

## **Submission of the Disability Working Group**

**To the Human Rights Committee**

**Prepared by Tina Minkowitz and Al Galves, with the assistance of Celia Brown, Myra Kovary and Eve Remba**

**On behalf of:**

**New York Organization For Human Rights and Against Psychiatric Assault  
Mind Freedom International  
Law Project for Psychiatric Rights  
WILD for Human Rights**

### **ALTERNATIVE REPORT ON FORCE DRUGGING, FORCED ELECTROSHOCK AND MENTAL HEALTH SCREENING OF CHILDREN: VIOLATION OF ARTICLE 7**

#### **Executive Summary**

1. The United States has a double standard on the use of mind-altering drugs. On the one hand, the U.S. understands the intentional infliction of mental suffering by administration of mind-altering drugs on a person as torture; yet on the other hand it condones the practice of force drugging when the victim is a person with psychosocial disabilities.
2. A report by five UN special rapporteurs condemned the force drugging of Guantánamo detainees as a violation of the right to free and informed consent and its “logical corollary, the right to refuse treatment”.
3. Force drugging and forced electroshock violate article 7 and article 18 of the Covenant; maintaining separate standards in relation to people with psychosocial disabilities violates article 2. A standard of legal capacity that disqualifies people with psychosocial disabilities from exercising free and informed consent denies equal protection of the law in violation of article 26.
4. Neuroleptic drugs<sup>1</sup> and electroshock inflict severe mental suffering and cause permanent neurological damage. Neuroleptics drugs can cause paralysis of the will along with uncontrollable restlessness. Electroshock leaves many people with irrevocable memory loss and cognitive disability.
5. Gender and racial disparities intersect with disability-based discrimination. Electroshock is administered twice as often to women as it is to men, often under circumstances that demonstrate a gender-related motive. Force

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<sup>1</sup> Neuroleptic drugs are a major category of drugs used in psychiatry and are among the most severe in their disruptive effects on consciousness. However, the principles at issue apply to any force drugging.

drugging in the community by court order is used in New York State disproportionately against people of color, mostly African Americans.

6. A new model of legal capacity being developed by people with disabilities would eliminate incapacity determinations and instead provide support to all who need it to facilitate their decision-making. The support model is based on choice in a context of interdependence, rather than self-sufficiency, as a paradigm for legal capacity. Since everyone has a will and is capable of making choices, legal capacity is accessible to all on an equal basis, with the applicable standard for children being articulated in CRC article 12, a right to freely express their views, which are to be given due weight in accordance with the child's age and maturity.
7. Adoption of the support model of legal capacity is necessary to eliminate discrimination in the right to free and informed consent, which underlies protection against medical practices amounting to torture or cruel, inhuman or degrading treatment or punishment.
8. Mass screening of children for mental illness with only passive consent by their parents (i.e. parents can opt out but no affirmative consent is required, and there is no requirement of consultation with the children at all), with the result that children are drugged with psychotropics, violates their rights under article 7.

## **1. The Committee's concerns**

1. In 1995, the Committee recommended increased efforts to eradicate persistent discrimination in the United States based on race and gender.<sup>2</sup> Disability-based discrimination similarly impedes equal implementation of the covenant, both alone and in combination with race and gender, as documented in this report.
2. The Committee has expressed concern about non-therapeutic medical experimentation on minors and people with impaired decision-making capacity including "mentally ill persons"<sup>3</sup> based on surrogate consent.<sup>4</sup> In a broad sense, the topics addressed by this report constitute non-therapeutic medical experimentation. Little is known about the relationship between the effects of electroshock and neuroleptic drugs on the brain, and changes in consciousness and behavior. It is, however, well established that these procedures cause serious neurological

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<sup>2</sup> Concluding Observations of the Human Rights Committee: United States of America. 03/10/95. U.N. Doc. CCPR/C/79/Add.50; A/50/40, paras 266-304 [hereafter Concluding Observations] paragraphs 270, 295.

<sup>3</sup> The preferred term is persons with psychosocial disabilities or users and survivors of psychiatry.

<sup>4</sup> Concluding Observations, supra note 2, paragraphs 286, 300; List of issues to be taken up in connection with the consideration of the second and third periodic reports of the United States of America, U.N. Doc. CCPR/C/USA/Q/3, 30 March 2006, paragraph 20.

damage as well as psychological trauma.<sup>5</sup> Use of these methods remains experimental and users often comment that they feel like “guinea pigs”. The question of whether they are therapeutic depends on context; in coercive circumstances the decision to treat states of consciousness or behavior as unhealthy and needing therapeutic treatment is essentially punitive, while with free and informed consent it is a philosophically controversial<sup>6</sup> but nevertheless valid individual choice. Forced administration of neuroleptic drugs or electroshock in psychiatry could therefore be treated as a type of nontherapeutic experimentation for which surrogate consent cannot be legitimately given. From a disability perspective, the concept of impaired decision-making capacity as a legal category justifying surrogate consent for adults is flawed because it inherently discriminates based on disability with the effect of restricting self-determination and impeding the equal exercise of rights.<sup>7</sup> For adults, therefore, free and informed consent is required; while for minors the limited right of participation in decision-making is insufficient protection and administration of psychotropic drugs should be prohibited.

