

From Privileges to Rights:
People Labeled with Psychiatric Disabilities Speak for Themselves

National Council on Disability
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Letter of Transmittal

January 20, 2000

The President
The White House
Washington, DC 20500

Dear Mr. President:

I am pleased to submit the National Council on Disability's (NCD) report From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves, which is based on the testimony of people with psychiatric disabilities who testified at an NCD hearing in 1998.

All the recommendations in this report emphasize the basic principle that people with psychiatric disabilities are, first and foremost, citizens who have the right to expect that they will be treated according to the principles of law that apply to all other citizens. All laws and policies that restrict the rights of people with psychiatric disabilities simply because of their disabilities are inharmonious with basic principles of law and justice, as well as with such landmark civil rights laws as the Americans with Disabilities Act.

We call on you, Mr. President and Congress, to address the problems described in this report, particularly by ensuring that people with psychiatric disabilities themselves are involved in a major way in making the policy changes that will enable them to claim their full citizenship rights.

We look forward to the day when the label of psychiatric disability has no more effect on people's rights than does the existence of any other disability label. Until that day, NCD believes that people with psychiatric disabilities will remain among the most underprivileged and disadvantaged of American citizens.

Sincerely,

Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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those who submitted written and other forms of testimony.

For many people, testifying and submitting testimony was an act of real courage. NCD recognizes and acknowledges this fact.

This report is based on their testimony.

Executive Summary

The National Council on Disability (NCD) is an independent federal agency mandated to make recommendations to the President and Congress on disability issues. NCD generally does its work in a cross-disability manner, emphasizing that people with disabilities should be the ones who make the major decisions about their lives. NCD endorses and supports the principles of independent living, which has achieved the success it has because it is rooted in two unwavering principles: self-determination and consumer direction.

People with psychiatric disabilities are routinely deprived of their rights in a way no other disability group has been. In order to learn more about the problems of psychiatric disability, NCD conducted a hearing specifically on this topic. At the hearing, held in Albany, New York, in November 1998, NCD heard testimony from mental health professionals, lawyers, advocates, and relatives of people with psychiatric disabilities. However, unlike most investigations on the topic of psychiatric disability, the primary participants in this hearing were people with psychiatric disabilities themselves, who testified passionately and eloquently both about the mistreatment they had experienced or witnessed, and their proposals for real and viable change. NCD heard testimony graphically describing how people with psychiatric disabilities have been beaten, shocked, isolated, incarcerated, restricted, raped, deprived of food and bathroom privileges, and physically and psychologically abused in institutions and in their communities. The testimony pointed to the inescapable fact that people with psychiatric disabilities are systematically and routinely deprived of their rights, and treated as less than full citizens or full human beings.

Forced treatment and abuse aren't synonymous with healing. When persons are admitted in a general hospital for any other problems--stroke, cancer, broken hip, X rays, tests--these persons wouldn't dream of allowing the doctors, nurses, or nursing aides to lock them up, shock them up, tie them up, or drug them up, and the staff wouldn't do it to them. Those patients are treated with compassion, caring, respect, and dignity, and persons who have serious enough emotional/mental problems need to be treated the same. (Bernice E. Loschen)

Finally, it is important to realize how cruelly this system preys on the worst fears and vulnerabilities of people in crisis. They isolate you from the rest of the world, and they become your only reference point. When they accuse someone of being treatment resistant, they are accusing them of not wanting to change their lives. I was told that this was the end of the line for me. If this didn't work, nothing would, and if I left, I would very likely kill myself. During the entire length of my treatment, they did nothing constructive for me, and they hurt me deeply. (Diana Rickard)

Joe Young of the New Jersey P&A testified about abuses he has witnessed in mental institutions.

Among the more egregious concerns: the administration of medication, often without consulting the resident, likely without informed consent, frequently with limited understanding of the likely effect on this particular individual, including possible long-term side effects, and often for

reasons of control rather than treatment; the absence not just of regular effective treatment programs, but of any purposeful activity (residents can still be seen sleeping in hallways and in the dayroom when bedrooms are locked); the arbitrary (and often dangerous) application of restraints, seclusion, and isolation; and the continued warehousing of individuals for months, if not years, after the expiration of any determination of [danger]. (Joe Young)

Diana Rickard testified about the degrading extent of the denial of basic human rights while she was institutionalized. The unit structure is based on privileges and punishments, which are referred to as consequences, since they maintain these are not punitive. [The structure] will not allow any kind of privacy whatsoever, and everything is a potential treatment issue, including nail-biting and not making one's bed. They maintain control through humiliation and fear of humiliation. (Diana Rickard)

NCD heard many reports of the routine use and overuse of psychiatric drugs, often against people's will.

