United States of America

Shadow Report Submission to the United Nations

Convention against Torture and

Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)

53rd Session in Geneva on November 12 and 13, 2014

Geneva, Switzerland

Voiceless Victims: Wards of the Court

I. Drafted 9/22/14

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 - 1. Medical Whistleblower Advocacy Network (MWAN) acts as a grassroots advocate for human rights for disabled persons and other individuals within the U.S.A. and abroad. MWAN human rights cases often involve issues with medical implications, such as protection of mandated reporters, medical abuse, medical fraud, psychiatric abuse, prisoner mistreatment, sexual assault, domestic violence and stalking. MWAN provides information, referrals, and also direct human rights defender advocacy services. MWAN has allowed victims of human rights violations to directly tell their own stories, assisting them when necessary with their time lines, helping them access documents, and doing research and analysis of their situations. Some who experienced human rights violations chose to tell their stories in their own words on MWAN's internet radio program. MWAN also works with other NGO organizations to advocate for the rights of the disabled and promote the protection of human rights.

III. Summary of Issues

- Right to Informed Consent
- Abuse and Neglect by Guardians
- Protection of Human Subjects
- Use of "off-label" Psychiatric Drugs

IV. Concluding Observations

- 2. In the United States, according to 2012 SAMHSA statistics there are an estimated 43.7 million adults aged 18 or older with mental illness. This represents 18.6% of all adults in the country.¹ The U.S.A. states clearly that "Under U.S. law, officials of all government agencies are prohibited from engaging in torture, at all times, and in all places." This would presume that vulnerable persons who are currently in court ordered guardianship would be protected from torture, cruel, inhuman or degrading treatment or punishment, but in reality there is little transparency or accountability for what actually happens to wards of the court especially in mental health cases.²
- 3. Wards of the court have surrogate decision makers for both legal and medical decisions, thus wards are prevented even from effective appeal to the Judge or even to their US Congressmen/Congresswomen. The U.S.A. mental health guardianship system offers few procedural protections, and has spawned a profit-driven professional guardianship industry that often enriches itself at the expense of society's most vulnerable members—the mentally ill.³ Yet despite numerous calls for reform, most states have done little to monitor professional guardians and prevent abuse and neglect. Secrecy, lack of transparency and lack of accountability makes a perfect environment for human rights violations of the mentally disabled.^{4 5 6}
- 4. Research can be disguised as "treatment," but instead actually be a harmful or deadly experiment done without the patient's knowledge or informed consent to treatment. Forcing wards of the court to take medications that are "off-label" (not approved for that

use by the Food and Drug Administration), is tantamount to human experimentation on the vulnerable wards of the court. Such violations of human subject provisions are routine with many patients in locked state and federal institutions given psychiatric drugs for "off-label uses." ⁷ Problems of patient abuse occur including: excessive dosing for purposes of chemical restraint, poly-pharmacy with multiple medications, lack of informed consent and the use of medication with little or no direct doctor/patient contact.⁸

- 5. In addition the use of medication with no real oversight of the process of diagnosis, means that patients can often not question the use of these medications because surrogate decision makers have been assigned by the court to make all medical decisions. Wards in mental health care have often been stripped of their legal rights and thus cannot assert their objections to treatment decisions. Unbiased independent review of medical charts is almost non-existent. Patient human rights have been ignored and there is no direct process to bring guardianship abuse or doctor/proxy/decision maker abuse to the attention of the court.
- 6. Deceptive and coercive marketing practices by the pharmaceutical industry are common place.⁹ The practice of marketing drugs for purposes not backed by science is called "off-label promotion." These drugs do not live up to their marketing promises but instead have been known to cause serious, even fatal side-effects, particularly in children and the elderly.¹⁰ Lives of some our most vulnerable citizens have been irreparably damaged and many have been lost to fatal adverse effects and even to suicide.^{11 12}

V. US Government Report

7. In its response to questions from the Human Rights Committee, the United States did not respond to the issue of mental health patients' *right to informed consent, abuse and neglect by guardians,* and the *use of "off-label" psychiatric drugs* because those issues were not specifically raised by the Committee. The United States of America agreed with the CAT Committee that ... "the intentional infliction of mental pain or suffering was appropriately included in the definition of torture to reflect the increasing

and deplorable use by certain States of various psychological forms of torture and illtreatment, such as mock executions, sensory deprivations, use of drugs, and confinement to mental hospitals." ¹³ And further stated that …" Psychological torture is redressable under the U.S. criminal laws."