## **2. Force drugging and electroshock of adults in psychiatry**

### a. Relevant ICCPR Articles

Article 2, guaranteeing non-discrimination in enjoyment of rights protected in the Covenant

Article 7, guaranteeing that no one will be tortured or subjected to cruel, inhuman or degrading treatment or punishment

Article 18, guaranteeing freedom of thought and that no one will be subjected to coercion that impairs the ability to have or adopt a religion or belief

Article 26, guaranteeing equal protection of the law

### b. Double standard for torture

3. Force drugging and forced electroshock strike fear into the heart of anyone placed at risk. The first Special Rapporteur on Torture mentioned neuroleptic drugs (commonly used in psychiatric institutions) as an

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<sup>5</sup> Breggin, *infra* note 16 (iatrogenic neurological disorders created by the neuroleptic drugs are evidence of brain damage); Robert Whitaker, The case against antipsychotic drugs: a 50-year record of doing more harm than good, in *Medical Hypotheses* (2004) 62, 5-13. See <http://psychrights.org/Research/Digest/Chronicity/NeurolepticResearch.htm> for research cited in Whittaker article, and <http://psychrights.org/Research/Digest/NLPs/neuroleptics.htm> for additional references.

<sup>6</sup> See <http://psychrights.org/Research/Digest/TheBrain/notbraindisease.htm>.

<sup>7</sup> See CEDAW General Comment No. 21, paragraphs 7-8 and discussion *infra* paragraphs 18-20 and 22-26.

example of physical torture<sup>8</sup>, and human rights organizations take up the cause of political prisoners who are considered sane by independent doctors but labeled mentally ill and drugged in their own countries.<sup>9</sup>

4. Five UN Special Rapporteurs investigating the situation at Guantánamo condemned both force-feeding and force-drugging of detainees as a violation of the right to free and informed consent and its logical corollary, the right to refuse treatment.<sup>10</sup> The report also noted that integration of medicine into a system of coercion violates medical ethics. The report does not distinguish between detainees based on disability.<sup>11</sup>
5. The United States maintains a double standard on forced psychotropic drugging and related procedures. In its reservations deposited with ratification of the Convention Against Torture, the United States included an understanding of the Senate that “mental pain or suffering refers to prolonged mental harm caused by or resulting from.... 2) the administration or application, or threatened administration or application, or mind altering substances or other procedures calculated to disrupt profoundly the senses or personality... or 4) the threat that another person will imminently be subjected to... the administration or application or mind altering substances or other procedures calculated to disrupt profoundly the senses or personality.”<sup>12</sup> Yet, in cases involving people with psychosocial disabilities, both federal and state law hold that an individual’s liberty interest in refusing psychotropic drugs can be limited based on a compelling government interest.<sup>13</sup>

### c. Force Drugging with Neuroleptics

6. The United States uses neuroleptic drugs extensively in psychiatry, and appears to have used them on detainees at Guantánamo. After Shah

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<sup>8</sup> Report by UN Special Rapporteur Mr. P. Kooijmans, 1985/33 E/CN.4/1986/15, 19 Feb. 1986, para. 119, [http://ap.ohchr.org/documents/dpage\\_e.aspx?m=103](http://ap.ohchr.org/documents/dpage_e.aspx?m=103)

<sup>9</sup> For example, Human Rights Watch, *Uzbekistan: Psychiatric Punishment Used to Quash Dissent* (Tashkent, October 25, 2005).

<sup>10</sup> Situation of detainees at Guantánamo Bay: Report of the Chairperson of the Working Group on Arbitrary Detention, Ms. Leila Zerrougui; the Special Rapporteur on the independence of judges and lawyers, Mr. Leandro Despouy; the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Mr. Manfred Nowak; the Special Rapporteur on freedom of religion or belief, Ms. Asma Jahangir and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Mr. Paul Hunt, U.N. Doc. E/CN.4/2006/120, [hereafter UN Guantánamo Report] paragraphs 54, 72-82.

<sup>11</sup> From the news article referred to infra note 14, it is likely that some if not all of those who were force drugged were labeled with mental illness.

<sup>12</sup> Declarations and Reservations to the Convention Against Torture, United States of America, see <http://www.ohchr.org/english/countries/ratification/9.htm#reservations>.

<sup>13</sup> *Riggins v. Nevada*, 504 U.S. 127 (1992); *Rivers v. Katz*, 495 N.E.2d 337 (1986). *Rivers* is a leading state law case on the issue of right of involuntary psychiatric inmates to refuse treatment.

Mohammed attempted suicide, he was forcibly injected with an unknown drug that left him feeling paralyzed and unable to “think or do anything” for one month.<sup>14</sup> Mohammed says that some people were being injected every month. This description is consistent with the drug haloperidol decanoate<sup>15</sup>, a long-acting neuroleptic delivered as monthly injections. Subjective reports and research confirm the disorienting effects of haloperidol and other neuroleptics, for example:

Your thoughts are broken, incoherent, you can't hold a train of thought for even a minute. You're talking about one subject and suddenly you're talking about another... Your mind is like a slot machine, every wheel spinning a different thought.<sup>16</sup>

I was horrified to see how I deteriorated intellectually, morally and emotionally from day to day. My interest in political problems quickly disappeared, then my interest in scientific problems, and then my interest in my wife and children.<sup>17</sup>

What we have found is that most people with schizophrenia dislike taking the drugs they are being prescribed... [T]he negative parts [of the side effects] are perceived as quite often worse than the illness itself.... [I]n the anonymity of phone calls to SANELINE, even the most deluded person is often extraordinarily articulate and lucid on the subject of their medication.....Almost all of our callers report sensations of being separated from the outside world by a glass screen, that their senses are numbed, their willpower drained and their lives meaningless. It is these insidious effects that appear to trouble our callers much more than the dramatic physical ones, such as muscular spasms.<sup>18</sup>

7. Besides disorientation and numbing, neuroleptics induce movement disorders that can also have a psychic dimension.

Recognized today as the most frequent (5% to 76% incidence) and distress EPS [extra-pyramidal syndrome, a type of adverse effect of neuroleptic drugs], akathisia was relatively ignored by researchers until recently. This may be partly because the problem is often subjective, described differently by patients: inability to sit still, a sense of gloom and anxiety originating in the abdomen, restless legs,

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<sup>14</sup> James Meek, “People the Law Forgot”, December 2, 2003, The Guardian. See also supra note 10, UN Guantánamo Report, paragraph 75.

