹ U.N. Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, U.N. Doc. A/HRC/22/53 (2013) (by Juan E. Méndez).

tries through organizations of persons with psychosocial disabilities in respective countries.¹² The study was conducted in 2011 and included Ghana, Kenya, Malawi, Rwanda, South Africa, Tanzania, and Uganda. Challenges are multi-layered as the report identifies seven major ones: 1) participation in political and public life; 2) marriage, family, parenthood, and relationships; 3) employment and income generating opportunities; 4) access to health; 5) torture, cruel, inhuman or degrading treatment or punishment; 6) living in the community, and; 7) access to justice.¹³ The study claims that, “[m]any of the health services in Africa are under resourced and mental health care services are disproportionately affected when countries face economic crisis as evidenced in 2011 for instance in Malawi” and that “[p]sychiatric institutions and practices in Africa are characterized by being extremely under resourced with torture, abuse and inhumane practices and discrimination within health care systems.”¹⁴ The report powerfully points out challenges of torture and ill-treatment in healthcare settings such as “chaining, shackles, tying with rope and various restraints,” “physical violence such as beatings and rape and sexual exploitation” as well as “name calling and verbal abuse.”¹⁵ The report concludes by stating, “there is no monitoring of psychiatric institutions or places where people are receiving treatment. Instances of violence are not investigated and there are no effective mechanisms of complaint. People with psychosocial disabilities are often deprived of their liberty based on their disability.”¹⁶ Thus action to prevent torture and ill-treatment against African persons with psychosocial disabilities in and out of healthcare settings is urgently needed.

In short, concentrating only on healthcare settings would mean to exclude majority of African persons with psychosocial disabilities from the discourse. At the same time, healthcare settings have specific connotations for persons with disabilities. First, persons with disabilities often encounter medicalization of their bodies to be rehabilitated and treated to become “normal.” “For a long time, it was assumed that challenges were natural and unavoidable consequences” of impairment, but this no longer holds true due to the “profound shift” in disabilities as human rights issues as enshrined in the CRPD.¹⁷ Although rehabilitation and medical treatment are essentially important for persons with disabilities, those alone are far from enough to understand lived experiences of persons with disabilities.¹⁸ Second, in Africa, a medical diagnosis is not accessible or available for many Africans with disabilities. Disability data on an objective assessment is largely missing, while “self-reporting” is often the only available data in the global South including Africa.¹⁹ This reality delays prevention, treatment and/or rehabilitation, if at all, while families and communities provide healthcare as well as any other support. Hence, family and community are important. The “dimensions of subjectivity and relationality are fundamentally intertwined.”²⁰ Such an interpersonal relationship is highlighted in the CRPD, which is one of the added-values.²¹ Therefore, this

¹² ROBB, *supra* note 6.

¹³ *Id.* at 28-37.

¹⁴ *Id.* at 34.

¹⁵ *Id.* at 35.

¹⁶ *Id.*

¹⁷ OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS [OHCHR], MONITORING THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: GUIDANCE FOR HUMAN RIGHTS MONITORS 5 (2010).

¹⁸ TOM SHAKESPEARE, *DISABILITY RIGHTS AND WRONGS* (2006).

¹⁹ SOPHIE MITRA, ALEKSANDRA POSARAC, & BRANDON VICK, *DISABILITY AND POVERTY IN DEVELOPING COUNTRIES: A SNAPSHOT FROM THE WORLD HEALTH SURVEY 24* (2011); HISAYO KATSUL, *DISABILITIES, HUMAN RIGHTS AND INTERNATIONAL COOPERATION: HUMAN RIGHTS-BASED APPROACH AND LIVED EXPERIENCES OF UGANDAN WOMEN WITH DISABILITIES 15* (2012).

²⁰ SARAH C. WHITE, *ANALYZING WELLBEING: A FRAMEWORK FOR DEVELOPMENT PRACTICE* 164 (2009).

²¹ Martin Scheinin, *CRPD in the Framework of Human Rights Treaties? Added Value or Watering Down Existing Standards?* Keynote Address, CRPD Seminar: Added Value? (May 21, 2008), www.kynnys.fi/images/stories/VIKE-web/vike_0508.scheinin.ppt.

paper contributes to the volume by teasing out some of the burning issues on the identified theme and beyond from the perspectives of African persons with psychosocial disabilities. The next section focuses on part of the solutions in national, regional, and international legal frameworks to realize human rights of African persons with psychosocial disabilities in and out of healthcare settings.

National, Regional and International Legal Frameworks as Possibilities: Operationalizing a Human Rights-Based Approach

According to the latest statistics of the African Commission of Human and Peoples' Rights, 10 African countries have legislation criminalizing torture, while seven have pending legislation, and 37 no legislation.²² In countries where torture is not a crime, the prosecution of torturers is currently extremely difficult, particularly when awareness of rights of persons with psychosocial disabilities is highly limited in Africa.²³ More precisely, instances of violence against persons with psychosocial disabilities are not investigated, while effective mechanisms of complaint tend to be missing.²⁴ That is, means of both duty-bearers and rights-holders to problematize and further criminalize torture and ill-treatment against persons with psychosocial disabilities are largely missing. One of the most prominent examples of the lack of means for the rights-holders is deprivation of their fundamental right to vote that is hindered by their national laws. For instance, those in Ghana, Tanzania, and Rwanda are not legally eligible to exercise their rights to cast a vote due to their disabilities. Even when their national laws entitle them to vote, in practice those in institutions and psychiatric facilities in Uganda and South Africa were unable to vote because of a high level of stigmatization.²⁵ Furthermore, "psychosocial disability rights defenders in Africa are often marginalized by the disability sector itself and are thus further weakened."²⁶ In this way, torture and ill-treatment against many persons with psychosocial disabilities in and out of healthcare settings tend to remain hidden in Africa today. In short, national legal frameworks contribute to reinforce the status quo in conjunction with other multiple layers of challenges including global ones.²⁷ This also means that legal frameworks have a possibility of becoming part of solutions, although legal solutions alone are insufficient as disabilities are extremely complicated and require multi-faceted solutions.

In Africa, a legal framework exists to address torture. The Guidelines and Measures for the Prohibition and Prevention of Torture, Cruel, Inhuman or Degrading Treatment or Punishment in Africa, the so-called "Robben Island Guidelines," was adopted by the African Commission in 2002.²⁸ This is the first regional instrument that concretely guides African States on how to implement the provisions of the African Charter on Human and People's Rights (1981, entered into force in 1986), also referred to as the "Banjul Charter," on the prohibition and prevention of torture as well as providing redress for victims.²⁹ A monitoring and follow-up Committee was also estab-

²² AFRICAN COMMISSION ON HUMAN AND PEOPLES' RIGHTS [ACHPR], *Torture Prevention Database*, <http://www.achpr.org/mechanisms/cpta/torture-db/> (last visited on Jul. 31, 2013).

²³ ROBB, *supra* note 6, at 37.

²⁴ *Id.* at 35.

²⁵ *Id.* at 28-29.

²⁶ *Id.* at 37.

²⁷ Compare KATSUI, *supra* note 19, at 142-67.

²⁸ African Commission on Human and People's Rights [ACHPR], *Resolution on Guidelines and Measures for Prohibition and Prevention of Torture, Cruel, Inhuman or Degrading Treatment or Punishment in Africa* (2002).

²⁹ African Charter on Human and People's Rights art. 5, Jun. 27, 1981, 1520 U.N.T.S. 245.

lished in 2004 as a result that was renamed in 2009 as the Committee for the Prevention of Torture in Africa with the same mandate. The Guideline, for instance, urges the Member States to criminalize torture and has impacted law modification processes in different African countries. However, the Guideline fails to mention persons with disabilities once, let alone persons with psychosocial disabilities. When not mentioned, persons with disabilities tend to be forgotten as the aforementioned example of the Millennium Development Goals verified. Regional frameworks would certainly benefit from explicitly including persons with disabilities.

When it comes to international frameworks, two United Nations Conventions are relevant: the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) and CRPD as well as their Optional Protocols. At present, 11 countries ratified both CAT and Optional Protocol of the CAT (OPCAT), while 20 ratified both CRPD and Optional Protocol of the CRPD (OPCRPD). On the one hand, National Preventative Mechanism (NPM) established by the OPCAT has the mandate to monitor places of detention where people with psychosocial disabilities are held, report on the conditions, and make recommendations to State Parties. In addition, they are mandated to enter dialogue with State Parties on methods to prevent torture. On the other hand, the Optional Protocol of the CRPD allows its parties to recognize the competence of the Committee on the Rights of Persons with Disabilities to consider complaints from individuals. Both Conventions establish independent international bodies for fulfilling the objectives of respective Conventions; Subcommittee on the Prevention of Torture and the Committee on the Rights of Persons with Disabilities.³⁰ Both the OPCAT and the CRPD deal also with national preventative mechanisms including monitoring.³¹ Such mechanisms could be linked with existing human rights institutions, such as the National Human Rights Commission in each country, and play a role in the protection of these persons against torture and other cruel, inhuman or degrading treatment or punishment, as Conventions are legally binding on those countries that have ratified them. In other words, even when national and regional frameworks do not pay sufficient attention to persons with disabilities, particularly persons with psychosocial disabilities, these international frameworks could be used as instruments to fill in the capacity gaps of both duty-bearers and rights-holders. For that, civil society needs to be strengthened to pressure governments to act accordingly. However, as mentioned before, persons with psychosocial disabilities in Africa are often marginalized even by the disability sector itself.³² Under such circumstances, establishment of an African Disability Forum becomes highly relevant, which is the theme of the next section.

