# United States of America

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## Human Rights of Persons with Disabilities

**Submitted by:**

ADAPT

Center for the Human Rights of Users and Survivors of Psychiatry

Nationwide Organizing Call to Action: Stop Forced "Mental Health" Treatment

Not Dead Yet

Self Advocates Becoming Empowered

The Opal Project

The U.S. Network of Users and Survivors of Psychiatry

**Endorsed by:**

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## Executive Summary

This joint submission provides information on the rights of people with disabilities (PWDs) in the United States (U.S.) under sections B, C, E and F, as stipulated in the *General Guidelines for the Preparation of Information under the Universal Periodic Review:*

- Section B raises concerns about limitations of the U.S. human rights framework that permits serious violations such as involuntary euthanasia, physician-assisted suicide, guardianship, civil commitment and compulsory mental health treatment.
- Section C discusses morbidity and mortality of people with psychiatric disabilities, deprivation of rights based on youth and disability, institutionalization and abuse of children in the mental health system, institutionalization and abuse of people with physical and developmental disabilities and abuses, and lack of alternatives to institutionalization.
- Section E presents best practices to support PWDs' right to live in the community and respect their legal capacity to make their own choices.
- Section F provides recommendations for realizing the rights of PWDs and for fortifying the human rights framework in the United States.

## SECTION B. Normative and Institutional Framework of the State

### 1) General normative framework on disability-based discrimination

1. 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 of the Child (CRC) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

2. The U.S. Constitution guarantees to all persons equal protection of the law. The standard for scrutiny of disability-related discrimination is lower than that applied to race and sex discrimination,[i] but on a par with discrimination based on sexual orientation.

3. Serious human rights violations persist despite the enactment of the Americans with Disabilities Act (ADA), which prohibits discrimination based on disability in employment, by state and local governments, and in public accommodations, and despite other enactments such as the Rehabilitation Act (of which Section 504 prohibits disability-based discrimination by federal agencies), the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act (IDEA). Despite the policy of non-discrimination articulated by these laws, there are many aspects of federal and state law and policy that are contrary to the principles of the ADA but remain in force.

### 2) Non-voluntary and Involuntary Euthanasia

4. Third party decisions to withhold life-sustaining treatment, without the consent of the person concerned, are an increasing human rights concern. These decisions may be made by a surrogate appointed by a court or by operation of law, or a health care provider in opposition to an

individual or surrogate decision in favor of treatment. In either case, current U.S. law does not adequately protect the individual's right to not be deprived of life.

5. First, with respect to decisions made by surrogates, other than those appointed by the individual through a document such as a durable power of attorney, constitutional standards must be met before life-sustaining treatment can be withdrawn. As discussed by the U.S. Supreme Court in *Cruzan* (1990)[ii], it cannot be assumed that surrogates are able to represent patient wishes. Use of surrogate decision-makers instead of requiring a best attempt to discern the wishes of the person concerned is contrary to the recognition of the legal capacity of PWDs on an equal basis with others, as required by CRPD Article 12 (to which the U.S. is a signatory) and constitutes discrimination based on disability under UDHR Articles 2 and 6, and ICCPR Article 26.

6. Decisions by physicians and other health care providers to withhold life-sustaining treatment in opposition to the decision of the individual or their surrogate present an even clearer violation of constitutional and human rights. Nevertheless, approximately 40 states authorize such decisions in some form under health care laws adopted over the last decade. Often labeled "futility" provisions, they do not require an objective determination that a particular health care treatment is futile, but rather confer civil and criminal immunity from liability based on vague and undefined professional judgments that treatment is inappropriate,[iii] and increasing cognitive disability is a factor in such considerations.[iv] Such measures violate the right to life of people with serious medical conditions, who are a subset of PWDs, under UDHR Article 3 and ICCPR Article 6, as well as CRPD Article 10.

### 3) Physician-Assisted Suicide

7. Laws permitting physician-assisted suicide in the states of Oregon and Washington do not adequately protect people from deprivation of their life without consent because they empower the physician over the patient. A double standard exists, in which these laws facilitate suicide by PWDs whose quality of life is seen by physicians to be poor, particularly individuals with significant physical disabilities, while in other situations "suicidality" is attributed to mental illness and physicians are empowered to detain the person and administer compulsory mental health treatment. Both aspects of this double standard constitute disability-based discrimination.