<sup>15</sup> See [http://www.drugs.com/pdr/HALOPERIDOL\\_DECANOATE.html](http://www.drugs.com/pdr/HALOPERIDOL_DECANOATE.html) for the complete Physicians Desk Reference information on haloperidol decanoate.

<sup>16</sup> Peter R. Breggin, M.D., *Psychiatric Drugs: Hazardous to the Brain*, 1983 p. 23.

<sup>17</sup> *Id.*, p. 25. These statements were quoted from former political prisoner Leonid Plyushch.

<sup>18</sup> David Cohen, “A Critique of the Use of Neuroleptic Drugs in Psychiatry,” in Fisher and Greenberg, eds., *From Placebo to Panacea: Putting Psychiatric Drugs to the Test*, 1997, p. 202.

and so forth ... Akathisia is frequently accompanied by a dysphoric mental state, described by some normal subjects as a "paralysis of will" ... A medical student who received 1 mg of HPL [haloperidol; 1 mg is a fraction of the usual dose] described the sensation of an external force forcing him to move.<sup>19</sup> [Internal references omitted]

8. It may be impossible to obtain accurate information about how prevalent force drugging is in the United States. The mass media promote the misconception that neuroleptics treat an illness, when in reality these drugs cause illness, brain damage and early death.<sup>20</sup> Neuroleptics are the primary drug used in institutions to numb people's minds and make them more manageable. There is no healing in psychiatric institutions except that which happens accidentally, from human interactions among people reaching out for mutual support. Coercion and control are the rule, and fear is the main weapon.<sup>21</sup> In this atmosphere, people will agree to take drugs by mouth to avoid an injection; will fear going to court and risking public humiliation; will believe what the doctors tell them because they are supposed to help and there is no alternative. Neuroleptic drugs are said to be "anti-psychotic" and are the *raison-d'être* of most psychiatric hospitalization; people who contest the label of "mental illness" or the efficacy of drugs are further labeled as "paranoid" and "lacking insight" thus justifying force drugging.<sup>22</sup> A comparatively small number of people go to court to refuse drugs, and only a handful of these succeed.<sup>23</sup> Liberal use is made of injections to supplement the regular dosing, justified on an "emergency" basis.<sup>24</sup> In addition to force drugging in institutions, 42 states

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<sup>19</sup> *Id.*, p. 206.

<sup>20</sup> Breggin, *supra* note 16 (iatrogenic neurological disorders created by the neuroleptic drugs are evidence of brain damage); Joukamaa et al., Schizophrenia, neuroleptic medication and mortality, *British Journal of Psychiatry* (2006), 188, 122-127 (increased mortality rate from natural causes correlated with use of neuroleptics, increasing in relation to number of neuroleptics used); Bonelli et al., The influence of psychotropic drugs on cerebral cell death: female neurovulnerability to antipsychotics, in *International Clinical Psychopharmacology* 2005, 20:145-149 (both typical and atypical neuroleptics were correlated with brain cell death in women); Straus et al., Antipsychotics and the risk of sudden cardiac death, in *Arch. Intern. Med.* 2004, 164:1293-1297 (current use of antipsychotics associated with increased risk of sudden cardiac death, even at low dosage); Levin et al., Death from Clozapine-Induced Constipation, *Psychosomatics* 43:1, January-February 2002; Gary G. Kohls, Preventive Psychiatry E-Newsletter #93 (Robert Whitaker, The case against antipsychotic drugs: a 50-year record of doing more harm than good, in *Medical Hypotheses* (2004) 62, 5-13.

<sup>21</sup> The situation is similar to that observed by the five Special Rapporteurs at Guantánamo, where access to medical attention is embedded in a coercive system, with the result that detainees cannot trust medical professionals and may forgo health care. *Supra* note 10. In psychiatric institutions, people who react naturally to coercion with avoidance and fear are penalized for breaking with the dominant ideology that coercion is for the person's own good.

<sup>22</sup> Mental Hygiene Law Court Monitoring Project, Part 1 of Report: Do Psychiatric Inmates Have the Right to Refuse Drugs? An Examination of *Rivers* Hearings in the Brooklyn Court, at <http://psychrights.org/States/NewYork/courtmonitoringreport.htm> [hereafter Court Monitoring Report].

<sup>23</sup> *Id.*

<sup>24</sup> *Rivers v. Katz*, *supra* note 13 expressly permits force drugging on an emergency basis.

and the District of Columbia now have laws authorizing compulsory treatment in the community<sup>25</sup>, the primary purpose of which is enforcing long-term compliance with drugs and subjection to psychiatric control. The public is misled to support these laws by campaigns equating mental illness with violence, and promoting neuroleptics as a treatment that can prevent violence.<sup>26</sup> Thus what amounts to physical and mental torture is justified as not only a public safety measure, but a humane medical treatment.

9. Discrimination<sup>27</sup> is woven throughout this story. People experiencing trauma and abuse, emotional distress or elation, have nowhere safe to go to ask for support and healing, and nowhere safe to simply exist.

