

Medical Whistleblower Advocacy Network

**Disability Rights**

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Submitted by:

Medical Whistleblower Advocacy Network

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Submitting and endorsing organizations jointly endorse this report as a statement of solidarity, but do not necessarily endorse every assertion or policy recommendation made herein.

## **I. SUMMARY:**

1. Medical Whistleblower Advocacy Network (MWAN) acts as a grassroots advocate for human rights for disabled persons and other individuals. 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.

2. In the last 4 years MWAN has placed representative disability cases in front of various state governmental agencies and the Department of Justice with very mixed results. Lack of awareness of the human rights issues led to inaction by numerous governmental agencies in many cases. Judges varied in their approaches, some chose to side with medical authorities and others were willing to consider human rights defenders information. In one case from Washington State, the victim's mother presented her story to the UN CERD Committee in Geneva and was then granted release of her son from a mental hospital and restoration of his rights.<sup>1</sup> In another case, however, the victim of human rights violations did not receive the care he needed in Minnesota and is now dead. A third case in Nebraska did eventually get positively resolved. But there were relapses in protection and the man still does not have all his needed services – such as day care and respite support. A fourth case from Colorado was lost to the guardianship process and hindered by direct interference in the mother's life leading to her hospitalization. Issues of alleged domestic violence and lack of adequate secure communication have created difficulties for MWAD going forward. A fifth case in Connecticut, involves a citizen from the Republic of China who was facing capital punishment and in pre-trial detention for years. He no longer faces a possible death sentence, as the state of Connecticut has abolished the death sentence. However he remains in a state of limbo, with no trial date set, due to questions over his demands that he represent himself and his lack of co-operation with the public defender.

3. During the process of providing human rights advocacy and human rights defender support MWAD was subjected to violations of human rights necessitating a move from the state of Kansas to our present location in Washington DC.

### **The United States Government should:**

4. Establish an independent federal governmental office for the investigation of Defenders of Human Rights complaints which is accountable to all 3 branches of government and works closely with the Department of Justice (DOJ) to prevent, investigate, and support prosecution of human rights violations. The office should also coordinate the collaborative

efforts of the many governmental and non-governmental agencies and organizations that affect quality of care in health-related settings.

5. Strengthen all appropriate Offices of Inspector General related to human rights and fund investigation of all defenders of human rights complaints.

6. Cross-training between those in the medical profession, law enforcement, the judiciary and other professions to provide more timely and effective investigation, to prosecute abuse and corruption, and to protect victims.

7. (See MWAN JS-14 UPR report Ninth Session of the Working Group on the UPR Human Rights Council 22 November – 3 December 2010)

8. (Recommendation 44. JS-14 indicated that there is no integrated system for the protection of human rights defenders and recommended establishing an independent federal office to prevent, investigate and prosecute violations against human rights defenders. As noted in A/HRC/WG.6/9/USA/3/Rev.1)

## **II. LEGAL FRAMEWORK**

9. The United Nations Charter and The Universal Declaration of Human Rights, and the General Assembly resolution 53/144 of 8 March 1999, adopted the Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms, known as the Declaration on human rights defenders and subsequent resolutions (see in particular resolution 58/178 of 22 December 2003). The U.S.A. has responsibility in relation to actions and omissions of non-State actors as provided in Article 12, paragraph 3 and Article 13 of the Declaration.

10. Universal Declaration of Human Rights, Article 204

11. International Covenant on Civil and Political Rights, Article 225

12. International Covenant on Civil and Political Rights, Articles 25 and 26

13. (See MWAN JS-14 UPR report Ninth Session of the Working Group on the UPR Human Rights Council 22 November – 3 December 2010)

### **III. U.S. COMPLIANCE WITH ITS INTERNATIONAL HUMAN RIGHTS OBLIGATIONS**

#### **International Human Rights Treaties**

14. President Barack Obama signed the Convention on the Rights of Persons with Disabilities treaty in 2009 and sent it to the U.S. Senate for ratification. Medical Whistleblower Advocacy Network (MWAN), The National Council on Independent Living (NCIL) along with many other disability advocates rallied the Senate alongside the U.S. International Council on Disabilities (USICD).<sup>ii</sup> Former Senator Bob Dole led a bipartisan effort of support to secure the 2/3 Senate vote needed for ratification. Unfortunately on December 4, 2012 the super-majority needed was not reached. Again in 2013 Foreign Relations Committee Chairman, Robert Mendez held two successful hearings on CRPD ratification, but because of opposition the CRPD was not passed. Committee Chairman Mendez brought the matter again forward in 2014, supported again strongly by former Senator Bob Dole and many organizations for the disabled and veterans.