8. Terminology such as 'death with dignity' used to justify assisted suicide masks discrimination. While there are two existing laws that apply only to people predicted to die within six months due to terminal conditions, laws have been proposed in other states (e.g. New Hampshire) that include people with non-terminal disabilities.[v] People with terminal conditions constitute a subset of PWDs and, moreover, physician predictions are not always accurate.[vi] Furthermore, 'indignities' are often described in terms that include people with non-terminal conditions as well, such as the need for assistance in daily activities like bathing and toileting. Like derogatory racist and sexist language, the equation of disability and "indignity" is an insult to the disability community.

9. The rhetoric of personal choice diverts attention from the fact that assisted suicide laws actually make physicians the gatekeepers of assisted suicide, granting them the power to determine who is eligible for assisted suicide and conferring blanket immunity for exercising that

power based on a mere claim of "good faith." In addition, the nominal safeguards in the law end at the point in which the lethal prescription is granted, with no requirements at the time the lethal dose is administered, raising concerns about involuntary administration by others in a society with a high prevalence of elder abuse by family members.[vii]

**4) Guardianship and deprivation of legal capacity**

10. Guardianship places PWDs under the control and supervision of others. An outdated mechanism, it does not take into account current values and knowledge about the importance of self-determination, and how to provide support to facilitate self-determination. 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.

**5) Civil commitment and compulsory mental health treatment**

11. The U.S. Supreme Court recognizes that civil commitment on mental health grounds, and compulsory mental health treatment, are infringements of the liberty interest guaranteed under the U.S. Constitution, but considers these infringements to be justified by state interests,[viii] and has not taken account of the serious violation of mental and physical integrity by such practices or their close connection with disability-based discrimination, as analyzed by UN Special Rapporteur on Torture Manfred Nowak.[ix] This amounts to inadequate constitutional protection for PWDs from practices that 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.

12. State law regulates and authorizes civil commitment and compulsory mental health treatment. For example, in New York State, Article 9 of the Mental Hygiene Law governs all admissions for inpatient mental health treatment, as well as compulsory outpatient treatment. Article 9 states a preference for informal admission or voluntary commitment; however the bulk of Article 9 provides for involuntary commitment in a variety of forms and for the legal review of such commitment. 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.

13. The Court of Appeals case Rivers v. Katz,[x] governs compulsory inpatient treatment in New York. *Rivers* established that involuntary "patients" have the right to refuse treatment if they are capable of making rational decisions about treatment, however, if found "incapable," the court may order compulsory treatment based on its assessment of factors such as risks and benefits. Courts nearly always find incapacity and order compulsory treatment, without giving reasons, suggesting that "incapacity" is difficult to separate from a diagnosis of mental illness. The use of a capacity standard to deprive people of the right to control their own body and health discriminates based on disability, and violates U.S. obligations under 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. CRPD Article 12 establishes that PWDs have legal capacity on an equal basis with others in all aspects of life, including the right to make decisions about mental health treatment.[xi]

## SECTION C. Implementation of human rights on the national and state levels

### 1) Morbidity/Mortality Rate for persons with psychiatric disabilities

14. A 2006 study[xii] indicated that for adults with a psychiatric history there is a 25-30 year reduction in the life expectancy when compared with their counterparts without a psychiatric history. Since the use of psychiatric drugs was cited as a primary causative factor in early mortality, there is a grave concern about the implications of the mass drugging of children and youth, as well as of adults. The failure to address iatrogenic mortality as an urgent public health issue and to take measures to prevent it, including the banning of such drugs and development of non-medical support and safer alternatives, violates UDHR Articles 3 and 25 and ICCPR Article 6.

### 2) Youth as a status that strips individuals with disabilities of legal rights

15. Young people are seen as having limited to no ability to make their own medical choices. In some states, such as New York, young people appear to have the right to be involved with their treatment decisions at 16 years old. In practice, they may only give informed consent to participate in treatment – they do not have the right to refuse treatment. Not only is the right to informed consent withheld from children, but their guardians are often not given full information about treatment options.