#### d. Forced Electroshock

10. Electroshock has a similar brain disabling effect to neuroleptic drugs, but the damage is more extensive. Electroshock, a procedure that involves applying sufficient electricity to the head to cause a grand mal seizure, wipes out memory and knowledge of self, for periods ranging from the period immediately after surgery, to permanently<sup>28</sup>. For some people extensive chunks of life are lost, including relationships with spouse and children, as well as creativity and professional skills.<sup>29</sup>
11. Electroshock is administered twice as often to women as to men<sup>30</sup>, and there are aspects of the harm that are gendered. Women have reported passivity or “ductility” after electroshock, being easily led and unable to

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<sup>25</sup> Chart compiled by Treatment Advocacy Center, [www.psychlaws.org](http://www.psychlaws.org).

<sup>26</sup> See <http://community-2.webtv.net/@HH!80!A2!2134BF518044/stigmanet/ARCHIVESInvoluntary/> for fear tactics used in a nationwide campaign for outpatient commitment led by Treatment Advocacy Center, *supra* note 24.

<sup>27</sup> In addition to disability-based discrimination, racial disparities can be stark. African Americans, representing 16% of the statewide population, account for 42% outpatient commitment court orders in New York, while Latinos, 15% of the population, account for 21% of court orders and whites, 62% of the population, account for 34% of court orders. The racial disparities are not accounted for by other factors. According to New York Lawyers for the Public Interest, possible reasons include: “conscious or unconscious bias on the part of some involved in referring and selecting people to whom to apply the law, people being selected from already-biased pools, unequal access to mental health treatment, Black or Hispanic people finding the treatment available less suited to their needs, and some combination of the above.” New York Lawyers for the Public Interest, Implementation of “Kendra’s Law” is Severely Biased (April 7, 2005).

<sup>28</sup> Harold Robertson and Robin Pryor, Memory and Cognitive Effects of ECT: Informing and Assessing Patients, *Advances in Psychiatric Treatment* (2006) 12: 228-238, p. 234.

<sup>29</sup> *Id.*

<sup>30</sup> Bonnie Burstow, *Electroshock as a Form of Violence Against Women*, *Violence Against Women* 12:4 (April 2006 Sage Publications); Survey on the Provision of Electroconvulsive Therapy (ECT) at New York State Psychiatric Centers by the Commission on Quality of Care (August 7, 2001) [hereafter CQC Survey].

resist rape.<sup>31</sup> Women are more likely than men to have experienced rape and other intra-familial violence, and to be struggling with these memories; electroshock can destroy the memories forever, along with the woman's ability to confront past abusers.<sup>32</sup> Electroshock has been used in many instances to enforce domesticity and compliance with a subordinate female role, and in collusion between psychiatrist and husband.<sup>33</sup>

12. A 2001 survey of New York State-run psychiatric institutions found that 38% of electroshock was done by court order, without free and informed consent.<sup>34</sup> The same survey revealed that electroshock is used on people with a variety of diagnoses, the most common denominator being severe adverse reaction to drugs, or inefficacy of drugs. It is noteworthy that no options other than drugs and electroshock were mentioned. In over half the anecdotes describing "typical" individuals undergoing electroshock, elements of behavior control are present; in particular electroshock is said to be justified to control assaultive or abusive behavior, as well as self-injury or attempted suicide. While a single course of electroshock is 6-10 treatments, some people are being prescribed "maintenance electroshock" weekly, with no foreseeable conclusion. In one instance, a man was electroshocked 56 times before it was determined that the treatment had no effect. The picture that emerges is one of institutional apathy and neglect; long-term institutional inmates are losing more of themselves with each electroshock, and there is virtually no one to care.

13. Survivors speak about electroshock:

During ECT [electroshock] you are made unconscious, heavily sedated by tranquillizers. Since a muscle relaxant completely relaxes your whole body, including your lungs, you cant breathe so you are administered artificial respiration (oxygen), then you are subjected to 150-200 volts if electricity to your delicate brain. ECT produces a nerve racking convulsion and leaves people brain damaged! You then wake up 10-20 minutes later in a "recovery room" with severe headaches and muscle pain, memory loss, jaw pain, confused, disorientated, and frightened. This is supposed to make you feel better or think straight!<sup>35</sup>

The attendant tells me I've been here 3 weeks. I know I'm getting more and more shock treatments. That man or someone comes in early in the morning. They wake me up and grab me and drag me to the same

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<sup>31</sup> Information from personal communications from electroshock survivors, who are not available to give permission to use their identities.

<sup>32</sup> Burstow, *supra* note 22.

<sup>33</sup> *Id.*

<sup>34</sup> Information in this paragraph is taken from CQC Survey, *supra* note 30.

<sup>35</sup> Personal communication, Diane Blakemore, New Zealand.



room. People push down on my arms and legs. The doctor puts the metal on my forehead on both sides. Now he always tells me to lift my head up and then puts a strap thing around the back of my head and in front over the metal things. It pulls on my hair. He says to open my mouth. I think I'm going to die each time. It's OK. I open my mouth and he sticks the black thing in it. Then I'm out. Nothing. Nothing till I wake up in my bed in the same dark room. Someone must carry me back from the other room each time. I hate to wake up. Most of the time I sleep but when I wake up, I remember where I am now because I hear the old ladies moaning, rocking, the same constant hum. When I look in the mirror I get more upset and want to cry again. I don't even look like me! My face is always red and broken out with pimples and blackheads, all blotchy and terrible. I don't know if I even wash or brush my teeth. I can't remember what I'm doing! I never wash my hair. It's sticky and itchy. I'm so tired. They just keep coming back and leading me to that room for more shocks. My arms have red blotches on them like finger marks. Why? They hold me down so hard on that black table. I guess that's why my back hurts. If I don't open my mouth fast enough they grab my face and pull my mouth open. I can't help it anymore. I cry and cry. I want to die. I can't think. I can't remember anything.<sup>36</sup>