#### **Freedom of expression, association and peaceful assembly, and the right to participate in public and political life**

##### **Election Voting Rights**

15. The efforts to ratify the CRPD highlighted the need for voting rights for the disabled. Election reform is much needed in order that people with disabilities can fully participate in the voting process. Barriers include: architectural and physical barriers to polling centers, lack of accessible technology, discriminatory actions during voting process, guardianship laws that bar registration, and discriminatory voter ID practices.

16. Because of the lack of voting rights for persons who live in the District of Columbia, no disabled person living within the District can actually have direct input into the Senate CRPD ratification process, as there is no elected person who serves in the Senate for the District. The United States government has systematically denied the residents of the District of Columbia the right to enjoy equal political participation in their own national legislature.<sup>iii</sup> The approximately 620,000 residents of the District of Columbia—the nation's capital—are denied the fundamental right to equal suffrage in the U.S. Congress.<sup>iv</sup> They're prohibited from voting for and electing representatives to the United States Senate and the United States House of Representatives. The residents of the District of Columbia are the only U.S. taxpaying citizens denied the right to universal and equal suffrage—fundamental rights guaranteed under Articles 25 and 26 of the ICCPR.

17. MWAN went to US Senate Majority Leader Senator Harry Reid's office the day of the 2014 USICD CRPD rally to express the wholehearted support for the treaty by the disabled community in Washington, DC. MWAN also spoke to the District's only elected Congressional representative, Eleanor Holmes Norton, to encourage her to advocate for the human rights of all disabled persons in the District of Columbia.

18. Representative Eleanor Holmes Norton is a non-voting member of the United States House of Representatives. She is only allowed to vote on procedural matters and in congressional committees. D.C. Residents have no representation in the U.S. Senate. As a result of the Twenty-third Amendment to the United States Constitution, adopted in 1961, the District is entitled to three electoral votes in the election of the President of the United States. There are active efforts to get a D.C. Voting Rights Act passed but equal suffrage for D.C. Residents has still not occurred.

## **Administration of Justice including impunity and rule of law**

### **Federal and State institutions monitoring human rights**

19. MWAN recommended that an independent human rights institution be established at the federal level to ensure implementation of human rights in all states. (JS-14, Recommendation 74)<sup>v</sup> There is currently no integrated system for the protection of human rights defenders, which can coordinate investigations, prosecutions and extend protection for victims/survivors/witnesses of human rights violations. Currently the Federal government does not consistently or systematically review state laws for loopholes that provide immunity, or lack of transparency or accountability to persons who violate human rights. Instead enforcement of human rights depends on the public's access to the civil court system and various governmental agencies to act as civil rights mechanisms for review of state laws. Unfortunately, these pathways to justice are not easy to access for victims of human rights violations. Many victims of human rights violations never receive the protection they need. The court system is costly, cumbersome and slow and difficult to navigate for those who are disabled. Some are refused access to the courts because their legal rights have been removed from them (wards of the court). Many disabled persons struggle to make themselves understood and thus their complaints are often ignored. The physical and emotional injuries that many victims endure are likely to affect their ability to concentrate, to make sound decisions, to recall events, and to respond to questions about their experiences. Mandated reporters of abuse and neglect are not protected when they come forward to report human rights issues, instead a culture of impunity often shrouds abuse especially in institutions and medical facilities. The state and federal governmental agencies do not always respond in a timely or adequate manner. Cross-training is still needed between those in the medical profession, law enforcement, the judiciary and other professions to provide more timely and effective investigation, to prosecute abuse and corruption, and to protect victims. Human rights training and education strategies must be incorporated into public policies.