16. Parents routinely lose custody of their children to foster care systems for either not complying with suggested courses of treatment (medical neglect) or not having enough money or insurance to pay for suggested treatments. Foster care has been described as "an institutionalized system of injustice" by the advocacy group Parents in Action.

17. Parents are often threatened with having their children taken away from them, and denied the right to choose what type of education their children shall experience. Even when their children are living in the community, parents are being denied supports and accommodations to aid their children in fully developing.

18. The failure to respect children's and parents' right to make mental health treatment decisions contrary to medical recommendations, and the failure to provide support to parents in raising children with disabilities, violates UDHR Articles 2, 3, 5 and 25, ICCPR Article 7 and CAT Articles 2 and 16, as well as CRC Articles 12 and 23 and CRPD Articles 7.3, 12 and 23.

### 3) Psychiatric institutionalization of children

19. Young people who have not committed any crime are nevertheless routinely incarcerated against their will in institutions. As well as being inherently unjust and discriminatory, very often these detentions are arbitrary, based on the type (if any) of health insurance (public or private). Young people are often unable to freely communicate with the outside world. They are often victims of sexual, physical, psychological, emotional abuse or neglect; in the U.S. "about 80% of 21 year old that were abused as children met criteria for at least one psychological disorder."[xiii] In the U.S., rape and abuse often occur in youth psychiatric facilities. Institutions are often overcrowded, poorly maintained, and do not allow for the privacy crucial for personhood. Institutionalization of children in mental health facilities, and the re-traumatizing abuse that

occurs in institutions, violates their rights to liberty and security of the person under UDHR Articles 2, 3 and 5, ICCPR Articles 2, 7 and 9, and CAT Articles 2 and 16, as well as CRPD Articles 7, 14 and 23.

20. Mental health diagnosis and institutionalization often violate the freedom of thought, expression and public participation under UDHR Article 18, 19 and 20, and ICCPR Articles 18, 19 and 21, as well as CRPD Articles 21 and 29. Very often the assigned diagnosis is based on the thoughts, religions, and beliefs that individuals hold, which may be out of step with conventional thought or religions. Once in a facility, religious practices and worship are often dictated by the rules of a facility, and religious observance is sometimes prohibited, as it is seen as symptomatic (i.e. magical thinking). Further, young people are often refused the right to gather among themselves in protest or form their own associations, and are routinely forced to comply with further mental health treatment if they want to be released.

21. Institutionalization results in violations of many other rights, including freedom from slavery and forced labor, and the right to an education. Young people all too often are treated as prisoners – some believe they are treated as slaves (Parents in Action)[xiv]. The needs of young people in institutions for rest and leisure are rarely accommodated on their own terms. Opportunities for fresh air are limited by the willingness and availability of the staff of the institutions and are often used as bargaining chips for compliance with treatment. Children in psychiatric institutions are denied a decent education as they are immediately filed into special education classes and awarded a high school "Individualized Education Plan Diploma" which symbolizes a certificate of attendance. Children in institutions are also denied the opportunity to learn another language, sex education, and preparation for higher education and future life.

**4) Abuse of children by drugs, electroshock, seclusion and restraint, and aversives**

22. The overmedication of children, including with drug cocktails (polypharmacy), is a systemic violation of the right to physical and mental integrity, and constitutes cruel and inhuman treatment or torture. Some children are drugged before it is developmentally appropriate for them to even speak. Central nervous system depressants known as "mood stabilizers" and "antipsychotics" are given to children as young as two years old.[xv] It is estimated that over 8 million children are being drugged in the U.S. each year, with approximately 1,300 deaths resulting from the practice. In New York State, in 2006, the Medicaid bill for psychiatric drugging of children was 82.8 million dollars (NY Post).[xvi] The routine practice of off-label prescribing is of grave concern, particularly in state-sponsored services. A lawsuit has been filed by the Law Project for Psychiatric Rights alleging that this practice constitutes Medicaid fraud.[xvii]

23. The invasive and brain damaging practice of electroshock (electroconvulsive treatment, ECT) on minors is widely accepted in the U.S., outside a few states, such as Texas, which have a ban for those under 16 years of age.