I am currently undergoing forced electroshock treatment. But I would not call this electroshock 'treatment.' It is not medical. The forced electroshock is horrible. It is horrible. Maybe God himself or herself allowed me to hold onto my faith. ... I am strong. But no human being is invincible.... I thank you a lot. I ask God to bless you in anticipation of your helping me in my torture and traumatization. God bless you. Do whatever is possible!<sup>37</sup>

14. The aftermath is equally traumatic, as survivors learn to live with a new disability.

I only remember being told this would help me. I remember feeling nauseous and disoriented. I forgot which way was left and right. I forgot where all the silverware was. I got yelled at for not knowing what to do when I got home....<sup>38</sup>

... My fear was due to bereavement (I lost my mother when only 6), abuse, neglect, living in institutions etc. and not something that

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<sup>36</sup> Margo Bouer, *After Shock – A Memoir: Lost Childhood*, Xlibris Corp. (2001).

<sup>37</sup> Paul Henri Thomas, *Do Something Please!* In *Mind Freedom Alerts*, February 13, 2001. After losing his court hearing to refuse electroshock, in September 2001 Thomas secured a transfer out of the facility that was shocking him.  
[http://www.mindfreedom.org/mindfreedom/news/010213\\_b.shtml](http://www.mindfreedom.org/mindfreedom/news/010213_b.shtml)

<sup>38</sup> Personal communication, Alma (last name withheld).

couldn't be explained. I needed help and love, not a barbaric form of brain busting abuse. Sometimes I think that damage to my brain restricts my progress that I could have otherwise made. At present I am trying to get a much needed education and am finding this extremely difficult. I have to read stuff over and over again and am aware of a dull ache and heaviness in my head a lot of the time. I feel stigmatised as I have to tell people I'm had ECT to try to explain why I can't seem to grasp subjects that quickly. I am confused but concerned about the possible damage done to my brain. I am looking to some form of legal help for compensation of a wasted life if that is at all possible.<sup>39</sup>

14. Electroshock is performed against the person's will a significant proportion of the time. However, even when the person has given consent, it is unlikely to have been based on full and accurate information. Only two states, California<sup>40</sup> and Texas<sup>41</sup>, require disclosure of the probability of irrevocable memory loss, and the American Psychiatric Association's model form claims, "most patients actually report that their memory is improved with ECT."<sup>42</sup> Of the New York State Psychiatric Institutions that disclosed informed consent information to the CQC Survey, none provided full or accurate information.<sup>43</sup> Survivors have organized the Committee for Truth in Psychiatry to campaign for accurate disclosure in informed consent to electroshock.<sup>44</sup>

#### e. Applicable Legal Standard

##### *i. Article 7*

15. All human beings have the right to not be subjected to torture or other cruel, inhuman or degrading treatment or punishment. States have a corresponding obligation to prevent such practices, which are more egregious when government officials or official policy are involved. Torture is defined with reference to the degree of severity of mental or physical pain and suffering<sup>45</sup> caused to victim, as well as the purposive

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<sup>39</sup> Personal communication, Pam (last name withheld).

<sup>40</sup> California Welfare and Institutions Code, § 5326.2.

<sup>41</sup> Texas Statutes, Health and Safety Code, § 578.003.

<sup>42</sup> <http://www.healthplace.com/Communities/Depression/ect/apa/consent.asp>.

<sup>43</sup> See Manhattan Psychiatric Center Electroshock Policy, Creedmoor Psychiatric Center Electroshock Policy, Pilgrim Psychiatric Center Electroshock Policy, New York State Psychiatric Institute Electroshock Policy, and Policy from Rockland Psychiatric Center, obtained through Freedom of Information Law and posted at <http://www.survivorlink.org>.

<sup>44</sup> <http://www.harborside.com/~equinox/ect.htm>.

<sup>45</sup> Mental suffering caused by drugs that subvert individual will is addressed explicitly in the Inter-American Convention to Prevent and Punish Torture, article 2, and as an application of the UN Convention Against Torture in Andrew Byrnes, Torture and other offences involving the violation of the physical or mental integrity of the human person, in Substantive and Procedural Aspects of International Criminal Law, Gabrielle Kirk McDonald and Olivia Swaak-Goldman, eds. (The Hague: Kluwer, 2000).

nature of the act. Discrimination is relevant as a purpose of torture and as a factor rendering people more vulnerable to torture.

16. Force drugging and forced electroshock can be seen as a type of corporal punishment, inflicting harm on the body to bring a person under social discipline and control. Medical practices, like educational methods, may constitute corporal punishment or a related violation prohibited under article 7.<sup>46</sup> Furthermore, nonconsensual administration of mind altering drugs and procedures can constitute torture per se<sup>47</sup>, irrespective of other purposes or social function.

17. Where medical treatment is concerned, free and informed consent is the factor that distinguishes between lawful and unlawful procedures.<sup>48</sup> Traditionally, free and informed consent includes the element of capacity. However, a capacity standard excludes people with psychosocial or intellectual disabilities from being able to decide for ourselves whether to accept a given treatment.<sup>49</sup> Psychiatric treatments in particular cause a high degree of pain, suffering, and subsequent trauma and disability, and are administered in an adversarial way, often with a purpose of coercion and punishment. The capacity standard cannot be allowed to serve as a cloak to legitimize torture and for the medical profession to escape human rights scrutiny.

## *ii. Articles 2 and 26*

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<sup>46</sup> Human Rights Committee General Comment No. 20, paragraph 5.