- 8. The U.S.A. did respond to issue of *protection of human subjects* stating that the United States is under constraints in the government's power to use individuals in non-consensual experimentation, including non-consensual medical treatment and experimentation. Federal law also prohibits non-consensual clinical investigations of medical products on human subjects in the U.S.A., and in foreign clinical investigations when the data are to be used to support drug or device approvals. Control of pharmaceutical and device products is vested by statute in the Food and Drug Administration (FDA) within HHS.¹⁴ The introduction of unapproved drugs and devices into interstate commerce is prohibited.
- 9. The Fourth, Fifth, Eighth, and Fourteenth Amendments to the Constitution, as well as federal statutes and agency rules, also restrict experimentation on prisoners. Specifically, the Fifth and Fourteenth Amendments proscribe deprivation of life, liberty or property without due process of law. ¹⁵ The Fourth Amendment proscribes unreasonable searches and seizures (including of a person's body), and the Eighth Amendment proscribes the infliction of cruel and unusual punishment. The Fifth and Fourteenth Amendment Due Process Clauses prohibit, inter alia, governmental action that "shocks the conscience," including acts of torture and cruel treatment, as well as punishing persons without first convicting them under appropriate standards. Torture is also absolutely prohibited by customary international law, and by U.S. domestic law, which prohibits acts of torture both inside and outside the United States, and at both the federal and state levels. It is unlawful for U.S. actors to commit an act of torture, under any circumstances, anywhere in the world.^{16 17}
- 10. The Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. 1997 et seq., permits the Attorney General to institute civil lawsuits against state institutions regarding

the civil rights of their residents, including the conditions of their confinement and use of excessive force. DOJ/CRD has utilized this statute to prosecute allegations of torture and cruel, inhuman, and degrading treatment or punishment.

- 11. Furthermore under the Detainee Treatment Act of 2005 (DTA), "No individual in the custody or under the physical control of the U.S. Government, regardless of nationality or physical location, shall be subject to cruel, inhuman, or degrading treatment or punishment." ¹⁸ Every U.S. official, wherever he or she may be, is also prohibited from engaging in acts that constitute cruel, inhuman or degrading treatment or punishment.
- 12. Under USA law, the Americans with Disabilities Act of 1990 (ADA) and the Rehabilitation Act of 1973 (Rehabilitation Act) restrict and regulate the use of solitary confinement for persons with disabilities. Title II of the ADA, 42 U.S.C. 12132, applies to state actors, while the Rehabilitation Act applies to federal facilities and facilities receiving funds from the federal government. Both statutes prohibit discrimination on the basis of disability instead require that persons with disabilities should be provided reasonable accommodation and modifications so that they can access services, programs, and activities, including mental health services.
- 13. Under 18 U.S.C. 242, individuals who acted under color of law may be prosecuted for willful deprivations of constitutional rights, such as the rights to be free from unreasonable seizure and from summary punishment or cruel and unusual punishment, and the right not to be deprived of liberty without due process of law.

VI. Legal Framework

CAT Articles 1, 2, 4, 5, 6, 7. 10, 11, 12, 13, 14, 15, 16, 22

VII. CAT Committee Comments

14. The Committee for the Prevention of Torture (CPT) has stated: "Patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of a person to a psychiatric establishment on an involuntary basis should not be construed as authorizing treatment without his consent. It follows that every competent patient, whether voluntary or involuntary, should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances." ¹⁹

VIII. Other UN Body Recommendations

- 15. The principle of Free, Prior and Informed Consent is an important human right which has been addressed in many international and domestic laws and practices. The U.S. is party to the Universal Declaration of Human Rights (UHDR), the International Covenant on Civil and Political Rights (ICCPR), the Convention against Torture (CAT), and the International Convention on the Elimination of Racial Discrimination (CERD), all of which must be applied without discrimination based on disability. The U.S. has signed but not yet ratified the Convention on the Rights of Persons with Disabilities (CRPD), as well as the Convention on the Rights (ICESCR). The human rights of patients are also delineated in the Universal Declaration on Bioethics and Human Rights.²⁰
- 16. The standards of the European Committee for the Prevention of Torture states that "consent to treatment can only be qualified as free and informed if it is based on full, accurate and comprehensible information about the patient's condition and the treatment proposed." Consequently, all patients should be provided systematically with relevant information about their condition and the treatment which it is proposed to prescribe for them."²¹