When I was in a psychiatric facility, because I questioned conditions, I was dragged into solitary confinement and held down on a bare mattress, forcibly injected with powerful psychiatric drugs, and held in solitary confinement. And I found since then that this is routine, that this is happening all over the--all over the psychiatric system. Usually forced psychiatric drugging occurs behind institutional walls, but in the last few years coerced drugging is now out in the community. Thirty-six U.S. states and the District of Columbia have involuntary outpatient commitment laws, which allow people to be court ordered to take their psychiatric drugs against their expressed wishes, even if they're living at home. (David Oaks)

Even though most people with psychiatric disabilities are capable of participating in the decisions affecting their own care, they are often subjected to forced treatment. Given appropriate supports and full protection of their civil rights, the great majority of people with psychiatric disabilities are quite able not only to participate in their own health care but to become fully productive and creative members of mainstream society. But those simple supports and protections are rarely provided. Millions of people with psychiatric disabilities exist as virtual outcasts. This massive discrimination costs our nation uncounted billions of dollars in obsolete services and lost productivity. More important, in the land of liberty and justice for all, it is morally intolerable. (Justin Dart, April 20, 1999)

Based on the testimony it received, NCD has concluded that the manner in which American society treats people with psychiatric disabilities constitutes a national emergency and a national disgrace. Because people with psychiatric disabilities are routinely deprived of their most fundamental rights, NCD believes that drastic change is necessary in a number of systems that deal with this population. Changes must be made not only in the mental health system, but in the criminal and civil justice systems, housing, income supports, education, job training, and many others, so that people with psychiatric disabilities are guaranteed their fundamental rights as American citizens.

NCD has also concluded that one of the reasons public policy concerning psychiatric disability is so different from that concerning other disabilities is the systematic exclusion of people with psychiatric disabilities from policymaking. It is rare that people with psychiatric disabilities are heard in public-policy forums, and when they are, it is usually in token numbers. NCD's hearing was unique because it focused its attention on the direct experiences of people with psychiatric disabilities themselves, and their calls for fundamental change.

The foremost change that is needed, as referred to by speaker after speaker, is the elimination of coercion from the provision of mental health services. Involuntary commitment and forced treatment, which often go unquestioned in discussions of mental health policy, were described again and again as being among the most painful and difficult experiences of people's lives. In addition, coercion was repeatedly noted as being a barrier to seeking out voluntary treatment, since people knew that once they entered the treatment system they could be coerced or involuntarily committed at any point. At a time when American citizens are being urged to do away with the stigma of mental illness and to voluntarily seek treatment for emotional difficulties, it becomes particularly important to ensure that people are able to do so without surrendering their fundamental rights.

Therefore, NCD recommends that the use of involuntary treatments, such as forced drugging and inpatient and outpatient commitment laws, should be viewed as inherently suspect and as incompatible with the principles of self-determination. Public policy should be directed toward establishing a totally voluntary mental health system.

NCD also recommends that aversive treatments, which involve the infliction of pain or the restriction of movement for purposes of changing behavior, should be banned, since they are also incompatible with self-determination principles. Practices that would often be illegal if administered to people without disabilities are routinely used on people with psychiatric disabilities in the name of "treatment." Such practices should shock the consciences of all Americans.

All of the recommendations in NCD's report follow the same basic principles: that people with psychiatric disabilities are, first and foremost, citizens who have the right to expect that they will be treated according to the principles of law that apply to all other citizens. All laws and policies that restrict the rights of people with psychiatric disabilities solely because of their disabilities are at odds with basic principles of law and justice, as well as with such landmark civil rights laws as the Americans with Disabilities Act (ADA).

NCD calls on the President and Congress to address the problems described in its report, particularly by ensuring that people with psychiatric disabilities themselves are involved in a major way in making the policy changes that will enable them to claim their full citizenship rights. NCD also calls on the media to address the problems described herein, and to avoid the negative stereotyping that has often typified public discussions of mental illness.