<sup>47</sup> See references supra note 45.

<sup>48</sup> UN Guantánamo Report, supra note 10, paragraphs 54, 72-82. The importance of this issue to persons with disabilities has been addressed in the proposed Supplement to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which provides for an equal right to self-determination including the right to accept and refuse treatment, and an obligation to “prevent unwanted medical and related interventions... from being performed on persons with disabilities.” See U.N. Doc. E/CN.5/2002/4, annex, paragraphs 27 and 33. The obligation of prevention is consistent with requirements under Convention Against Torture articles 2 and 16. The EU Charter of Fundamental Rights, [http://www.europarl.europa.eu/charter/default\\_en.htm](http://www.europarl.europa.eu/charter/default_en.htm), article 3, does not differentiate between experimentation and interventions, but requires free and informed consent to be respected in the medical and biological fields, as part of the right to respect for integrity of the person (which is also the aim of ICCPR article 7, see Human Rights Committee General Comment No. 20, paragraph 1). The Committee on Economic, Social and Cultural Rights treats nonconsensual medical treatment and experimentation on a par, saying that freedoms in the right to health include “the right to be free from torture, nonconsensual medical treatment and experimentation,” see CESCR General Comment No. 14, paragraph 8.

<sup>49</sup> Court Monitoring Report, supra note 22; CQC Survey (indicating 38% electroshock done by court order), supra note 30; Anne Krauss, Justice Hall Reserves Judgement in Forced Shock Case, [http://www.ect.org/news/thomas\\_reserve.html](http://www.ect.org/news/thomas_reserve.html); Linda Andre, How Do Psychiatrists Decide to Use Forced Electroshock? <http://www.ect.org/news/catch22.html>.

18. All people are ensured the rights guaranteed in the ICCPR without distinction of any kind, including disability.<sup>50</sup> This entails not only a facial guarantee of formal equality, but an examination of deeper influences that may have the effect of depriving people of human rights on a basis of equality. Thus the capacity standard has to be scrutinized for its effect on equal enjoyment of rights under article 7.
19. Discrimination is also manifested in targeting people for compulsory change of socially devalued physical or mental characteristics<sup>51</sup> in violation of article 7. Giving such practices a medical imprimatur does not change their fundamental nature as violence against the integrity of an individual human being.
20. Even where a right is not explicitly recognized in the Covenant, States have the obligation to prevent discrimination in their own laws. The many laws that make distinctions in relation to legal capacity of adults<sup>52</sup>, where disability is an explicit or implicit factor in determining the right of an individual to represent him or herself, deny equal protection to people with disabilities. CEDAW acknowledges legal capacity as fundamental to a person's autonomy and independence, necessary to establish oneself economically and take action to assert one's rights.<sup>53</sup> These values are no less important to women and men with disabilities, than to non-disabled women and men.

### *iii. Article 18*

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<sup>50</sup> See Committee on Economic, Social and Cultural Rights General Comment No. 5 (non-discrimination obligation "based on certain specified grounds or 'other status clearly applies to discrimination based on disability").

<sup>51</sup> For the purpose it does not matter whether or not one accepts the premise of psychiatry that certain characteristics are symptoms of a disease. Discrimination is based on the social significance of psychiatric labeling. Generally, any disability has a social dimension consisting of the extent to which environmental or attitudinal barriers impact on the person's life. This is true even for people with chronic health conditions like diabetes, who would qualify as persons with disabilities under international definitions. See definitions in World Programme of Action Concerning Disabled Persons, U.N. GAOR 37/52, 3 December 1982; Standard Rules on the Equalization of Opportunities for Persons with Disabilities, U.N. GAOR 48/96, annex, 20 December 1993; Possible Definition of "Disability": Discussion Text Suggested by Chair (in negotiations of Convention on the Rights of Persons with Disabilities), <http://www.un.org/esa/socdev/enable/rights/ahc7pddisability.htm>.

<sup>52</sup> This includes mental health laws, which have an implicit or explicit dimension of incapacity. The other major premise of mental health laws, prediction of dangerous behavior, is also a form of discrimination. Dangerous behavior either constitutes a criminal offense, in which case there already exists an adequate social response, or it is behavior that people are legally free to engage in (leaving aside rules for civil liability or other types of government regulation which also operate neutrally with respect to disability). When disability contributes to a violent crime, the crime should be punished, not the disability.

<sup>53</sup> CEDAW Article 15; CEDAW General Recommendation No. 21, paragraphs 7-8.

21. The freedom of thought, conscience and belief is guaranteed to all people, along with the right to not be subjected to coercion that would impair the ability to have or adopt a belief of the person's own choice. Forced drugging and electroshock can damage a person's ability to maintain a chosen belief, due to cognitive impairment and disruption of thought and personality in general. There is also an element of proselytizing and conversion in the attempt to induce people to abandon a belief in themselves as capable actors living out difficult experiences, and adopt the belief system of biopsychiatry that sees such crises as evidence of a defective brain and need for externally-directed control.

#### f. An Inclusive Construction of Legal Capacity

22. Traditionally, legal capacity is constructed as a binary system that distinguishes two classes of people. Those who possess legal capacity are equal with each other in rights and responsibilities, and are entitled to enforce their rights and accept responsibilities directly, without intermediaries. Those who do not possess legal capacity may be excluded from some rights and responsibilities, and must rely on a surrogate decision-maker to enforce their rights or discharge responsibilities on their behalf.