24. Restraint and seclusion is used as a form of control and punishment to instill fear in children so they are compliant, and can lead to death.[xviii] Further, restraint and seclusion are retraumatizing to someone who has experienced physical, sexual, psychological, emotional abuse or neglect in the past. Even if children themselves are not secluded or restrained, they are

in environments where they know it occurs, which can be just as detrimental to one's sense of security of person. There are institutions in the United States that have eliminated these practices, proving it can be done successfully.[xix]

25. The practices of applying skin shocks ("aversives") and withholding of food or toilet paper are also cruel and inhuman treatment and may be considered torture. Despite efforts to create a ban on aversives in New York State, such practices are permitted.

### 5) Institutionalization of persons with physical and developmental disabilities

26. Institutionalizing people is a violation of a person's right to liberty and security of person. Whether it is 6 people or more, in intermediate care facilities (ICFs) or group homes, people are not in charge of their lives. They can't leave.

27. The 1999 U.S. Supreme Court decision of *Olmstead* holds, under the Title II of the ADA, that services must be provided in the most integrated setting appropriate to an individual's needs. Although most states are moving people with developmental disabilities from large institutions to community living arrangements, institutionalization of people with disabilities remains a common practice. The system is still biased toward institutions and too often PWDs are neither afforded the choice of where to live, nor provided with adequate supports and services to maintain themselves in the community.

28. When States institutionalize PWDs who have committed crimes in secure facilities rather than allowing them to go to trial, the person has an endless sentence. Some people prefer to face the criminal justice system because they have more rights in that system than in the secure facilities.

29. There are currently 1.5 million Americans in nursing facilities[xx] and 129,000 in ICFs.[xxi] Although there isn't a system to track the number of persons with developmental disabilities in ICFs who would like to live in the community, there is data for nursing facility residents. According to the Centers for Medicare and Medicaid Services, 20% of individuals in nursing homes have expressed an interest in living in the community.[xxii] Another study conducted by Access Living and the Center for Urban Research and Learning at Loyola University in Chicago found that 64.5% of nursing home residents surveyed expressed that they would prefer to live elsewhere given the opportunity.[xxiii]

30. The institutionalization of PWDs in facilities that they are unable to leave, either because they are locked in or because the services they need are not provided in the community, violates the right to liberty and security of the person under UDHR Article 3 and ICCPR Article 9, as well as CRPD Articles 14 and 19, to which the U.S. is a signatory.

### 6) Abuses of people with developmental disabilities in institutions

31. People continue to be abused and murdered when living in institutions. In the past several years, many examples of abuses have been documented in Texas institutions for PWDs. In March 2009 it was discovered that employees of the Corpus Christi State School had been forcing mentally disabled residents to fight each other for the staff's amusement. In June 2009, 45-year old Michael Nicholson was suffocated to death by Lubbock State School worker

Donnell Smith. Smith was charged with manslaughter, but 5 other staff witnesses to the incident have not been charged.[xxiv] These high profile events followed years of allegations that went mostly un-investigated and unprosecuted. In fiscal year 2008, the Corpus Christi school had almost 1,000 allegations of abuse, neglect or mistreatment, of which 60 were confirmed. On average, about 300 employees are fired or suspended every year for abusing or neglecting residents in Texas institutions. Of 75 employees fired for serious physical or sexual abuse in the past 10 years, only 13 were charged with crimes for their acts. Of those, only two have served jail time.[xxv]

32. These events also followed a December 2008 Department of Justice Civil Rights Division investigation documenting pervasive substandard conditions and multiple violations of residents' civil rights in the state institutions.[xxvi] The settlement agreement, like those the DOJ has established in other states, does not require that Texas move residents to a community-based system for PWDs as required by the ADA.

33. The abuse of PWDs in institutions violates the right to security of the person and freedom from torture and ill-treatment, under UDHR Articles 3 and 5, and ICCPR Articles 7 and 9, as well as CRPD Articles 14, 15, 16 and 17, to which the U.S. is a signatory.