## **Equality and Non-discrimination**

### **Mental Health**

20. The US government has a "duty to protect" those who are most vulnerable and to provide equal access to treatment and community integration for all those with disabilities regardless of what that disability might be. Serious violations and discrimination against persons with disabilities are still occurring on a daily basis, often masked as "good intentions" on the part of health professionals. Often authorities employ a substituted decision making process that denies the disabled a voice in their own lives. Atrocious human rights violations have taken place when people with disabilities are stripped of their rights through court facilitated denial of "legal capacity." Under the existing legal system, being placed under guardianship as a ward of the court is sometimes equated to "legal death." Forced psychiatric treatment, and forced institutionalization can be psychologically damaging. State laws allow inpatient and outpatient commitment and forced treatment with mind-altering drugs and electroshock for both youth and adults. Youth in particular have no right to object to these traumatic and abusive practices. Interventions that result in humiliation, isolation, injury and /or pain should not be considered appropriate and should not be permitted.

21. We have as a society often discriminated against certain classes of persons and manipulated them into medical research based on their availability to be targeted. Personal circumstances that result in their vulnerability include: disability, age, gender, sexual orientation, race, ethnicity, religious belief, immigration status, detention or incarceration, or financial dependence on welfare. Ethical principles for use of human subjects are now delineated in The Common Rule and the Belmont Report, but they are not applied to the "extra-label" use of pharmaceutical drugs. Extra label or off label use of psychiatric drugs means these drugs have not yet met Food and Drug Administration (FDA) approval for that particular use. Many psychiatric medications are often used on patients without their full informed consent and often on wards of the court, who essentially have no input into medical decisions. Medical professionals also withhold critical information from patients and third party decision makers regarding adverse side effects and lack of efficacy for the diagnosed problem.

22. Greater attention should be paid to providing the services that are deemed by the disabled themselves to be most beneficial and effective. There should be parity for persons wishing to use non-drug interventions and therapies, as well as proper provision of community support and resources. Trauma-informed care and peer-run alternatives to the traditional medical model do exist. The lack of appropriate services for the disabled, however, is often a product of a lack of funding and planning – not because such alternatives are impossible to provide.

23. There has been a growing reliance on drug therapy as opposed to non-drug therapies. Coercive pharmaceutical management of, and substituted decision making for all disabled persons should not be the norm. Third-party decision makers should be held to strict constitutional standards of conduct because of the possibility for financial and personal conflicts of interest.

24. Community resources and programs should instead support informed decision making regarding the use of medications as well as decreasing reliance on medications and restraints. Provision for day care, respite care and in home care for mental patients is preferable to institutional care. MWAN supports the recommendation of The National Council on Disability<sup>vi</sup> to Congress that the U.S.A. move toward a policy of a totally voluntary mental health system.<sup>vii viii</sup>

### **Right to Life, Liberty and Security of Person**

#### **Medicaid/Medicare Institutional Bias**

25. Those with disabilities often are not included as equal decision makers when important decisions are being made in both health care and housing. There is a bias toward institutionalized care by the Centers for Medicaid and Medicare. Medicaid and Medicare are federal programs that provide health coverage to low-income children and adults as well as long term services and supports for persons with disabilities and low income seniors. The Centers for Medicaid and Medicare need to use a definition of community integration that permits disabled persons to be fully integrated into the community and enjoy the benefits of being able to choose and control their housing options. Instead institutional bias in federal Medicaid/Medicare funding now limit access to community based services and supports through waiting lists, cost caps and other limitations. The result is that disabled persons are forced into institution-like settings such as group homes, segregated buildings and other provider-owned facilities. Because the medical community is essentially a profit making enterprise with patients paying for services, service provider agencies prefer institutionalized services which are paid at a higher rate. In a risk adverse environment, the medical establishment encourages the removal of legal rights from the disabled and transfer of medical decision-making to third party decision makers. Instead it is always preferable to protect autonomy and self-determination. In order to integrate fully into the community disabled people often need long term community based supports and services. It is inherent in the right to health that all disabled persons should receive adequate access to health services including treatment facilities and preventative health services. States should be required to provide rehabilitative services and provide assistance for daily living activities and health-related tasks, as necessary, to all eligible individuals. Third-party decision makers should not be allowed to do involuntary euthanasia by withholding life-sustaining treatment. End of life decisions should always be made respecting the inherent dignity of person. Nothing is more personal to an individual than the moment and circumstances of one's own death.