Initiative to Establish an African Disability Forum: As a Concluding Remark

In a country without any social welfare or strong legislative system, non-governmental organizations inform social changes.³³ That is, persons themselves become the agents of change. Persons with psychosocial disabilities and their families face “the greatest stigma and discrimination,” while they are least likely to be considered part of disability movement.³⁴ In reality, independent

³⁰ Convention on the Rights of Persons with Disabilities, art. 34, Dec. 13, 2006, 2515 U.N.T.S. 3.

³¹ Optional Protocol of Convention Against Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment, art. 3-4, 17-23, Dec. 18, 2002, 2375 U.N.T.S. 237; Convention on the Rights of Persons with Disabilities, *supra* note 30, at art. 16, 33.

³² ROBB, *supra* note 6, at 37.

³³ Maria Berghs, *Paying for Stories of Impairment—Parasitic or Ethical? Reflections Undertaking Anthropological Research in Post-Conflict Sierra Leone*, 13 SCANDINAVIAN J. OF DISABILITY RES., no. 4, 255, 266 (2011).

³⁴ Donald Njelesani, *Sierra Leone Country Report for Plan West Africa's Regional Office*, International Centre for Disability and Rehabilitation, University of Toronto (2013), 29.

organizations representing persons with psychosocial disabilities are absent in many parts of the world, especially in low- and middle-income countries.³⁵ The formation of the Pan African Network of Users and Survivors of Psychiatry (PANUSP) in 2005 was an attempt to include the underrepresented segment of the population into the human rights discourse. Today, nine African national organizations of persons with disabilities (DPOs) belong to the PANUSP, while PANUSP will be a member of an African Disability Forum (ADF).

The lack of a unified voice of African DPOs and especially that of persons with psychosocial disabilities is a major problem not only for the African disability movement but also for the regional and international entities such as the African Union, the African Development Bank and UN agencies. It means that decision makers seldom hear the issues of persons with psychosocial and other disabilities. The African Disability Forum will be formed to address such issues among others as this lack of voice and to hold governments and regional bodies to account for the lack of support to persons with disabilities and for their lack of implementation of human rights instruments such as the CAT and the CRPD.

The ADF would seek to strengthen and unify the representative voices of DPOs and persons with disabilities in Africa. The African Continent is immense with great regional diversity, and it is not possible for one organization to expect to fully reflect and represent such diversity. Rather, the ADF would include and build upon existing structures, capacities and successes including the marginalized groups of persons among persons with disabilities such as those with psychosocial disabilities.

The ownership and representation need to remain in the hands of African persons with disabilities, including persons with psychosocial disabilities, for strengthening their capacity as well as that of duty-bearers. As challenges are intertwined, structural, and diverse at different levels, so too must be the solutions, not only in the healthcare sector but beyond, especially when it comes to African persons with psychosocial disabilities.

³⁵ MALAWI HUMAN RIGHTS COMMISSION, *supra* note 9, at 40.



Human Rights Council

Twenty-second session

Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Report of the Special Rapporteur on torture and
other cruel, inhuman or degrading treatment or
punishment, Juan E. Méndez***Summary*

The present report focuses on certain forms of abuses in health-care settings that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment. It identifies the policies that promote these practices and existing protection gaps.

By illustrating some of these abusive practices in health-care settings, the report sheds light on often undetected forms of abusive practices that occur under the auspices of health-care policies, and emphasizes how certain treatments run afoul of the prohibition on torture and ill-treatment. It identifies the scope of State's obligations to regulate, control and supervise health-care practices with a view to preventing mistreatment under any pretext.

The Special Rapporteur examines a number of the abusive practices commonly reported in health-care settings and describes how the torture and ill-treatment framework applies in this context. The examples of torture and ill-treatment in health settings discussed likely represent a small fraction of this global problem.

A/HRC/22/53

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I. Introduction

1. The present report is submitted to the Human Rights Council in accordance with Council resolution 16/23.

2. Reports of country visits to Tajikistan and Morocco are contained in documents A/HRC/22/53/Add.1 and Add.2, respectively. A/HRC/22/53/Add.3 contains an update on follow-up measures and A/HRC/22/53/Add.4 contains observations made by the Special Rapporteur on some of the cases reflected in the communication reports A/HRC/20/30, A/HRC/21/49 and A/HRC/22/67.

II. Activities of the Special Rapporteur

A. Upcoming country visits and pending requests

3. The Special Rapporteur plans to visit Bahrain in May 2013 and Guatemala in the second half of 2013 and is engaged with the respective Governments to find mutually agreeable dates. The Special Rapporteur has accepted an invitation to visit Thailand in February 2014. He also notes with appreciation an outstanding invitation to visit Iraq.

4. The Special Rapporteur has reiterated his interest to conduct country visits to a number of States where there are pending requests for invitations: Cuba; Ethiopia; Ghana; Kenya; United States of America; Uzbekistan; Venezuela (Bolivarian Republic of) and Zimbabwe. The Special Rapporteur has also recently requested to visit Chad, Côte d'Ivoire, Dominican Republic, Georgia, Mexico and Viet Nam.

B. Highlights of key presentations and consultations

5. On 10 September 2012, the Special Rapporteur participated in a Chatham House event in London hosted by REDRESS on "Enforcing the absolute prohibition against torture".

6. On 26 September 2012, the Special Rapporteur met the Director General of the National Human Rights Commission of the Republic of Korea, who was visiting Washington D.C.

7. Between 22 and 24 October 2012, the Special Rapporteur presented his interim report (A/67/279) to the General Assembly and participated in two side events: one, held at the Permanent Mission of Denmark to the United Nations in New York, on "Reprisals against victims of torture and other ill-treatment" and the other organized jointly with the World Organisation Against Torture, Penal Reform International, the Centre for Constitutional Rights and Human Rights Watch on "The death penalty and human rights: the way forward". He also met with representatives of the Permanent Missions of Guatemala and Uruguay.

8. On 17 November 2012, the Special Rapporteur participated in a symposium organized by New York University on the practice of solitary confinement, entitled "Solitary: wry fancies and stark realities".

9. From 2 to 6 December 2012, the Special Rapporteur conducted a follow-up visit to Uruguay (A/HRC/22/53/Add.3), at the invitation of the Government, to assess improvements and identify remaining challenges regarding torture and other cruel, inhuman or degrading treatment or punishment.

10. From 13 to 14 December 2012, the Special Rapporteur convened an expert meeting on “Torture and ill-treatment in healthcare settings” at the Center for Human Rights and Humanitarian Law, American University in Washington, DC.

III. Applying the torture and ill-treatment protection framework in health-care settings

11. Mistreatment in health-care settings¹ has received little specific attention by the mandate of the Special Rapporteur, as the denial of health-care has often been understood as essentially interfering with the “right to health”.

12. While different aspects of torture and ill-treatment in health-care settings have been previously explored by the rapporteurship and other United Nations mechanisms, the Special Rapporteur feels that there is a need to highlight the specific dimension and intensity of the problem, which often goes undetected; identify abuses that exceed the scope of violations of the right to health and could amount to torture and ill-treatment; and strengthen accountability and redress mechanisms.

13. The Special Rapporteur recognizes that there are unique challenges to stopping torture and ill-treatment in health-care settings due, among other things, to a perception that, while never justified, certain practices in health-care may be defended by the authorities on grounds of administrative efficiency, behaviour modification or medical necessity. The intention of the present report is to analyse all forms of mistreatment premised on or attempted to be justified on the basis of health-care policies, under the common rubric of their purported justification as “health-care treatment”, and to find cross-cutting issues that apply to all or most of these practices.

A. Evolving interpretation of the definition of torture and ill-treatment

14. Both the European Court of Human Rights (ECHR) and the Inter-American Court of Human Rights have stated that the definition of torture is subject to ongoing reassessment in light of present-day conditions and the changing values of democratic societies.²

15. The conceptualization of abuses in health-care settings as torture or ill-treatment is a relatively recent phenomenon. In the present section, the Special Rapporteur embraces this ongoing paradigm shift, which increasingly encompasses various forms of abuse in health-care settings within the discourse on torture. He demonstrates that, while the prohibition of torture may have originally applied primarily in the context of interrogation, punishment or intimidation of a detainee, the international community has begun to recognize that torture may also occur in other contexts.

16. The analysis of abuse in health-care settings through the lens of torture and ill-treatment is based on the definition of these violations provided by the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and its authoritative interpretations. In order to demonstrate how abusive practices in health-care

¹ Health-care settings refers to hospitals, public and private clinics, hospices and institutions where health-care is delivered.