### 7) The lack of community based alternatives to institutionalization

34. The reason people do not often have any real alternative to institutional placement is the institutional bias in Medicaid funding for long-term services. Financial assistance for community-based services has been provided since the 1980s through the Home and Community Based Services Waiver (HCBS) program under Medicaid. However, under Medicaid laws, states are required to provide institutional services (i.e. nursing facility care), while community-based services are optional. To provide alternatives to nursing facilities or intermediate care facilities, states go through an arduous application process to secure a Medicaid HCBS Waiver, permitting the state to use Medicaid funds to provide home and community-based services as alternatives to institutional placements.

35. Even when states are approved to provide home and community-based services, access to these alternatives is limited. Although there are often no waiting lists for nursing facilities, the federal government authorizes only a certain number of HCBS "slots", which often results in waiting lists for these services. Although states have an option to choose approaches that guarantee access to community-based services, they are unlikely to do so because they want to control their costs.

36. Spending patterns demonstrate the impact of these policies. The spending data trends for seniors and people with physical disabilities demonstrate that spending for long-term services and supports remains significantly biased toward nursing facilities. In fact, only 32.6% of the spending on long-term care for the seniors and persons with physical disabilities is spent for home and community-based services, while the remaining 67.4% funds nursing facilities.[xxvii] Large variations in state spending indicate different degrees of progress in achieving deinstitutionalization for people with developmental disabilities. In 2008, seven states (IL, LA, AR, TX, NJ, DC and MS) spent less than 50% of their Medicaid long-term care funds for people

with developmental disabilities in the community, while 14 states spent more that 80% of funds in the community.[xxviii]

37. These federal and state policies deprive persons with disabilities of liberty, the freedom of movement and the right to live in the community, and of social services necessary to the free development of the personality, contrary to UDHR Articles 3, 13, 22 and 25, and ICCPR Articles 2, 9 and 12, as well as CRPD Article 19, to which the U.S. is a signatory.

## SECTION E. Achievements, best practices, and challenges for the rights of people with disabilities

### 1) Peer-run crisis respite

38. More opportunities must be developed for people to exercise their right to a life in the community. One positive model is peer-run crisis respite, a safe, home-like environment where people are supported to work through emotional crises; program staff are themselves individuals with psychosocial disabilities.[xxix] Program philosophy and practice support full community re-integration at the earliest opportunity.

### 2) Affordable housing without bundled services

39. A primary barrier to community integration is the lack of affordable housing. Many “supportive housing programs” offer “bundled services” which means that PWDs must participate in services which they may not want, including therapy and medication, in order to keep their housing. “Housing First” is a viable alternative; According to Pathways to Housing, the organization which created the model, it is “based on the belief that housing is a basic human right. Pathways moves homeless people with psychiatric disabilities directly from the streets into apartments of their own, instantly making them part of a community.”[xxx] The units are scattered throughout communities, not clustered together, and all participants are given the choice as to whether to accept other services.

### 3) Consumer control and Money Follows the Person demonstration (MFP)

40. Organizations run by PWDs, such as the Centers for Independent Living, have led the way in developing models for giving seniors and PWDs a real choice where they live. Even without funding dedicated for this purpose, organizations such as Topeka Independent Living Resource Center (Topeka, KS), the Center for Disability Rights (Rochester, NY) and Liberty Resources (Philadelphia, PA), have gone into nursing facilities to support individuals who wish to make the transition to the community, and then have provided them with the supports to do so.

41. Giving people direct control over their services is critical to their success in living independently. Programs like the Consumer Directed Personal Assistance Program (New York) and Self Directed Personal Assistance Services (Montana) give PWDs direct control over their services. These programs often serve individuals with more significant disabilities who would otherwise be unable to secure traditional assistance to live independently.

42. The state of Texas created a Money Follows the Person program which allows people to move from nursing facilities to the community without having to spend time on a waiting list for

community-based services. This policy also permits public money, up to the amount that was spent on them in the nursing home, to "follow" them to the community.