23. Women have successfully established that equal legal capacity with men is a human right.<sup>54</sup> Children now have an evolving right to participate in decision-making concerning themselves.<sup>55</sup> It is only people with disabilities whose legal capacity is still questioned in human rights discourse, although this may soon change with the finalization of an International Convention on the Rights of Persons with Disabilities.<sup>56</sup>

24. Until recently, disability was understood as an individual problem, characterized medically and requiring medical judgment to determine matters of policy. However, with the development of the Convention, people with disabilities have fully emerged as a human rights constituency and disability as a prohibited ground of discrimination. Like physical environments, products, websites and educational strategies, the legal system needs to be made accessible to people with disabilities and others whose needs were not taken into account in the original design. A support model of legal capacity does just that.

25. The traditional model of legal capacity posits individuals as acting in isolation, outside any matrix of social relationships. The support

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<sup>54</sup> CEDAW Article 15.

<sup>55</sup> CRC Article 12.

<sup>56</sup> See working text at <http://www.un.org/esa/socdev/enable/rights/ahc7ann2rep.htm>. Draft article 12 provides that people with disabilities have legal capacity on an equal basis with others.

model<sup>57</sup> acknowledges that other people may be involved in our decision-making processes, and opens up legal capacity to people who need a high degree of support to make important decisions. The role of a support person is always secondary to the person receiving support, who is free to make decisions on his or her own authority. Support provides resources for decision-making according to each individual's needs, to equalize opportunities to exercise legal capacity. Support can go from very little to a great deal, and can encompass the assistance needed to seek and obtain support. The support model upholds the value of self-determination and choice, in an interdependent social context.<sup>58</sup> The support model of legal capacity, like other systems designed to be accessible to people with disabilities, is likely to benefit non-disabled people as well. A model of legal capacity based on interdependence rather than self-sufficiency could make it easier for other communities disadvantaged by the traditional model to have alternative styles of decision-making formally acknowledged.

26. For people with psychosocial disabilities, a support model of legal capacity removes the punitive consequences of seeking help or acknowledging distress and limitations. States have both a positive obligation to equalize resources for self-determination according to individual need, and a negative obligation to refrain from imposing services against a person's will, which, in the case of interventions compromising physical or mental integrity, can amount to torture.

### **3. Mental health screening and drugging of children**

27. The MindFreedom USA Campaign is focusing its effort on opposing the widespread use of mental health screening in schools that is being sponsored by the Federal government.
28. Its plan is to work with the Freedom Center on developing a kit that can be used by communities and human rights groups throughout the United States to effectively oppose screening that is based on unreliable assessment instruments, that does not require adequate informed consent and that coerces young people into treatment that uses psychotropic drugs as a primary modality.

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<sup>57</sup> See Amita Dhanda, Advocacy Note on Legal Capacity at <http://www.wnusp.org/wnusp%20evas/Dokumenter/LegalCapacityNote.doc> and Canadian Association for Community Living, Report of the C.A.C.L. Task Force on Alternatives to Guardianship (August 1992) at [http://www.worldenable.net/rights/adhoc3meet\\_guardianship.htm](http://www.worldenable.net/rights/adhoc3meet_guardianship.htm) for theoretical background.

<sup>58</sup> This not only equalizes opportunities for people with disabilities; it is also consistent with the recognition that human rights and inter-related (Vienna Declaration on Human Rights), and that realization of economic, social and cultural rights is necessary to the free and full development of the personality (UDHR article 22).

29. The Committee is also working on mobilizing members to encourage their Congresspeople to support Representative Paul's bill that prohibits the use of Federal funds for screening in schools and requires active informed consent in order for any school child to be screened or treated.
30. We consider this screening initiative to be a violation of human rights for the following reasons.
31. The great majority of screening will use Teen Screen, an instrument that was developed by Columbia University. Recent information found that Teen Screen is being used in 460 communities in 42 states. Teen Screen has been shown to be an invalid assessment instrument. It results in unacceptably large numbers of false positives - more than 70 percent of screenees being falsely identified as at risk for depression and suicide.<sup>59</sup> Validity coefficients of at least 75 percent are required for an instrument to be considered valid.
32. There is good reason to believe that the great majority of children who are referred for treatment will be given psychotropic drugs (including neuroleptics<sup>60</sup>). A recent article in the Journal of the American Academy of Adolescent Psychiatrists found that nine of every ten children who sees a recently trained child psychiatrist will be prescribed a psychotropic drug.<sup>61</sup>
33. The U.S. Food and Drug Administration (FDA) recently required the drug companies to include a Black Box Warning on all anti-depressant medicine because of evidence that the medicine causes increases in risk of suicidal ideation, suicidal behavior, violent behavior, hallucinations, psychosis, mania, akathisia (uncontrollable motor activity and anxiety), diabetes, and heart failure. There is also clear evidence that use of the psycho-stimulants that are used to treat ADHD causes increased risk of addiction to amphetamines.<sup>62</sup> In view of these facts, any prescription of psychotropic drugs to a child is a violation of human rights.
34. As for informed consent, most of these screening initiatives are funded by the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services (SAMHSA). In its

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<sup>59</sup> U.S. Preventive Task Force. *Screening for suicide risk*. Washington, DC: Office of Disease Prevention and Health Promotion, May, 2004.

<sup>60</sup> A Tennessee study found that the use of neuroleptic drugs on low-income children doubled between 1996 and 2001. Amanda Gardner, Use of Antipsychotics Doubles for Low-Income Kids, <http://www.healthday.com/view.cfm?id=520474>.

<sup>61</sup> Stubbe, D.W. & Thomas, W.J. (2002). A survey of early-career child and adolescent psychiatrists: Professional activity perception. *Journal of the American Academy of Adolescent Psychiatry*, 41 123-130.