² World Organization Against Torture (OMCT), *The Prohibition of Torture and Ill-treatment in the Inter-American Human Rights System: A Handbook for Victims and Their Advocates* (2006), p. 107, citing Inter-American Court of Human Rights, *Cantoral-Benavides v. Peru*, Series C, No. 69 (2000) para. 99; ECHR, *Selmouni v. France*, Application No. 25803/94 (1999), para. 101.

settings meet the definition of torture, the following section provides an overview of the main elements of the definition of torture.

B. Applicability of the torture and ill-treatment framework in health-care settings

1. Overview of key elements of the definition of torture and ill-treatment

17. At least four essential elements are reflected in the definition of torture provided in article 1, paragraph 1, of the Convention against Torture: an act inflicting severe pain or suffering, whether physical or mental; the element of intent; the specific purpose; and the involvement of a State official, at least by acquiescence (A/HRC/13/39/Add.5, para. 30). Acts falling short of this definition may constitute cruel, inhuman or degrading treatment or punishment under article 16 of the Convention (A/63/175, para. 46). The previous Special Rapporteurs have covered in great detail the main components of the definition of torture. Nevertheless, there are a few salient points worth elaborating for the purpose of the present report.

18. The jurisprudence and authoritative interpretations of international human rights bodies provide useful guidance on how the four criteria of the definition of torture apply in the context of health-care settings. ECHR has noted that a violation of article 3 may occur where the purpose or intention of the State's action or inaction was not to degrade, humiliate or punish the victim, but where this nevertheless was the result.³

19. The application of the criteria of severe pain or suffering, intent, and involvement of a public official or other person acting in an official capacity, by consent or acquiescence to abuses in health-care settings, is relatively straightforward. The criterion of the specific purpose warrants some analysis.⁴

20. The mandate has stated previously that intent, required in article 1 of the Convention, can be effectively implied where a person has been discriminated against on the basis of disability. This is particularly relevant in the context of medical treatment, where serious violations and discrimination against persons with disabilities may be defended as "well intended" on the part of health-care professionals. Purely negligent conduct lacks the intent required under article 1, but may constitute ill-treatment if it leads to severe pain and suffering (A/63/175, para. 49).

21. Furthermore, article 1 explicitly names several purposes for which torture can be inflicted: extraction of a confession; obtaining information from a victim or a third person; punishment, intimidation and coercion; and discrimination. However, there is a general acceptance that these stated purposes are only of an indicative nature and not exhaustive. At the same time, only purposes which have "something in common with the purposes expressly listed" are sufficient (A/HRC/13/39/Add.5, para. 35).

22. Although it may be challenging to satisfy the required purpose of discrimination in some cases, as most likely it will be claimed that the treatment is intended to benefit the "patient", this may be met in a number of ways.⁵ Specifically, the description of abuses

³ See *Peers v. Greece*, Application No. 28524/95 (2001), paras. 68, 74; *Groni v. Albania*, Application No. 25336/04 (2009), para. 125.

⁴ Open Society Foundations, *Treatment or Torture? Applying International Human Rights Standards to Drug Detention Centers* (2011), p. 10.

⁵ *Ibid.*, p. 12.

outlined below demonstrates that the explicit or implicit aim of inflicting punishment, or the objective of intimidation, often exist alongside ostensibly therapeutic aims.

2. The scope of State core obligations under the prohibition of torture and ill-treatment

23. The Committee against Torture interprets State obligations to prevent torture as indivisible, interrelated, and interdependent with the obligation to prevent cruel, inhuman, or degrading treatment or punishment (ill-treatment) because “conditions that give rise to ill-treatment frequently facilitate torture”.⁶ It has established that “each State party should prohibit, prevent and redress torture and ill-treatment in all contexts of custody or control, for example, in prisons, hospitals, schools, institutions that engage in the care of children, the aged, the mentally ill or disabled, in military service, and other institutions as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm”.⁷

24. Indeed, the State’s obligation to prevent torture applies not only to public officials, such as law enforcement agents, but also to doctors, health-care professionals and social workers, including those working in private hospitals, other institutions and detention centres (A/63/175, para. 51). As underlined by the Committee against Torture, the prohibition of torture must be enforced in all types of institutions and States must exercise due diligence to prevent, investigate, prosecute and punish violations by non-State officials or private actors.⁸

25. In *da Silva Pimentel v. Brazil*, the Committee on the Elimination of Discrimination against Women observed that “the State is directly responsible for the action of private institutions when it outsources its medical services” and “always maintains the duty to regulate and monitor private health-care institutions”.⁹ The Inter-American Court of Human Rights addressed State responsibility for actions of private actors in the context of health-care delivery in *Ximenes Lopes v. Brazil*.¹⁰

26. Ensuring special protection of minority and marginalized groups and individuals is a critical component of the obligation to prevent torture and ill-treatment. Both the Committee against Torture and the Inter-American Court of Human Rights have confirmed that States have a heightened obligation to protect vulnerable and/or marginalized individuals from torture, as such individuals are generally more at risk of experiencing torture and ill-treatment.¹¹

C. Interpretative and guiding principles

1. Legal capacity and informed consent

27. In all legal systems, capacity is a condition assigned to agents that exercise free will and choice and whose actions are attributed legal effects. Capacity is a rebuttable

⁶ General comment No. 2 (2007), para. 3.

⁷ *Ibid.*, para. 15.

⁸ General comment No. 2, paras. 15, 17 and 18. See also Committee against Torture, communication No. 161/2000, *Dzemažl et al. v. Serbia and Montenegro*, para. 9.2; Human Rights Committee, general comment No. 20 (1992), para. 2.

⁹ Communication No. 17/2008, para. 7.5.

¹⁰ Inter-American Court of Human Rights. (Series C) No. 149 (2006), paras. 103, 150; see also Committee on the Elimination of Discrimination against Women, general recommendation No. 19 (1992), para. 9.

¹¹ Committee against Torture, general comment No. 2, para. 21; *Ximenes Lopes v. Brazil*, para. 103.

presumption; therefore, “incapacity” has to be proven before a person can be designated as incapable of making decisions. Once a determination of incapacity is made, the person’s expressed choices cease to be treated meaningfully. One of the core principles of the Convention on the Rights of Persons with Disabilities is “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (art. 3 (a)). The Committee on the Rights of Persons with Disabilities has interpreted the core requirement of article 12 to be the replacement of substituted decision-making regimes by supported decision-making, which respects the person’s autonomy, will and preferences.¹²

28. The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health observed that informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision. Guaranteeing informed consent is a fundamental feature of respecting an individual’s autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services (A/64/272, para. 18).

29. As the Special Rapporteur on the right to health observed, while informed consent is commonly enshrined in the legal framework at the national level, it is frequently compromised in the health-care setting. Structural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised (*ibid.*, para. 92).

30. The intimate link between forced medical interventions based on discrimination and the deprivation of legal capacity has been emphasized both by the Committee on the Rights of Persons with Disabilities and the previous Special Rapporteur on the question of torture.¹³

2. Powerlessness and the doctrine of “medical necessity”

31. Patients in health-care settings are reliant on health-care workers who provide them services. As the previous Special Rapporteur stated: “Torture, as the most serious violation of the human right to personal integrity and dignity, presupposes a situation of powerlessness, whereby the victim is under the total control of another person.”¹⁴ Deprivation of legal capacity, when a person’s exercise of decision-making is taken away and given to others, is one such circumstance, along with deprivation of liberty in prisons or other places (A/63/175, para. 50).

32. The mandate has recognized that medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose, may constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned (*ibid.*, paras. 40, 47). This is particularly the case when intrusive and irreversible, non-consensual treatments are performed on patients from marginalized groups, such as persons with disabilities, notwithstanding claims of good intentions or medical necessity. For example, the mandate has held that the discriminatory character of forced psychiatric interventions, when committed against persons with psychosocial disabilities, satisfies both intent and purpose required under the article 1 of the Convention against Torture, notwithstanding claims of “good intentions” by medical professionals (*ibid.*, paras. 47, 48). In other examples, the administration of non-consensual medication or involuntary

¹² See CRPD/C/ESP/CO/1.

¹³ Convention on the Rights of Persons with Disabilities, art. 25 (d); see also CRPD/C/CHN/CO/1 and Corr.1, para. 38; A/63/175, paras. 47, 74.

¹⁴ A/63/175, para. 50.

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sterilization is often claimed as being a necessary treatment for the so-called best interest of the person concerned.

33. However, in response to reports of sterilizations of women in 2011, the International Federation of Gynecology and Obstetrics emphasized that “sterilization for prevention of future pregnancy cannot be ethically justified on grounds of medical emergency. Even if a future pregnancy may endanger a woman’s life or health, she ... must be given the time and support she needs to consider her choice. Her informed decision must be respected, even if it is considered liable to be harmful to her health.”¹⁵

34. In those cases, dubious grounds of medical necessity were used to justify intrusive and irreversible procedures performed on patients without full free and informed consent. In this light, it is therefore appropriate to question the doctrine of “medical necessity” established by the ECHR in the case of *Herczegfalvy v. Austria* (1992),¹⁶ where the Court held that continuously sedating and administering forcible feeding to a patient who was physically restrained by being tied to a bed for a period of two weeks was nonetheless consistent with article 3 of the European Convention for the Protection of Human Rights and Fundamental Freedoms because the treatment in question was medically necessary and in line with accepted psychiatric practice at that time.