## **Right to Life, Liberty and Security of Person**

### **Excessive Force by Police**

26. On April 29, 2014 MWAN supplied written testimony to the Hearing before the Senate Committee on the Judiciary - Subcommittee on the Constitution, Civil Rights and Human Rights, "Law Enforcement Responses to Disabled Americans: Promising Approaches for Protecting Public Safety."

27. The public still sees people with psychiatric disabilities as dangerous rather than as victims of crime and violence. In most instances, they are more frequently victims of violence rather than perpetrators. The assessment of dangerousness must be cautiously done with full regard to human rights. Many with mental illness have been shot unnecessarily by police. Some protocols call for unnecessary routing of individuals directly into the mental health system rather than leaving them to continue their lives in the community. If the disabled person is in crisis, then it is important to listen carefully so as to discern what is really wrong. Persons who are fearful, are in the moment of their distress often not able to accurately describe or articulate what the problem is. Unjustifiable pressures for compliance can occur when persons are in positions of authority over the disabled person or have commanding influence. Persons with diminished autonomy are entitled to protection. A behavioral problem with a disabled person may be the first signal to the outside world that there is a serious situation of medical fraud, abuse or neglect. Given the possibility that these essential human rights and ethical concerns might be being violated, a crisis presented by the disabled person may actually need law enforcement scrutiny for proper protection of the person as well as the safety of the public at large.

28. In addition, there needs to be greater scientific study into the increased propensity for violence when patients are under the effects of psychiatric drugs. The Food and Drug Administration is the Federal regulatory agency involved in approving psychiatric medications. Black box warning labels required by the Food and Drug Administration were placed on medications due to specific scientific information available to the FDA about the possibility of violent thoughts and behaviors, and also risk of suicidal ideation.

29. These FDA mandated warnings need to be heeded by medical professionals and patients alike. Prescription medication package inserts delineating side effects and warnings need to be read and understood by patients and third party decision makers. Better communication between the local police and the FDA's adverse event reporting system is critical to the protection of patients and also for the safety of the general public.

## **Right to Life, Liberty and Security of Person**

### **The Death Penalty**

30. The death penalty was abolished in the state of Connecticut in 2012. 18 states do not have the death penalty. 29 states have not had an execution in the last 5 years. 143 innocent people have been freed from death row.<sup>ix</sup> MWAN actively protested the death penalty in Kansas and attended state congressional hearings on the subject. In Kansas there was bipartisan support for abolition and there were almost enough votes to abolish the death penalty.<sup>x</sup> Many were swayed with the argument that it cost more to execute someone than to keep him in prison for 40 years and tax payer dollars could be spent in better ways.<sup>xi</sup> Kansas has had no executions since 1976 and has 10 people currently on death row, which is costing the state a great deal in legal costs for appeals and public defenders.

31. In 2002 The Supreme Court set the federal standard to protect intellectually disabled persons from being executed. The Supreme Court ruled in the *Atkins v. Virginia* case that executing inmates with intellectual disabilities was unconstitutional. However the death penalty case being decided by the US Supreme Court in *Hall v Florida* might open the doors to allowing the states to override the federal minimum standard. So persons with mental illness or intellectual disabilities may be facing capital punishment when individual states attempt to redefine the intellectual minimum standard used for sentencing in capital punishment cases, rather than abiding by federal standards.

## **Right to Social Security and Adequate Standard of Living**

### **Housing**

32. For people with disabilities housing has become the single biggest barrier to community integration. There has been a continuing disparate impact of lack of affordable rental housing primarily due to the foreclosure crisis and shrinking supply of housing affordable to low income populations. The Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999) held that unnecessary institutionalization constitutes discrimination under the Americans with Disabilities Act (ADA). But the United States Department of Housing and Urban Development (HUD) has not incorporated the principles of *Olmstead* and the Americans with Disabilities Act fully into their housing policies.

33. Disabled persons are often extremely low income because they often are totally dependent on social programs and when working they earn less than their able bodied counterparts. So inadequate incomes and high rents, coupled with the need for accessible features in their homes means many disabled are under housed or even homeless. Deep cuts in the Fair Housing programs and inadequate funding to The National Housing Trust Fund (NHTF) have left many disabled persons homeless or chronically under housed. Limited housing subsidies and lack of eviction protections mean that many disabled persons are precariously housed, couch surfing, doubling up or in temporary shelter – thus at risk of homelessness.