### Section F. Recommendations

43. In order to remedy the human rights violations discussed above and give effect to best practices, the U.S. must:

a) Ratify the CRPD, CRC and ICESCR without any reservations, understandings or declarations, without further delay.
b) Align the standard for review of disability-based discrimination under the U.S. constitution with the common standard under international law for discrimination based on race, sex and disability.
c) Ensure that guardianship is abolished and replaced by a system of support for people to make their own decisions.
d) Until guardianship is abolished, provide access to lawyers and protective services so that individuals can get out of institutions even if their guardian says "no".
e) Undertake comprehensive review at both the federal and state levels, with the participation of PWDs, to abolish all laws and mechanisms that restrict the legal capacity of PWDs, and to create supportive measures for the exercise of legal capacity that respect the will and preferences of the person.[xxxi]
f) Prohibit by federal law the withholding or withdrawal of life-sustaining medical treatment in violation of the individual's decision in favor of such treatment, or the decision of a surrogate upholding the person's wishes.
g) Collect data about the circumstances surrounding any surrogate decision to withhold life-sustaining treatment, to permit investigation of potential conflict of interest. Such data should include diagnoses, prognoses, financial circumstances, the type of medical treatment withheld or withdrawn (including food and water), and evidence of legal or financial disputes concerning the identity or decisions of the surrogate.
h) Investigate at the federal level abuses of laws legalizing assisted suicide and any funding policies that favor assisted suicide over treatment or support services.
i) Prohibit civil commitment and compulsory mental health treatment under federal law, as forms of disability-based discrimination and violence, which may amount to torture and ill-treatment and cannot be justified by any legitimate state interest.
j) Ensure that states repeal or nullify their mental health laws, such New York's MHL Article 9, in their entirety, and ensure that laws require free and informed consent of the person concerned as the only basis for inpatient and outpatient mental health treatment. In the case of children, or if the person's will and intention is unclear, intrusive and irrevocable measures such as electroshock and neuroleptic drugs[xxxii] must not be used.
k) Ensure that states and private entities offering mental health services do not institutionalize children based on disability or compel them to receive mental health treatment against their will or that of their parents; and should ensure that parents receive support to raise children with disabilities in the community. Shift federal and state funding from institutions to community-based supports.
l) Make available alternatives to the traditional system such as youth-to-youth peer support, family support, and strength-based innovative community-based models that have shown to be effective, such as the SAMHSA-recognized Wrap-around and System of Care

services. These options should be youth and family centered, culturally competent, and advance the human potential of children.

m) Ensure that electroshock is banned everywhere for children under 16 years of age.
n) Ensure that restraint, seclusion, and aversive interventions are eliminated nationwide from all schools, mental health facilities and other institutions.
o) Ensure that DOJ CRIPA settlement agreements are directed towards improving community integration. Minimum requirements for any agreement should include provision of services in the most integrated setting and the recognition and acceptance that all individuals can be served in the community; individual involvement; informed decision-making and choice; person-centered planning; developing and expanding community capacity; monitoring of community placements; and quality assurance.
p) End the institutional bias in federal law, which requires states to provide institutional services while making community-based services optional. The Community Choice Act (S683/HR1670) would establish a national program of community-based attendant services and supports for PWDs, regardless of age or diagnosis. This legislation would allow individuals who are entitled to institutional services to choose where they receive their services and supports.
q) Create peer-run crisis respite centers in every state and every county as a meaningful alternative to psychiatric emergency rooms.
r) Adopt the Housing First model as federal policy.

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**References:**

[i] City of Cleburne v. Cleburne Living Center, Inc., 473 U.S. 432 (1985).

[ii] Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261 (1990).

[iii] Fine & Mayo, Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act, Ann Intern Med 2003; 138: 743-746.

[iv] The Journal of the American Medical Association, Volume 281(10).March 10, 1999.937-941, Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs

[v] New Hampshire H.B. 304, Death With Dignity Act (2009). See also, Baron, C.H. et al. (1996). Statute: A model act to authorize and regulate physician-assisted suicide. Harvard Journal on Legislation, 33 (1), p.11.