35. The doctrine of medical necessity continues to be an obstacle to protection from arbitrary abuses in health-care settings. It is therefore important to clarify that treatment provided in violation of the terms of the Convention on the Rights of Persons with Disabilities – either through coercion or discrimination – cannot be legitimate or justified under the medical necessity doctrine.

3. Stigmatized identities

36. In a 2011 report (A/HRC/19/41), the United Nations High Commissioner for Human Rights examined discriminatory laws and practices and acts of violence against individuals based on sexual orientation and gender identity in health-care settings. She observed that a pattern of human rights violations emerged that demanded a response. With the adoption in June 2011 of resolution 17/19, the Human Rights Council formally expressed its “grave concern” regarding violence and discrimination based on sexual orientation and gender identity.

37. Many policies and practices that lead to abuse in health-care settings are due to discrimination targeted at persons who are marginalized. Discrimination plays a prominent role in an analysis of reproductive rights violations as forms of torture or ill-treatment because sex and gender bias commonly underlie such violations. The mandate has stated, with regard to a gender-sensitive definition of torture, that the purpose element is always fulfilled when it comes to gender-specific violence against women, in that such violence is inherently discriminatory and one of the possible purposes enumerated in the Convention is discrimination (A/HRC/7/3, para. 68).

38. In the context of prioritizing informed consent as a critical element of a voluntary counselling, testing and treatment continuum, the Special Rapporteur on the right to health has also observed that special attention should be paid to vulnerable groups. Principles 17 and 18 of the Yogyakarta Principles, for instance, highlight the importance of safeguarding informed consent of sexual minorities. Health-care providers must be cognizant of, and adapt to, the specific needs of lesbian, gay, bisexual, transgender and intersex persons (A/64/272, para. 46). The Committee on Economic, Social and Cultural Rights has

¹⁵ *Ethical Issues in Obstetrics and Gynecology* (2012), pp. 123–124.

¹⁶ Application No. 10533/83, paras. 27, 83.

indicated that the International Covenant on Economic, Social and Cultural Rights proscribes any discrimination in access to health-care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of sexual orientation and gender identity.¹⁷

IV. Emerging recognition of different forms of abuses in health-care settings

39. Numerous reports have documented a wide range of abuses against patients and individuals under medical supervision. Health providers allegedly withhold care or perform treatments that intentionally or negligently inflict severe pain or suffering for no legitimate medical purpose. Medical care that causes severe suffering for no justifiable reason can be considered cruel, inhuman or degrading treatment or punishment, and if there is State involvement and specific intent, it is torture.

A. Compulsory detention for medical conditions

40. Compulsory detention for drug users is common in so-called rehabilitation centres. Sometimes referred to as drug treatment centres or “reeducation through labor” centres or camps, these are institutions commonly run by military or paramilitary, police or security forces, or private companies. Persons who use, or are suspected of using, drugs and who do not voluntarily opt for drug treatment and rehabilitation are confined in such centres and compelled to undergo diverse interventions.¹⁸ In some countries, a wide range of other marginalized groups, including street children, persons with psychosocial disabilities, sex workers, homeless individuals and tuberculosis patients, are reportedly detained in these centres.¹⁹

41. Numerous reports document that users of illicit drugs who are detained in such centres undergo painful withdrawal from drug dependence without medical assistance, administration of unknown or experimental medications, State-sanctioned beatings, caning or whipping, forced labour, sexual abuse and intentional humiliation.²⁰ Other reported abuses included “flogging therapy”, “bread and water therapy”, and electroshock resulting in seizures, all in the guise of rehabilitation. In such settings, medical professionals trained to manage drug dependence disorders as medical illnesses²¹ are often unavailable.

42. Compulsory treatment programmes that consist primarily of physical disciplinary exercises, often including military-style drills, disregard medical evidence (A/65/255, paras. 31, 34). According to the World Health Organization (WHO) and the United Nations Office on Drugs and Crime (UNODC), “neither detention nor forced labour have been recognized by science as treatment for drug use disorders”.²² Such detention – frequently

¹⁷ General comment No. 14 (2000), para. 18.

¹⁸ See World Health Organization (WHO), *Assessment of Compulsory Treatment of People Who Use Drugs in Cambodia, China, Malaysia and Viet Nam* (2009).

¹⁹ Human Rights Watch (HRW), *Torture in the Name of Treatment: Human Rights Abuses in Vietnam, China, Cambodia, and LAO PDR* (2012), p. 4.

²⁰ See Daniel Wolfe and Roxanne Saucier, “In rehabilitation’s name? Ending institutionalized cruelty and degrading treatment of people who use drugs”, *International Journal of Drug Policy*, vol. 21, No. 3 (2010), pp. 145-148.

²¹ United Nations Office on Drugs and Crime (UNODC) and WHO, “Principles of drug dependence treatment”, discussion paper, 2008.

²² *Ibid.*, p. 15.

without medical evaluation, judicial review or right of appeal – offers no evidence-based²³ or effective treatment. Detention and forced labour programmes therefore violate international human rights law and are illegitimate substitutes for evidence-based measures, such as substitution therapy, psychological interventions and other forms of treatment given with full, informed consent (A/65/255, para. 31). The evidence shows that this arbitrary and unjustified detention is frequently accompanied by – and is the setting for – egregious physical and mental abuse.

Overview of developments to date

43. The numerous calls by various international and regional organizations to close compulsory drug detention centres,²⁴ as well as the numerous injunctions and recommendations contained in the recently released guidelines by WHO on pharmacotherapy for opiate dependence,²⁵ the UNODC policy guidance on the organization's human rights responsibilities in drug detention centres,²⁶ and resolutions by the Commission on Narcotic Drugs,²⁷ are routinely ignored.²⁸ These centres continue to operate often with direct or indirect support and assistance from international donors without any adequate human rights oversight.²⁹

44. Notwithstanding the commitment to scale-up methadone treatment and evidence-based treatment as opposed to punitive approaches, those remanded to compulsory treatment in the punitive drug-free centres continue to exceed, exponentially, the number receiving evidence-based treatment for drug dependence.³⁰

B. Reproductive rights violations

45. The Special Rapporteur has, on numerous occasions, responded to various initiatives in the area of gender mainstreaming and combating violence against women, by, inter alia, examining gender-specific forms of torture with a view to ensure that the torture protection framework is applied in a gender-inclusive manner.³¹ The Special Rapporteur seeks to complement these efforts by identifying the reproductive rights practices in health-care settings that he believes amount to torture or ill-treatment.

46. International and regional human rights bodies have begun to recognize that abuse and mistreatment of women seeking reproductive health services can cause tremendous and lasting physical and emotional suffering, inflicted on the basis of gender.³² Examples of such violations include abusive treatment and humiliation in institutional settings;³³

²³ See for example WHO, UNODC, UNAIDS, *Technical Guide for Countries to Set Targets for Universal Access to HIV Prevention, Treatment and Care for Injecting Drug Users* (WHO, 2009).

²⁴ World Medical Association, "Call for compulsory drug Detention centers to be closed", press statement, 17 May 2011; United Nations entities, "Compulsory drug detention and rehabilitation centres", joint statement, March 2012.

²⁵ See Wolfe and Saucier, "In rehabilitation's name".

²⁶ "UNODC and the promotion and protection of human rights", position paper, 2012, p. 8.

²⁷ Such as resolutions 55/12 (2012); 55/2 (2012) and 55/10 (2012).

²⁸ See Wolfe and Saucier, "In rehabilitation's name".

²⁹ HRW, submission to the Special Rapporteur on the question of torture, 2012.

³⁰ See Wolfe and Saucier, "In rehabilitation's name".

³¹ See A/54/426, A/55/290.

³² CAT/C/CR/32/5, para. 7 (m); Human Rights Committee general comment No. 28 (2000), para. 11.

³³ See Center for Reproductive Rights, *Reproductive Rights Violations as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment: A Critical Human Rights Analysis* (2011).

involuntary sterilization; denial of legally available health services³⁴ such as abortion and post-abortion care; forced abortions and sterilizations;³⁵ female genital mutilation;³⁶ violations of medical secrecy and confidentiality in health-care settings, such as denunciations of women by medical personnel when evidence of illegal abortion is found; and the practice of attempting to obtain confessions as a condition of potentially life-saving medical treatment after abortion.³⁷

47. In the case of *R.R. v. Poland*, for instance, ECHR found a violation of article 3 in the case of a woman who was denied access to prenatal genetic testing when an ultrasound revealed a potential foetal abnormality. The Court recognized “that the applicant was in a situation of great vulnerability”³⁸ and that R.R.’s access to genetic testing was “marred by procrastination, confusion and lack of proper counselling and information given to the applicant”.³⁹ Access to information about reproductive health is imperative to a woman’s ability to exercise reproductive autonomy, and the rights to health and to physical integrity.