## Freedom of Movement

### Transportation

34. Lack of available accessible transportation continues to be a major problem for disabled persons. There still remain persistent gaps in compliance with the Americans with Disabilities Act. Many who do not have the option to drive a car, therefore are dependent on other modes of transportation. Thus the lack of access to affordable dependable transportation disproportionately harms the disabled. Because of increased health related needs, lack of transportation can negatively impact health and isolate patients from providers. Some disabled persons do not leave the house because of unavailability of appropriate and affordable transportation. Disabled persons in rural communities are even less likely to have adequate accessible transportation, in part due to lack of funding for public transportation. Disabled persons need both public and private systems of transportation that will provide them with connectivity and independence.

### III. CONCLUSION

35. The United States government should:

- Ratify the CRPD without any reservations, understandings or declarations that undermine the treaty.
- Establish a human rights institution at the federal level in order to ensure implementation of human rights in all states. (Recommendation 74)
- Review laws at the Federal and State levels with a view to bringing them in line with its international human rights obligations. (Recommendation 65)
- Incorporate human rights training and education strategies in their public policies. (Recommendation 87)
- Implement the recommendations for a totally voluntary mental health system as presented by the National Disability Council 2012 report to Congress National Disability Policy: A Progress Report.
- In death penalty cases, individual state laws, which draw a hard line with IQ ceilings should be considered unconstitutional and should not be allowed to override federal law.
- Address the need for affordable, accessible, integrated housing by funding the National Housing Trust Fund and make the Protecting Tenants at Foreclosure Act permanent.

Enact such legislation as may be necessary to grant the residents of the District of Columbia equal representation in the U.S. Congress, consistent with its obligations under Article 25 of the ICCPR.

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<sup>i</sup> M.O.M.S. Movement Of Mothers-and-Others Standing-up-together collaborated with CHRUSP (Center for the Human Rights of Users and Survivors of Psychiatry) and other organizations to submit a paper to the United Nations Committee on the Elimination of Racial Discrimination (CERD) in July, 2014.

<sup>ii</sup> U.S. International Council on Disabilities (USICD) [www.usicd.org](http://www.usicd.org)

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<sup>iii</sup> "Statement on the subject of The District of Columbia Fair and Equal Voting Rights Acts" (PDF) American Bar Association. September 14, 2006.

<sup>iv</sup> The Inter-American Commission on Human Rights of the Organization of American States which on December 29, 2003, concluded in their report that the United States is violating the District of Columbia's rights under Articles II and XX of the American Declaration of the Rights and Duties of Man by denying District of Columbia citizens an effective opportunity to participate in the Congress. [Inter-American Commission on Human Rights (Organization of American States) REPORT N° 98/03] The commission reiterated the following recommendation to the United States: "Provide the Petitioners with an effective remedy, which includes adopting the legislative or other measures necessary to guarantee to the Petitioners the effective right to participate, directly or through freely chosen representatives and in general conditions of equality, in their national legislature".

<sup>v</sup> UPR Recommendations Supported by the U.S. Government June 2014

<sup>vi</sup> National Council on Disability, 1331 F Street, NW, Suite 850, Washington, DC 20004

<sup>vii</sup> The National Disability Council's 2008 report *Inclusive Livable Communities for People with Psychiatric Disabilities*

<sup>viii</sup> The National Disability Council's 2012 statutorily mandated report to Congress *National Disability Policy: A Progress Report*

<sup>ix</sup> National Coalition to Abolish the Death Penalty, 1620 L. St. NW Ste. 250, Washington, DC 20036, 202-331-4090

<sup>x</sup> Kansas Coalition to Abolish the Death Penalty, Address: P.O. Box 2065 Topeka, KS 66601-2065, Contact: Mary Sloan, Email: info@ksabolition.org, Phone: 785-235-0214

<sup>xi</sup> Charles Hamilton Houston Institute for Race & Justice Harvard Law School, "Eleven Million Points of Light: How Abolition of the Death Penalty in North Carolina Could Improve Public Safety, Increase Opportunities, and Build Prosperity." A Policy Brief. April 30, 2010.