[vi] Death with Dignity Act Annual Reports, http://www.oregon.gov/DHS/ph/pas/ar-index.shtml; Lamont, E.B., et al.1999. *Oncology* (Huntington). August 13 (8): 1165-70; Maltoni, M, et al. 1994. *European Journal of Cancer.* 30A (6): 764-6; Christakis and Iwashyna. 1998. Archives of Internal Medicine. November 23,158(21): 2389-95; Lynn, J, et al. 1997. New Horizons. Feb 5(1): 56-61.

[vii] Oregon Death With Dignity Act (1994); National Elder Abuse Incidence Study (1998), Page 1.

[viii] Addington v. Texas, 441 U.S. 418 (1979) (civil commitment); U.S. v. Sell, Riggins v. Nevada, 504 U.S. 97 (1992).

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

[x] 67 N.Y.2d 485 (1986).

[xi] See A/63/175, paragraphs 44 and 73-74.

[xii] Parks, et al. (2006). *Morbidity and Mortality in People with Severe Mental Illness*. National Association of State Mental Health Program Directors Medical Directors' Council. Accessed April 5, 2010 at www.nasmhpd.org.

[xiii] http://www.childhelp.org/pages/statistics.

[xiv] http://www.parentsinaction.net/english/Press/Amsterdam_News_7-24-08.htm

[xv] NYS Office of Mental Health. (June, 2008). Treatment of Children with Mental Disorders. http://www.omh.state.ny.us/omhweb/booklets/ChildrensBook.htm.

[xvi] NY Post, (Feb. 3, 2008). Edelman & Klein. http://www.nypost.com/p/news/regional/item_2Wl4M4I3UvHtboNRlyT0FI;jsessionid=0880A72B4C8460E5267C2C0C9A0B99C4

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[xvii] *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.

[xviii] Daly, J.(October 19, 2007). SAMHSA asses alternatives to seclusion, Restraint. Psychiatric News, 42 (20), 8. American Psychiatric Association. http://pn.psychiatryonline.org/content/42/20/8.2.full.

[xix] SAMHSA NEWS. (2003). Seclusion and Restraint: Breaking the bonds. SAMHSA News, XI (2), http://www.samhsa.gov/SAMHSA_news/VolumeXI_2/text_only/article6txt.htm

[xx] US Center for Disease Control and Prevention, http://www.cdc.gov/NCHS/fastats/nursingh.htm

[xxi] US Centers for Medicare and Medicaid Services, http://www.cms.hhs.gov/CertificationandComplianc/09_ICFMRs.asp

[xxii] From the Minimum Data Set question Q1a, fourth quarter of 2009, http://www.cms.hhs.gov/MDSPubQIandResRep/06_q1areport.asp#TopOfPage

[xxiii] http://www.luc.edu/curl/pdfs/nursinghomestudy.pdf

[xxiv] Emily Ramshaw, Abuse of Power: One Family's Fight, The Texas Tribune, January 21, 2010. http://www.texastribune.org/stories/2010/jan/21/abuse-power-one-familys-fight/

[xxv] Emily Ramshaw,Abuse of Power, *The Texas Tribune*, January 20, 2010 http://www.texastribune.org/stories/2010/jan/20/abuse-power/

[xxvi] Statewide CRIPA Investigation of the Texas State Schools and Centers, December 1, 2008. http://www.justice.gov/crt/split/documents/TexasStateSchools_findlet_12-1-08.pdf

[xxvii] Based on data from Medicaid HCBS Expenditures: FY 2003 through FY 2008, http://www.hcbs.org/files/166/8256/HCBSWaivers2008_final.pdf

[xxviii] Martin Kitchener, Terence Ng, Nancy Miller, and Charlene Harrington Medicaid Home And Community-Based Services: National Program Trends, *Health Affairs*, 24, no. 1 (2005): 206-212

[xxix] As of this writing, programs exist in New York (2), Maine, New Hampshire, West Virginia, Ohio, California, Nebraska, Alaska and Georgia; new programs are starting in Vermont and New Mexico. Source: M-Power website. Last accessed March 5 at http://www.m-power.org/peer_run_respite

[xxx] Pathways to Housing website. Last accessed March 5 at http://www.pathwaystohousing.org/content/housing_and_services

[xxxi] See CRPD Article 12.

[xxxii] See A/63/175, paragraphs 40 and 47.