48. Some women may experience multiple forms of discrimination on the basis of their sex and other status or identity. Targeting ethnic and racial minorities, women from marginalized communities⁴⁰ and women with disabilities⁴¹ for involuntary sterilization⁴² because of discriminatory notions that they are “unfit” to bear children⁴³ is an increasingly global problem. Forced sterilization is an act of violence,⁴⁴ a form of social control, and a violation of the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment.⁴⁵ The mandate has asserted that “forced abortions or sterilizations carried out by State officials in accordance with coercive family planning laws or policies may amount to torture”.⁴⁶

49. For many rape survivors, access to a safe abortion procedure is made virtually impossible by a maze of administrative hurdles, and by official negligence and obstruction. In the landmark decision of *K.N.L.H. v. Peru*, the Human Rights Committee deemed the denial of a therapeutic abortion a violation of the individual’s right to be free from ill-treatment.⁴⁷ In the case of *P. and S. v. Poland*, ECHR stated that “the general stigma attached to abortion and to sexual violence ..., caus[ed] much distress and suffering, both physically and mentally”.⁴⁸

50. The Committee against Torture has repeatedly expressed concerns about restrictions on access to abortion and about absolute bans on abortion as violating the prohibition of torture and ill-treatment.⁴⁹ On numerous occasions United Nations bodies have expressed

³⁴ See CAT/C/PER/CO/4, para. 23.

³⁵ E/CN.4/2005/51, paras. 9, 12.

³⁶ A/HRC/7/3, paras. 50, 51, 53; CAT/C/IDN/CO/2, para. 16.

³⁷ CAT/C/CR/32/5, para. 6 (j).

³⁸ ECHR, *R.R. v. Poland*, Application No. 27617/04 (2011), para. 159.

³⁹ *Ibid.*, para. 153.

⁴⁰ See ECHR, *V.C. v. Slovakia*, Application No. 18968/07 (2011).

⁴¹ A/67/227, para. 28; A/HRC/7/3, para. 38.

⁴² A/64/272, para. 55.

⁴³ See Open Society Foundations, *Against Her Will: Forced and Coerced Sterilization of Women Worldwide* (2011).

⁴⁴ See Committee on the Elimination of Discrimination against Women, general recommendation No. 19, para. 22; Human Rights Committee, general comment No. 28, paras. 11, 20.

⁴⁵ A/HRC/7/3, paras. 38, 39.

⁴⁶ *Ibid.*, para. 69.

⁴⁷ Communication No. 1153/2003 (2005), para. 6.3.

⁴⁸ ECHR, Application No. 57375/08 (2012), para. 76.

⁴⁹ See CAT/C/PER/CO/4, para. 23.

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concern about the denial of or conditional access to post-abortion care.⁵⁰ often for the impermissible purposes of punishment or to elicit confession.⁵¹ The Human Rights Committee explicitly stated that breaches of article 7 of the International Covenant on Civil and Political Rights include forced abortion, as well as denial of access to safe abortions to women who have become pregnant as a result of rape⁵² and raised concerns about obstacles to abortion where it is legal.

C. Denial of pain treatment

51. In 2012, WHO estimated that 5.5 billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain.⁵³ Despite the repeated reminders made by the Commission on Narcotic Drugs to States of their obligations,⁵⁴ 83 per cent of the world population has either no or inadequate access to treatment for moderate to severe pain. Tens of millions of people, including around 5.5 million terminal cancer patients and 1 million end-stage HIV/AIDS patients, suffer from moderate to severe pain each year without treatment.⁵⁵

52. Many countries fail to make adequate arrangements for the supply of these medications.⁵⁶ Low- and middle-income countries account for 6 per cent of morphine use worldwide while having about half of all cancer patients and 95 per cent of all new HIV infections.⁵⁷ Thirty-two countries in Africa have almost no morphine available at all.⁵⁸ In the United States, over a third of patients are not adequately treated for pain.⁵⁹ In France, a study found that doctors underestimated pain in over half of their AIDS patients.⁶⁰ In India, more than half of the country's regional cancer centres do not have morphine or doctors trained in using it. This is despite the fact that 70 per cent or more of their patients have advanced cancer and are likely to require pain treatment.⁶¹

53. Although relatively inexpensive and highly effective medications such as morphine and other narcotic drugs have proven essential "for the relief of pain and suffering"⁶², these types of medications are virtually unavailable in more than 150 countries.⁶³ Obstacles that unnecessarily impede access to morphine and adversely affect its availability include overly restrictive drug control regulations⁶⁴ and, more frequently, misinterpretation of otherwise appropriate regulations,⁶⁵ deficiency in drug supply management; inadequate infrastructure,⁶⁶ lack of prioritization of palliative care⁶⁷; ingrained prejudices about using

⁵⁰ See CAT/C/CR/32/5, para. 7 (m); A/66/254, para. 30.

⁵¹ CAT/C/CR/32/5, para. 7 (m).

⁵² General comment No. 28, para. 11; see also CCPR/CO.70/ARG, para. 14.

⁵³ WHO, "Access to Controlled Medicines Programme", briefing note (2012), p. 1.

⁵⁴ Resolutions 53/4 (2010) and 54/6 (2011).

⁵⁵ WHO, "Access", p. 1.

⁵⁶ See HRW, "Please Do Not Make Us Suffer Any More...": *Access to Pain Treatment as a Human Right* (2009).

⁵⁷ Open Society Foundations, "Palliative care as a human right", Public Health Fact Sheet, 2012.

⁵⁸ *Ibid.*

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

⁶¹ HRW, *Unbearable Pain: India's Obligation to Ensure Palliative Care* (2009), p. 3.

⁶² Single Convention on Narcotic Drugs, 1961, preamble.

⁶³ Joseph Amon and Diederik Lohman, "Denial of pain treatment and the prohibition of torture, cruel, inhuman or degrading treatment or punishment", *INTERIGHTS Bulletin*, vol. 16, No. 4 (2011), p. 172.

⁶⁴ See HRW, "Please Do Not Make Us Suffer".

⁶⁵ E/INCB/1999/1, p. 7.

⁶⁶ A/65/255, para. 40.

opioids for medical purposes;⁶⁸ and the absence of pain management policies or guidelines for practitioners.⁶⁹

Applicability of torture and ill-treatment framework

54. Generally, denial of pain treatment involves acts of omission rather than commission,⁷⁰ and results from neglect and poor Government policies, rather than from an intention to inflict suffering. However, not every case where a person suffers from severe pain but has no access to appropriate treatment will constitute cruel, inhuman, or degrading treatment or punishment. This will only be the case when the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment; when the State is, or should be, aware of the suffering, including when no appropriate treatment was offered; and when the Government failed to take all reasonable steps⁷¹ to protect individuals' physical and mental integrity.⁷²

55. Ensuring the availability and accessibility of medications included in the WHO Model List of Essential Medicines is not just a reasonable step but a legal obligation under the Single Convention on Narcotic Drugs, 1961. When the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment (A/HRC/10/44 and Corr.1, para. 72).

56. In a statement issued jointly with the Special Rapporteur on the right to health, the Special Rapporteur on the question of torture reaffirmed that the failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment. Governments must guarantee essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment.⁷³

D. Persons with psychosocial disabilities

57. Under article 1 of the Convention on the Rights of Persons with Disabilities, persons with disabilities include those who have long-term intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. These are individuals who have been either neglected or detained in psychiatric and social care institutions, psychiatric wards, prayer

⁶⁷ Palliative care is an approach that seeks to improve the quality of life of patients diagnosed with life-threatening illnesses, through prevention and relief of suffering. WHO Definition of Palliative Care (see www.who.int/cancer/palliative/definition/en/).

⁶⁸ E/INCB/1999/1, p. 7.

⁶⁹ HRW, "Please Do Not Make Us Suffer", p. 2.

⁷⁰ Amon and Lohman, "Denial", p. 172.

⁷¹ See for example ECHR, *Osman v. United Kingdom*, Application No. 23452/94 (1998), paras. 115-122; Committee on Economic, Social and Cultural Rights, general comment No. 14.

⁷² Amon and Lohman, "Denial", p. 172.

⁷³ Joint letter to the Chairperson of the fifty-second session of the Commission on Narcotic Drugs, 2008, p. 4.

camps, secular and religious-based therapeutic boarding schools, boot camps, private residential treatment centres or traditional healing centres.⁷⁴

58. In 2008 the mandate made significant strides in the development of norms for the abolition of forced psychiatric interventions on the basis of disability alone as a form of torture and ill-treatment (see A/63/175). The Convention on the Rights of Persons with Disabilities also provides authoritative guidance on the rights of persons with disabilities and prohibits involuntary treatment and involuntary confinement on the grounds of disability, superseding earlier standards such as the 1991 Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (1991 Principles).

59. Severe abuses, such as neglect, mental and physical abuse and sexual violence, continue to be committed against people with psychosocial disabilities and people with intellectual disabilities in health-care settings.⁷⁵

60. There are several areas in which the Special Rapporteur would like to suggest steps beyond what has already been proposed by the mandate in its efforts to promote the Convention on the Rights of Persons with Disabilities as the new normative paradigm and call for measures to combat impunity.