- 17. Guardianship keeps people in institutions and negates the right of people with disabilities to exercise legal capacity, an aspect of the right to recognition as persons before the law, in violation of UDHR Articles 2 and 6, and ICCPR Article 26, and in violation of CRPD Article 12.
- 18. Often guardianship and the use of surrogate decision-makers is used to circumvent informed consent rather than making an honest attempt to discern the wishes of the person. To refuse to recognize the individual patient's human right to informed consent is contrary to the recognition of the legal capacity of persons with disabilities on an equal basis with others, as required by CRPD Article 12 and constitutes discrimination based on disability under UDHR Articles 2 and 6, and ICCPR Article 26. ^{22 23}
- Civil commitment laws create a separate regime of detention and involuntary treatment applicable only to persons with psychosocial disabilities that is discriminatory in purpose and effect, contrary to U.S. obligations under UDHR Articles 2, 3 and 5, ICCPR Articles 2, 7 and 9, and CAT Articles 2 and 16, as well as CRPD Articles 14, 17 and 25.
- 20. In situations of civil commitment and compulsory mental health treatment the U.S. Supreme Court recognizes infringements of the liberty interest (a Constitutional Right) but asserts that these infringements are justified by state interests.^{24 25} These practices pose a serious violation of mental and physical integrity by their close connection with disability-based discrimination, as analyzed by UN Special Rapporteur on Torture Manfred Nowak.²⁶
- Inadequate constitutional protections for persons with disabilities may constitute torture or ill-treatment, and violates U.S. obligations under UDHR Articles 2, 3 and 5, ICCPR Articles 2, 7 and 9, and CAT Articles 2 and 16, as well as CRPD Articles 4, 5, 15 and 17.
- 22. To refuse to recognize the individual patient's human right to informed consent, is contrary to the recognition of the legal capacity of persons with disabilities on an equal basis with others, as required by CRPD Article 12 and constitutes discrimination based

on disability under UDHR Articles 2 and 6, and ICCPR Article 26.

23. ECHR cases indicate that the guarantee of liberty is perhaps the most important human right in relation to the detention of mentally disordered people. ²⁷ ²⁸ ²⁹

IX. Recommended Questions

- What measures will the U.S.A. take to ensure the human rights protections for wards of the court?
- Why has the U.S. government not taken steps to curtail the wholesale use of "off-label" use of psychiatric medications in violation of the Common Rule?
- What will the federal government do to supervise the state courts guardianship system?

X. Suggested Recommendations for the U.S. government

- Ratify the CRPD, CRC and ICESCR without any reservations, understandings or declarations, and without further delay in order to be in compliance of international recognized standards regarding the human right of informed consent.
- Establish a federal database tracking system to facilitate tacking of complaints received by HHS, FDA or the DOJ regarding complaints of psychiatric abuse in psychiatric facilities, psychiatric nursing homes and in outpatient treatment.
- Establish a separate database used to record and process allegations of misconduct which have been lodged by the wards against their court assigned guardian or medical treatment team.
- Include persons with disabilities in the review policies at both the federal and state levels, to abolish all laws and mechanisms that restrict the legal capacity of any person (especially those with disabilities) and to create supportive measures for the exercise of legal capacity that respect the will and preferences of the person.

 Evaluate all guardianship cases in the State Court system to see if they are in compliance with U.S. Department of Health, Education, and Welfare Codes for the conduct of social and behavioral research and consistent with the ethical code of conduct established by the American Psychological Association, published in 1973.

² Leonnig, Carol D., Lena H. Sun and Sarah Cohen. "Misplaced Trust: Special Report." The Washington Post (June 15-16, 2003).

³ Fields, Robin, Evelyn Larrubia and Jack Leonard. "Guardians for Profit." Los Angeles Times (November 13-16, 2005).