NCD looks forward to the day when the label of psychiatric disability has no more effect on people's rights than does any other disability label. Until that day, NCD believes that people with psychiatric disabilities will remain among the most underprivileged and disadvantaged of American citizens.

The recommendations that follow center on the importance of self-determination, dignity, and choice as the cornerstone of public policy for people in this highly disempowered population. As Congress stated when it passed ADA, disability is a natural part of the human experience that in no way should limit the ability of people to make choices, pursue meaningful careers, live independently, and participate fully in all aspects of American society. NCD believes that these recommendations, if implemented, would help to ensure that the public policy goals articulated in ADA become a reality for people labeled with psychiatric disabilities in the United States.

Core Recommendations

Therefore, NCD has developed 10 core recommendations in this report. These policy recommendations should be viewed from the context of the larger report, which follows. These deeply held core beliefs form, however, a dynamic backdrop to highlight the human and civil rights of people who have experienced the mental health system, people who should be viewed as the true experts on their experiences, beliefs, and values, which should be used as a guiding force for changing public policy related to these issues in America.

1. Laws that allow the use of involuntary treatments such as forced drugging and inpatient and outpatient commitment should be viewed as inherently suspect, because they are incompatible with the principle of self-determination. Public policy needs to move in the direction of a totally voluntary community-based mental health system that safeguards human dignity and respects individual autonomy.
2. People labeled with psychiatric disabilities should have a major role in the direction and control of programs and services designed for their benefit. This central role must be played by people labeled with psychiatric disabilities themselves, and should not be confused with the roles that family members, professional advocates, and others often play when "consumer" input is sought.
3. Mental health treatment should be about healing, not punishment. Accordingly, the use of aversive treatments, including physical and chemical restraints, seclusion, and similar techniques that restrict freedom of movement, should be banned. Also, public policy should move toward the elimination of electro-convulsive therapy and psycho surgery as unproven and inherently inhumane procedures. Effective humane alternatives to these techniques exist now and should be promoted.
4. Federal research and demonstration resources should place a higher priority on the development of culturally appropriate alternatives to the medical and biochemical approaches to treatment of people labeled with psychiatric disabilities, including self-help, peer support, and other consumer/survivor-driven alternatives to the traditional mental health system.
5. Eligibility for services in the community should never be contingent on participation in treatment programs. People labeled with psychiatric disabilities should be able to select from a menu of independently available services and programs, including mental health services, housing, vocational training, and job placement, and should be free to reject any service or program. Moreover, in part in response to the Supreme Court's decision in *Olmstead v. L C.*, State and federal governments should work with people labeled with psychiatric disabilities and others receiving publicly-funded care in institutions to expand culturally appropriate home- and community-based supports so that people are able to leave institutional care and, if they choose, access an effective, flexible, consumer/survivor-driven system of supports and services in the community.
6. Employment and training and vocational rehabilitation programs must account for the wide range of abilities, skills, knowledge, and experience of people labeled with psychiatric disabilities by administering programs that are highly individualized and responsive to the abilities, preferences, and personal goals of program participants.
7. Federal income support programs like Supplemental Security Income and Social Security Disability Insurance should provide flexible and work-friendly support options so that people with episodic or unpredictable disabilities are not required to participate in the current "all or nothing" federal disability benefit system, often at the expense of pursuing their employment

goals.

8. To assure that parity laws do not make it easier to force people into accepting "treatments" they do not want, it is critical that these laws define parity only in terms of voluntary treatments and services.

9. Government civil rights enforcement agencies and publicly-funded advocacy organizations should work more closely together and with adequate funding to implement effectively critical existing laws like the Americans with Disabilities Act, Fair Housing Act, Civil Rights of Institutionalized Persons Act, Protection and Advocacy for Individuals with Mental Illness Act, and Individuals with Disabilities Education Act, giving people labeled with psychiatric disabilities a central role in setting the priorities for enforcement and implementation of these laws.

10. Federal, state, and local governments, including education, health care, social services, juvenile justice, and civil rights enforcement agencies, must work together to reduce the placement of children and young adults with disabilities, particularly those labeled seriously emotionally disturbed, in correctional facilities and other segregated settings. These placements are often harmful, inconsistent with the federally-protected right to a free and appropriate public education, and unnecessary if timely, coordinated, family-centered supports and services are made available in mainstream settings.