1. A new normative paradigm

61. Numerous calls by the mandate to review the anti-torture framework in relation to persons with disabilities⁷⁶ remain to be addressed. It is therefore necessary to reaffirm that the Convention on the Rights of Persons with Disabilities offers the most comprehensive set of standards on the rights of persons with disabilities, inter alia, in the context of health care, where choices by people with disabilities are often overridden based on their supposed “best interests”, and where serious violations and discrimination against persons with disabilities may be masked as “good intentions” of health professionals (A/63/175, para. 49).

62. It is necessary to highlight additional measures needed to prevent torture and ill-treatment against people with disabilities, by synthesizing standards and coordinating actions in line with the Convention on the Rights of Persons with Disabilities.⁷⁷

2. Absolute ban on restraints and seclusion

63. The mandate has previously declared that there can be no therapeutic justification for the use of solitary confinement and prolonged restraint of persons with disabilities in psychiatric institutions; both prolonged seclusion and restraint may constitute torture and ill-treatment (A/63/175, paras. 55-56). The Special Rapporteur has addressed the issue of solitary confinement and stated that its imposition, of any duration, on persons with mental disabilities is cruel, inhuman or degrading treatment (A/66/268, paras. 67-68, 78). Moreover, any restraint on people with mental disabilities for even a short period of time

⁷⁴ See HRW, “*Like a Death Sentence*”: *Abuses against Persons with Mental Disabilities in Ghana* (2012).

⁷⁵ In November 2012, the Inter-American Commission on Human Rights approved precautionary measures to protect 300 individuals in Guatemala City’s psychiatric facility, where unspeakable forms of abuses were documented.

⁷⁶ See A/58/120; A/63/175, para. 41.

⁷⁷ See for example Organization of American States, Committee for the Elimination of all Forms of Discrimination against Persons with Disabilities, resolution CEDDIS/RES.1 (I-E/11) (2011), annex.

may constitute torture and ill-treatment.⁷⁸ It is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions. The environment of patient powerlessness and abusive treatment of persons with disabilities in which restraint and seclusion is used can lead to other non-consensual treatment, such as forced medication and electroshock procedures.

3. Domestic legislation allowing forced interventions

64. The mandate continues to receive reports of the systematic use of forced interventions worldwide. Both this mandate and United Nations treaty bodies have established that involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.⁷⁹ Forced interventions, often wrongfully justified by theories of incapacity and therapeutic necessity inconsistent with the Convention on the Rights of Persons with Disabilities, are legitimized under national laws, and may enjoy wide public support as being in the alleged “best interest” of the person concerned. Nevertheless, to the extent that they inflict severe pain and suffering, they violate the absolute prohibition of torture and cruel, inhuman and degrading treatment (A/63/175, paras. 38, 40, 41). Concern for the autonomy and dignity of persons with disabilities leads the Special Rapporteur to urge revision of domestic legislation allowing for forced interventions.

4. Fully respecting each person’s legal capacity is a first step in the prevention of torture and ill-treatment

65. Millions of people with disabilities are stripped of their legal capacity worldwide, due to stigma and discrimination, through judicial declaration of incompetency or merely by a doctor’s decision that the person “lacks capacity” to make a decision. Deprived of legal capacity, people are assigned a guardian or other substitute decision maker, whose consent will be deemed sufficient to justify forced treatment (E/CN.4/2005/51, para. 79).

66. As earlier stated by the mandate, criteria that determine the grounds upon which treatment can be administered in the absence of free and informed consent should be clarified in the law, and no distinction between persons with or without disabilities should be made.⁸⁰ Only in a life-threatening emergency in which there is no disagreement regarding absence of legal capacity may a health-care provider proceed without informed consent to perform a life-saving procedure.⁸¹ From this perspective, several of the 1991 Principles may require reconsideration as running counter to the provisions of the Convention on the Rights of Persons with Disabilities (A/63/175, para. 44).

5. Involuntary commitment in psychiatric institutions

67. In many countries where mental health policies and laws do exist, they focus on confinement of people with mental disabilities in psychiatric institutions but fail to effectively safeguard their human rights.⁸²

⁷⁸ See CAT/C/CAN/CO/6, para. 19 (d); ECHR, *Bures v. Czech Republic*, Application No. 37679/08 (2012), para. 132.

⁷⁹ A/63/175, paras. 44, 47, 61, 63; Human Rights Committee, communication No. 110/1981, *Viana Acosta v. Uruguay*, paras. 2.7, 14, 15.

⁸⁰ See also A/64/272, para. 74.

⁸¹ *Ibid.*, para. 12.

⁸² WHO, “Mental health legislation and human rights – denied citizens: including the excluded”, p. 1.

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68. Involuntary commitment to psychiatric institutions has been well documented.⁸³ There are well-documented examples of people living their whole lives in such psychiatric or social care institutions.⁸⁴ The Committee on the Rights of Persons with Disabilities has been very explicit in calling for the prohibition of disability-based detention, i.e. civil commitment and compulsory institutionalization or confinement based on disability.⁸⁵ It establishes that community living, with support, is no longer a favourable policy development but an internationally recognized right.⁸⁶ The Convention radically departs from this approach by forbidding deprivation of liberty based on the existence of any disability, including mental or intellectual, as discriminatory. Article 14, paragraph 1 (b), of the Convention unambiguously states that “the existence of a disability shall in no case justify a deprivation of liberty”. Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished. This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness (A/HRC/10/48, paras. 48, 49).

69. Deprivation of liberty on grounds of mental illness is unjustified if its basis is discrimination or prejudice against persons with disabilities. Under the European Convention on Human Rights, mental disorder must be of a certain severity in order to justify detention.⁸⁷ The Special Rapporteur believes that the severity of the mental illness is not by itself sufficient to justify detention; the State must also show that detention is necessary to protect the safety of the person or of others. Except in emergency cases, the individual concerned should not be deprived of his liberty unless he has been reliably shown to be of “unsound mind”.⁸⁸ As detention in a psychiatric context may lead to non-consensual psychiatric treatment,⁸⁹ the mandate has stated that deprivation of liberty that is based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture (A/63/175, para. 65). In making such an assessment, factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.⁹⁰

70. Moreover, the effects of institutionalization of individuals who do not meet appropriate admission criteria, as is the case in most institutions which are off the monitoring radar and lack appropriate admission oversight,⁹¹ raise particular questions under prohibition of torture and ill-treatment. Inappropriate or unnecessary non-consensual

⁸³ See Thomas Hammarberg, “Inhuman treatment of persons with disabilities in institutions”, Human Rights Comment (2010).

⁸⁴ See Dorottya Karsay and Oliver Lewis, “Disability, torture and ill-treatment: taking stock and ending abuses”, *The International Journal of Human Rights*, vol. 16, No. 6 (2012), pp. 816-830.

⁸⁵ See also CRPD/C/HUN/CO/1, paras. 27-28.

⁸⁶ See CRPD/C/CHN/CO/1 and Corr.1, paras. 92-93.

⁸⁷ See Peter Bartlett, “A mental disorder of a kind or degree warranting confinement: examining justifications for psychiatric detention”, *The International Journal of Human Rights*, vol. 16, No. 6 (2012), pp. 831-844.

⁸⁸ See ECHR, *Winterwerp v. The Netherlands*, Application No. 6301/73 (1979) and ECHR, *E v. Norway*, Application No. 11701/85 (1990).

⁸⁹ See Bartlett, “A mental disorder”.

⁹⁰ Stop Torture in Healthcare, “Torture and ill-treatment of people with disabilities in healthcare settings”, Campaign Briefing, 2012.

⁹¹ See CAT/C/JPN/CO/1, para. 26.

institutionalization of individuals may amount to torture or ill-treatment as use of force beyond that which is strictly necessary.⁹²

E. Marginalized groups

1. Persons living with HIV/AIDS

71. Numerous reports have documented mistreatment of or denial of treatment to people living with HIV/AIDS by health providers.⁹³ They are reportedly turned away from hospitals, summarily discharged, denied access to medical services unless they consent to sterilization,⁹⁴ and provided poor quality care that is both dehumanizing and damaging to their already fragile health status.⁹⁵ Forced or compulsory HIV testing is also a common abuse that may constitute degrading treatment if it is “done on a discriminatory basis without respecting consent and necessity requirements” (A/HRC/10/44 and Corr.1, para. 65). Unauthorized disclosure of HIV status to sexual partners, family members, employers and other health workers is a frequent abuse against people living with HIV that may lead to physical violence.

2. Persons who use drugs

72. People who use drugs are a highly stigmatized and criminalized population whose experience of health-care is often one of humiliation, punishment and cruelty. Drug users living with HIV are often denied emergency medical treatment.⁹⁶ In some cases the laws specifically single out the status of a drug user as a stand-alone basis for depriving someone of custody or other parental rights. Use of drug registries – where people who use drugs are identified and listed by police and health-care workers, and their civil rights curtailed – are violations of patient confidentiality⁹⁷ that lead to further ill-treatment by health providers.