<sup>62</sup> Jennifer Corbett Dooren, "FDA urges stronger warning on ADHD." *Wall Street Journal*. March 15, 2006.

funding of such efforts, SAMHSA does not require its grantees to provide for active informed consent of parents and requires no provision of informed consent for children.<sup>63</sup>

35. There is evidence that many schools are using passive consent in which the child can be screened if the parent doesn't object. In some schools, the screening is made part of the curriculum so that informed consent requirements can be by-passed.<sup>64</sup> And it is very unlikely that even the active consent is truly informed consent, i.e. in which the parents are given complete information about the screening instruments that are used and the true facts about psychotropic drugs administered to children.
36. There is no evidence that children are provided an opportunity for any kind of informed consent, in violation of their rights under Convention on the Rights of the Child, article 12, which requires that children have the right to freely express their views on matters concerning themselves, with those views being given due weight according to the child's age and maturity. Since the CRC is the only human rights instrument to address this issue, we would urge the Committee to adopt the standard used in CRC as relevant with respect to all issues concerning informed consent by children that arise in the context of the Covenant. We would further note that this standard must be applied without any discrimination based on disability.
37. Neither does SAMHSA require the use of screening instruments that meet a minimum standard of validity and reliability.
38. MindFreedom is not opposed to efforts to identify children who are having difficulty managing their emotions and behavior and, therefore, are failing in school. We understand that there are children who suffer both life-threatening and development trauma early in their lives. Such children grow up with severe handicaps. Due to the effects of trauma, they suffer from elevated levels of anxiety. They overreact to stressful situations. Such children are at tremendous risk because they will do poorly in school, which will keep them from gaining the skills they need to succeed in later life and negatively affect their self-concept. They will also have trouble getting along with other children, which will inflict further damage. We think it is a good idea to identify such children and make an effort to help them. We believe the schools are an appropriate setting in which to do that. But we don't think mandatory or widespread screening with instruments based on the DSM and with referral to mainstream mental health practitioners is the way to do it. We believe there are more safe, humane and effective ways of doing it. For example:

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<sup>63</sup> Teleconference with Charles Curie, Administrator of the U.S. Substance Abuse and Mental Health Services Administration, October 27, 2005.

<sup>64</sup> Teen Screen Facts Page. Freeing the Beehive State. [www.Freebeehive.org](http://www.Freebeehive.org).



- Sitting down with a child and finding out what is going on that is causing the difficulties. What is going on at home? What does the child want to learn? How does the child want to learn it? What is the child afraid of, troubled about, upset with? What changes would the child like to see?
- Providing the child with alternative environments in which the child can become more comfortable, feel more safe, feel more affirmed, in which the child can learn what the child wants to learn, how the child wants to learn it and when the child wants to learn it, in which the child can be helped to address issues like getting along with other kids, feeling OK about himself or herself, learning how to manage the strong emotions like anger, hatred, jealousy, fear, sadness, etc.
- Providing environments in which the child can develop his or her unique talents, abilities, passions - even if they don't involve learning how to read, write and do arithmetic. We understand that at some point all children need to learn academic skills but how and when they do it has to be designed for the individual child, not the one-size-fits-all approach we use now.

39. It is important to acknowledge the degree to which the screening initiative is a victim of the domination of America's mental health system by mainstream psychiatry. It is due to that domination that the screening effort will result in millions of children being administered psychotropic drugs which are not only ineffective but are also harmful to the brains and entire organism.

40. As currently practiced in the United States, the mental health screening and prescription of psychotropic drugs to children violates article 7. Active, fully informed consent by parents, and provision for consultation that takes account of the children's views, would address part of the concern. However, since children cannot refuse medical treatment on their own authority, informed consent may not adequately protect their rights. Psychotropic drugging of children should be prohibited, along with similar violations of integrity that have irreversible effects (such as sterilization), as a per se violation of article 7, which aims to protect the physical and mental integrity of all human beings.

#### **4. Conclusion**

41. Force drugging and forced electroshock of disabled and non-disabled people, adults and children, women and men, of all racial and ethnic backgrounds, is an injury with often lifelong effects. Disability is no excuse to give license to the medical profession to inflict pain and suffering

without free and informed consent. Since the legal capacity standard for informed consent, as currently constructed, serves to perpetuate the infliction of suffering and deprive people with disabilities of a remedy against it, legal capacity must be redesigned in an inclusive model. Psychotropic drugging of children, who still do not have full legal capacity, must be prohibited.

## 5. Recommendations

42. We respectfully request the Committee to consider the following concluding observations:

- Nonconsensual administration of electroshock or psychotropic drugs such as neuroleptics violates ICCPR article 7. The United States should take effective measures to stop these practices.
- Legal standards allowing nonconsensual administration of electroshock or psychotropic drugs such as neuroleptics on persons with disabilities violate ICCPR articles 2 and 26. The United States should ensure that such legal standards, whether embodied in federal or state statutes or judicial decisions, are modified.
- Failure to accord legal capacity to persons with disabilities on an equal basis with others, including the provision of supported decision-making as a means of accessibility, violates ICCPR article 26. The United States should ensure that federal and state law are modified to reflect an inclusive model of legal capacity and eliminate surrogate decision-making; and should develop and implement measures to facilitate supported decision-making.
- The United States should cease all federal support for mandatory mental health screening, and prevent the further drugging of children.
- The United States should implement the recommendations of the National Council on Disability report "From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves"<sup>65</sup>.

Contact information:

Tina Minkowitz

+1-518-494-0174

tminkowitz@earthlink.net

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<sup>65</sup> <http://www.ncd.gov/newsroom/publications/2000/pdf/privileges.pdf>, see March 17, 2006 comments by Disability Working Group.