⁵ Wood, Erica F. "State-Level Adult Guardianship Data: An Exploratory Survey," American Bar Association Commission on Law and Aging for the National Center on Elder Abuse, August 2006.

⁶ Yeoman, Barry. "Stolen Lives." AARP: The Magazine (January-February 2004).

⁷ Jones, Allen. (2004) "TMAP Critique," January 20, 2004, PschRights.org, <u>http://psychrights.org/Drugs/</u>AllenJonesTMAPJanuary20.pdf

⁸ United States ex rel Law Project for Psychiatric Rights v. Matsutani, et al. US District Court, District of Alaska, Case No. 3:09-cv-0080-TMB.

⁹ Jones, Allen, "Introduction to the documents on Big Pharma Corruption in Research & Clinical Trials," Revised January 20, 2004, The Law Project for Psychiatric Rights http://psychrights.org/

¹⁰ Jackson, Grace E., MD, "What Doctors May Not Tell You About Psychiatric Drugs" Public Lecture, UCE Birmingham June 2004

¹¹ March 21, 2000 Report to the court by Dr. Loren R. Mosher M.D. regarding Eric Harris and Luvox use prior to the Columbine High School shooting, Scoteria Associates

¹² Jackson, Grace E. (2005) "Rethinking Psychiatric Drugs: A Guide for Informed Consent." Bloomington, IN: Author House.

¹ Substance Abuse and Mental Health Services Administration, Results from the 2012 National Survey on Drug Use and Health: Mental Health Findings, NSDUH Series H-47, HHS Publication No. (SMA) 13-4805. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2013.

⁴ United States Government Accountability Office GAO Testimony Before the Special Committee on Aging, U.S. Senate, GUARDIANSHIPS, Little Progress in Ensuring Protection for Incapacitated Elderly People Statement of Barbara D. Bovbjerg, Director Education, Workforce, and Income Security, September 7, 2006, GAO-06- 1086T.

¹³ ¶ 95 of the Initial Report U.S. Initial Report (CAT/C/28/Add.5, February 9, 2000) and in its Second Periodic Report (CAT/C/48/Add.3, June 29, 2005.

¹⁴ 21 U.S.C. 355 (a) and 360 (k)

¹⁵ United States Responses to Questions from the United Nations Human Rights Committee Concerning the Fourth Periodic Report of the United States on the International Covenant on Civil and Political Rights (ICCPR) Appendix 16: ¶¶ 187-189 of the U.S. Government's Fourth Periodic Report

¹⁶ CAT/C/USA/CO/2 25 July 2006 Committee Against Torture, Thirty-sixth session, 1-19 May 2006, Consideration Of Reports Submitted By States Parties Under Article 19 Of The Convention, Conclusions and recommendations of the Committee against Torture, United States Of America

¹⁷ United Nations Committee Against Torture, Convention Against Torture, Periodic Report Of The United States Of America, Paragraph 258

¹⁸ Detainee Treatment Act of 2005 Pub. L. No. 109-163, 42 U.S.C. 2000dd

¹⁹ CPT/Inf (98) 12 [EN] - Publication Date: 31 August 1998 para 41

²⁰ The Universal Declaration on Bioethics and Human Rights, adopted by acclamation October 2005 by the General Conference of UNESCO

²¹ CPT Standards, 2002, CPT/inf/E (2002) 1, V. Involuntary placement in psychiatric establishments, para 41, Extract from the 8th General Report [CPT/Inf (98) 12]

²² See also UDHR Articles 2, 3, 6 and 25, ICCPR Articles 7 and 26, CAT Articles 2 and 16, and CRPD Articles 12, 15, 17 and 25.

²³ See A/63/175, paragraphs 44 and 73-74.

²⁴ Addington v. Texas, 441 U.S. 418 (1979) (civil commitment)

²⁵ U.S. v. Sell, Riggins v. Nevada, 504 U.S. 97 (1992).

²⁶ See U.N. Doc. A/63/175 (2008), particularly paragraphs 40, 44, 47, 49, 50, 61-65, 73-74.

²⁷ Winterwerp v Netherlands (1979) 2 EHRR 387

²⁸ Stanley Johnson v United Kingdom [1997] EHRLR 105-8

²⁹ Aerts v Belgium, ECHR Reports of Judgments and Decisions 1998