73. A particular form of ill-treatment and possibly torture of drug users is the denial of opiate substitution treatment, including as a way of eliciting criminal confessions through inducing painful withdrawal symptoms (A/HRC/10/44 and Corr.1, para. 57). The denial of methadone treatment in custodial settings has been declared to be a violation of the right to be free from torture and ill-treatment in certain circumstances (*ibid.*, para. 71). Similar reasoning should apply to the non-custodial context, particularly in instances where Governments impose a complete ban on substitution treatment and harm reduction measures.⁹⁸ The common practice of withholding anti-retroviral treatment from HIV-positive people who use drugs, on the assumption that they will not be capable of adhering to treatment, amounts to cruel and inhuman treatment, given the physical and psychological suffering as the disease progresses; it also constitutes abusive treatment based on unjustified discrimination solely related to health status.

⁹² ECHR, *Mouisel v. France*, Application No. 67263/01 (2002), para. 48; see also Nell Monroe, “Define acceptable: how can we ensure that treatment for mental disorder in detention is consistent with the UN Convention on the Rights of Persons with Disabilities?”, *The International Journal of Human Rights*, vol. 16, No. 6 (2012).

⁹³ Campaign to Stop Torture in Health Care, “Torture and ill-treatment in health settings: a failure of accountability”, *Interights Bulletin*, vol. 16, No. 4 (2011), p. 162.

⁹⁴ Open Society Foundations, *Against Her Will* (footnote 43 above).

⁹⁵ See HRW, *Rhetoric and Risk: Human Rights Abuses Impeding Ukraine’s Fight against HIV/AIDS* (2006).

⁹⁶ *Ibid.*, p. 44.

⁹⁷ A/65/255, para. 20.

⁹⁸ See HRW, *Lessons Not Learned: Human Rights Abuses and HIV/AIDS in the Russian Federation* (2004).

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74. By denying effective drug treatment, State drug policies intentionally subject a large group of people to severe physical pain, suffering and humiliation, effectively punishing them for using drugs and trying to coerce them into abstinence, in complete disregard of the chronic nature of dependency and of the scientific evidence pointing to the ineffectiveness of punitive measures.

3. Sex workers

75. A report on sex workers documented negative and obstructive attitudes on the part of medical workers, including denial of necessary health-care services.⁹⁹ Public health rationales have in some instances led to mandatory HIV testing and exposure of their HIV status, accompanied by punitive measures.¹⁰⁰ Breaches of privacy and confidentiality are a further indignity experienced by sex workers in health settings.¹⁰¹ Most recently, the Committee against Torture noted “reports of alleged lack of privacy and humiliating circumstances amounting to degrading treatment during medical examinations”.¹⁰² The mandate has observed that acts aimed at humiliating the victim, regardless of whether severe pain has been inflicted, may constitute degrading treatment or punishment because of the incumbent mental suffering (E/CN.4/2006/6, para. 35).

4. Lesbian, gay, bisexual, transgender and intersex persons

76. The Pan American Health Organization (PAHO) has concluded that homophobic ill-treatment on the part of health professionals is unacceptable and should be proscribed and denounced.¹⁰³ There is an abundance of accounts and testimonies of persons being denied medical treatment, subjected to verbal abuse and public humiliation, psychiatric evaluation, a variety of forced procedures such as sterilization, State-sponsored forcible anal examinations for the prosecution of suspected homosexual activities, and invasive virginity examinations conducted by health-care providers,¹⁰⁴ hormone therapy and genital-normalizing surgeries under the guise of so called “reparative therapies”.¹⁰⁵ These procedures are rarely medically necessary,¹⁰⁶ can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma (A/HRC/14/20, para. 23). The Committee on the Elimination of Discrimination against Women expressed concern about lesbian, bisexual, transgender and intersex women as “victims of abuses and mistreatment by health service providers” (A/HRC/19/41, para. 56).

77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to

⁹⁹ Campaign to Stop Torture in Health Care, “Torture”, p. 163; see also A/64/272, para. 85.

¹⁰⁰ WHO and the Global Coalition on Women and AIDS, “Violence against sex workers and HIV prevention” (WHO, 2005), p. 2.

¹⁰¹ Campaign to Stop Torture in Health Care, “Torture”, p. 163.

¹⁰² CAT/C/AUT/CO/4-5, para. 22.

¹⁰³ PAHO, “‘Cures’ for an illness that does not exist” (2012), p. 3.

¹⁰⁴ See HRW, *In a Time of Torture: The Assault on Justice in Egypt’s Crackdown on Homosexual Conduct* (2003).

¹⁰⁵ PAHO/WHO, “‘Therapies’ to change sexual orientation lack medical justification and threaten health”, news statement, 17 May 2012; and submission by Advocates for Informed Choice to the Special Rapporteur on the question of torture, 2012.

¹⁰⁶ PAHO/WHO, “‘Therapies’”.

fix their sex”,¹⁰⁷ leaving them with permanent, irreversible infertility and causing severe mental suffering.

78. In many countries transgender persons are required to undergo often unwanted sterilization surgeries as a prerequisite to enjoy legal recognition of their preferred gender. In Europe, 29 States require sterilization procedures to recognize the legal gender of transgender persons. In 11 States where there is no legislation regulating legal recognition of gender,¹⁰⁸ enforced sterilization is still practised. As at 2008, in the United States of America, 20 states required a transgender person to undergo “gender-confirming surgery” or “gender reassignment surgery” before being able to change their legal sex.¹⁰⁹ In Canada, only the province of Ontario does not enforce “transsexual surgery” in order to rectify the recorded sex on birth certificates.¹¹⁰ Some domestic courts have found that not only does enforced surgery result in permanent sterility and irreversible changes to the body, and interfere in family and reproductive life, it also amounts to a severe and irreversible intrusion into a person’s physical integrity. In 2012, the Swedish Administrative Court of Appeals ruled that a forced sterilization requirement to intrude into someone’s physical integrity could not be seen as voluntary.¹¹¹ In 2011, the Constitutional Court in Germany ruled that the requirement of gender reassignment surgery violated the right to physical integrity and self-determination.¹¹² In 2009, the Austrian Administrative High Court also held that mandatory gender reassignment, as a condition for legal recognition of gender identity, was unlawful.¹¹³ In 2009, the former Commissioner for Human Rights of the Council of Europe observed that “[the involuntary sterilization] requirements clearly run counter to the respect for the physical integrity of the person”.¹¹⁴

79. The mandate has noted that “members of sexual minorities are disproportionately subjected to torture and other forms of ill-treatment because they fail to conform to socially constructed gender expectations. Indeed, discrimination on grounds of sexual orientation or gender identity may often contribute to the process of the dehumanization of the victim, which is often a necessary condition for torture and ill-treatment to take place.”¹¹⁵ “Medically worthless” practices of subjecting men suspected of homosexual conduct to non-consensual anal examinations to “prove” their homosexuality¹¹⁶ have been condemned by the Committee against Torture, the Special Rapporteur on the question of torture and the Working Group on Arbitrary Detention, which have held that the practice contravenes the prohibition of torture and ill-treatment (A/HRC/19/41, para. 37).

5. Persons with disabilities

80. Persons with disabilities are particularly affected by forced medical interventions, and continue to be exposed to non-consensual medical practices (A/63/175, para. 40). In the case of children in health-care settings, an actual or perceived disability may diminish the

¹⁰⁷ A/HRC/19/41, para. 57.

¹⁰⁸ Commissioner for Human Rights of the Council of Europe, *Discrimination on Grounds of Sexual Orientation and Gender Identity in Europe* (2011), pp. 86-87.

¹⁰⁹ D. Spade, “Documenting gender”, *Hastings Law Journal*, vol. 59, No. 1 (2008), pp. 830-831.

¹¹⁰ *XY v. Ontario*, 2012 HRTO 726 (CanLII), judgement of 11 April 2012.

¹¹¹ Mål nr 1968-12, Kammarrätten i Stockholm, Avdelning 03, http://du2.pentagonvillan.se/images/stories/Kammarrattens_dom_-_121219.pdf, p. 4.

¹¹² Federal Constitutional Court, *1 BvR 3295/07*. Available from www.bundesverfassungsgericht.de/entscheidungen/rs20110111_1bvr329507.html.

¹¹³ Administrative High Court, No. 2008/17/0054, judgement of 27 February 2009.

¹¹⁴ “Human rights and gender identity”, issue paper (2009), p. 19.

¹¹⁵ A/56/156, para. 19. See also E/CN.4/2001/66/Add.2, para. 199.

¹¹⁶ Working Group on Arbitrary Detention, opinion No. 25/2009 (2009), para. 29.

weight given to the child's views¹¹⁷ in determining their best interests, or may be taken as the basis of substitution of determination and decision-making by parents, guardians, carers or public authorities.¹¹⁸ Women living with disabilities, with psychiatric labels in particular, are at risk of multiple forms of discrimination and abuse in health-care settings. Forced sterilization of girls and women with disabilities has been widely documented.¹¹⁹ National law in Spain, among other countries,¹²⁰ allows for the sterilization of minors who are found to have severe intellectual disabilities. The Egyptian Parliament failed to include a provision banning the use of sterilization as a "treatment" for mental illness in its patient protection law. In the United States, 15 states have laws that fail to protect women with disabilities from involuntary sterilization.¹²¹

V. Conclusions and recommendations

A. Significance of categorizing abuses in health-care settings as torture and ill-treatment

81. **The preceding examples of torture and ill-treatment in health-care settings likely represent a small fraction of this global problem. Such interventions always amount at least to inhuman and degrading treatment, often they arguably meet the criteria for torture, and they are always prohibited by international law.**

82. **The prohibition of torture is one of the few absolute and non-derogable human rights,¹²² a matter of *jus cogens*,¹²³ a peremptory norm of customary international law. Examining abuses in health-care settings from a torture protection framework provides the opportunity to solidify an understanding of these violations and to highlight the positive obligations that States have to prevent, prosecute and redress such violations.**

83. **The right to an adequate standard of health care ("right to health") determines the States' obligations towards persons suffering from illness. In turn, the absolute and non-derogable nature of the right to protection from torture and ill-treatment establishes objective restrictions on certain therapies. In the context of health-related abuses, the focus on the prohibition of torture strengthens the call for accountability and strikes a proper balance between individual freedom and dignity and public health concerns. In that fashion, attention to the torture framework ensures that system inadequacies, lack of resources or services will not justify ill-treatment. Although resource constraints may justify only partial fulfilment of some aspects of the right to health, a State cannot justify its non-compliance with core obligations, such as the absolute prohibition of torture, under any circumstances.¹²⁴**

84. **By reframing violence and abuses in health-care settings as prohibited ill-treatment, victims and advocates are afforded stronger legal protection and redress**

¹¹⁷ Committee on the Rights of the Child, general comment No. 12 (2009), para. 21.

¹¹⁸ See A/HRC/20/5, para. 53 (d); A/63/175, para. 59.

¹¹⁹ See Independent Expert for the Secretary-General's Study on Violence against Children, *World Report on Violence against Children* (2009).

¹²⁰ Open Society Foundations, *Against Her Will* (footnote 43 above), p. 6, A/64/272, para. 71.

¹²¹ Open Society Foundations, *Against Her Will*, p. 6.

¹²² Convention against Torture, art. 2, para. 2, International Covenant on Civil and Political Rights, art. 7.

¹²³ See International Criminal Tribunal for the Former Yugoslavia, *Prosecutor v. Furundzija*, case No. IT-95-17/1-T, judgement (1998).

¹²⁴ See Committee on Economic, Social and Cultural Rights, general comment No. 14.

for violations of human rights. In this respect, the recent general comment No. 3 (2012) of the Committee against Torture on the right to a remedy and reparation offers valuable guidance regarding proactive measures required to prevent forced interventions. Notably, the Committee considers that the duty to provide remedy and reparation extends to all acts of ill-treatment,¹²⁵ so that it is immaterial for this purpose whether abuses in health-care settings meet the criteria for torture per se. This framework opens new possibilities for holistic social processes that foster appreciation of the lived experiences of persons, including measures of satisfaction and guarantees of non-repetition, and the repeal of inconsistent legal provisions.

B. Recommendations

85. The Special Rapporteur calls upon all States to:

(a) Enforce the prohibition of torture in all health-care institutions, both public and private, by, inter alia, declaring that abuses committed in the context of health-care can amount to torture or cruel, inhuman or degrading treatment or punishment; regulating health-care practices with a view to preventing mistreatment under any pretext; and integrating the provisions of prevention of torture and ill-treatment into health-care policies;

(b) Promote accountability for torture and ill-treatment in health-care settings by identifying laws, policies and practices that lead to abuse; and enable national preventive mechanisms to systematically monitor, receive complaints and initiate prosecutions;

(c) Conduct prompt, impartial and thorough investigations into all allegations of torture and ill-treatment in health-care settings; where the evidence warrants it, prosecute and take action against perpetrators; and provide victims with effective remedy and redress, including measures of reparation, satisfaction and guarantees of non-repetition as well as restitution, compensation and rehabilitation;

(d) Provide appropriate human rights education and information to health-care personnel on the prohibition of torture and ill-treatment and the existence, extent, severity and consequences of various situations amounting to torture and cruel, inhuman or degrading treatment or punishment; and promote a culture of respect for human integrity and dignity, respect for diversity and the elimination of attitudes of pathologization and homophobia. Train doctors, judges, prosecutors and police on the standards regarding free and informed consent;

(e) Safeguard free and informed consent on an equal basis for all individuals without any exception, through legal framework and judicial and administrative mechanisms, including through policies and practices to protect against abuses. Any legal provisions to the contrary, such as provisions allowing confinement or compulsory treatment in mental health settings, including through guardianship and other substituted decision-making, must be revised. Adopt policies and protocols that uphold autonomy, self-determination and human dignity. Ensure that information on health is fully available, acceptable, accessible and of good quality; and that it is imparted and comprehended by means of supportive and protective measures such as a wide range of community-based services and supports (A/64/272, para. 93). Instances of treatment without informed consent should be investigated; redress to victims of such treatment should be provided;

¹²⁵ General comment No. 3, para. 1.

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(f) Ensure special protection of minority and marginalized groups and individuals as a critical component of the obligation to prevent torture and ill-treatment¹²⁶ by, inter alia, investing in and offering marginalized individuals a wide range of voluntary supports that enable them to exercise their legal capacity and that fully respect their individual autonomy, will and preferences.

1. Denial of pain relief

86. The Special Rapporteur calls upon all States to:

(a) Adopt a human rights-based approach to drug control as a matter of priority to prevent the continuing violations of rights stemming from the current approaches to curtailing supply and demand (A/65/255, para. 48). Ensure that national drug control laws recognize the indispensable nature of narcotic and psychotropic drugs for the relief of pain and suffering; review national legislation and administrative procedures to guarantee adequate availability of those medicines for legitimate medical uses;

(b) Ensure full access to palliative care and overcome current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine. States should devise and implement policies that promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use;

(c) Develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programmes and developing the necessary standards, guidelines and clinical protocols.

2. Compulsory detention for medical reasons

87. The Special Rapporteur calls upon all States to:

(a) Close compulsory drug detention and “rehabilitation” centres without delay and implement voluntary, evidence-based and rights-based health and social services in the community. Undertake investigations to ensure that abuses, including torture or cruel, inhuman and degrading treatment, are not taking place in privately-run centres for the treatment of drug dependence;

(b) Cease support for the operation of existing drug detention centres or the creation of new centres. Any decision to provide funding should be made only following careful risk assessment. If provided, any such funds should be clearly time-limited and provided only on the conditions that the authorities (a) commit to a rapid process for closing drug detention centres and reallocating said resources to scaling up voluntary, community-based, evidence-based services for treatment of drug dependence; and (b) replace punitive approaches and compulsory elements to drug treatment with other, evidence-based efforts to prevent HIV and other drug-related harms. Such centres, while still operating as the authorities move to close them, are subject to fully independent monitoring;

(c) Establish an effective mechanism for monitoring dependence treatment practices and compliance with international norms;

¹²⁶ See Committee on Economic, Social and Cultural Rights, general comment No. 14, para. 43 (a)-(f).

(d) Ensure that all harm-reduction measures and drug-dependence treatment services, particularly opioid substitution therapy, are available to people who use drugs, in particular those among incarcerated populations (A/65/255, para. 76).

3. Lesbian, gay, bisexual, transgender and intersex persons

88. The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.

4. Persons with psychosocial disabilities

89. The Special Rapporteur calls upon all States to:

(a) Review the anti-torture framework in relation to persons with disabilities in line with the Convention on the Rights of Persons with Disabilities as authoritative guidance regarding their rights in the context of health-care;

(b) Impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as neuroleptics, the use of restraint and solitary confinement, for both long- and short-term application. The obligation to end forced psychiatric interventions based solely on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation;¹²⁷

(c) Replace forced treatment and commitment by services in the community. Such services must meet needs expressed by persons with disabilities and respect the autonomy, choices, dignity and privacy of the person concerned, with an emphasis on alternatives to the medical model of mental health, including peer support, awareness-raising and training of mental health-care and law enforcement personnel and others;

(d) Revise the legal provisions that allow detention on mental health grounds or in mental health facilities, and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned. Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished.

5. Reproductive rights

90. The Special Rapporteur calls upon all States to ensure that women have access to emergency medical care, including post-abortion care, without fear of criminal penalties or reprisals. States whose domestic law authorizes abortions under various circumstances should ensure that services are effectively available without adverse consequences to the woman or the health professional.

¹²⁷ Convention on the Rights of Persons with Disabilities, art. 4, para. 2.

Notes

Notes

Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture's 2013 Thematic Report brings together contributions by more than thirty international experts in response to the United Nations Special Rapporteur on Torture Juan E. Méndez's provocative thematic report on torture and other abusive practices in healthcare settings.

Each piece in this unique volume provides novel insights into essential topics and pressing issues at the forefront of the intersecting medical, legal, and policy fields. The questions raised by the Special Rapporteur's report and the array of innovative perspectives offered in response by each contributing author illustrate a profound commitment to tackling the challenges that continue to arise in promoting and protecting the human rights of persons in diverse healthcare settings globally.

