

# The Application of Universal Human Rights Law to People with Mental Disabilities

by Debra Benko and Brittany Benowitz\*

Historically, the international human rights community has associated abusive psychiatric practices primarily with the wrongful institutionalization of political dissidents in the former Soviet Union. Abuses inflicted upon people with mental disabilities, including people with psychiatric disabilities and developmental disabilities, have been overwhelmingly ignored. Only recently has the international community begun to hear the voices of advocates for people with mental disabilities and to reflect changed attitudes toward this group.

Increased advocacy for people with mental disabilities by organizations such as Mental Disability Rights International (MDRI) and by grassroots organizations worldwide has been crucial in bringing international attention to this issue. Since its inception in 1993, MDRI has documented human rights abuses and discrimination against people with mental disabilities in thirteen countries in Latin America and Eastern Europe. In addition, MDRI has argued that international human rights conventions and standards should apply to people with mental disabilities and that these standards should require governments and human rights bodies to protect the rights of people with mental disabilities.

There is growing recognition within the international community that violations of the fundamental human rights of people with mental disabilities warrant increased international action. The United Nations General Assembly has adopted non-binding resolutions such as the "Principles for the Protection of Mental Illness" (MI Principles), during the

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last decade. The MI Principles can be used as interpretative guidelines to the requirements of binding human rights convention protections. The UN Human Rights Commission resolution 2000/51 called upon all countries to improve reporting on the enforcement of human rights conventions as they apply to people with mental disabilities. In addition, the Commission asked UN Special Rapporteur on Disability, Bengt Lindqvist, to develop recommendations to improve the international legal system's protections of people with mental disabilities. As the international community awaits the outcome of Lindqvist's work, activists are demanding the adoption of a specialized UN convention on the rights of people with disabilities.

## Human Rights Violations against People with Mental Disabilities

Violations of basic human rights of people with mental disabilities occur worldwide. People with mental disabilities



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Children at the Psychiatric Facility in Guadalajara, Mexico.

are so marginalized that even human rights activists have failed to advocate for them. In *The New York Times Magazine* article "The Global Willowbrook," advocate Holly Burkhalter noted that mainstream human rights organizations have generally ignored the rights of people with mental disabilities, stating, "It's a poor reflection on the well-funded human rights community that these issues have been invisible to us."

In Hungary, MDRI found a long history of people with mental illness or developmental disabilities being permanently institutionalized in psychiatric facilities and social care homes. For the most part, no independent judicial review is available to protect people placed in social care homes. Once people are declared mentally incompetent, they are typically condemned to a lifetime of institutionalization, even though authorities at the homes reported to MDRI that at least 50 percent could live in the community with appropriate support. In fact, model programs have demonstrated that nearly all people with mental disabilities can be integrated into the community.

Perhaps the most horrific example of inhuman and degrading treatment documented by MDRI is that some people in Hungarian and Bulgarian institutions are kept in cages for long periods of time. Although the use of cages in Hungary has declined since the release of MDRI's report, some Hungarian psychiatric professionals have defended the use of cages, and they continue to be used in a number of social care homes. In October 2001, MDRI and a representative from Amnesty International investigated Bulgarian psychiatric facilities and documented the use of cages there. Amnesty has publicly condemned the use of cages in psychiatric institutions as "inhuman and degrading treatment," violating human rights law, and has issued an "Urgent

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Action” letter-writing campaign to call upon the Bulgarian government to end such abuses.

In many countries, institutionalization is life-threatening. With shortages of food and inadequate heat and hygiene, there is a high risk of infectious diseases in psychiatric facilities. In Armenia, MDRI visited an institution that had a 30 percent annual mortality rate—an exceedingly high death rate that cannot be accounted for by the individuals’ disabilities.

Women with mental disabilities have been an especially vulnerable population in many countries due to discrimination on the basis of both gender and disability. Women who have survived violence and trauma in countries such as Kosovo have been improperly detained in institutions because women with psychiatric diagnoses are excluded from community services. In many cases, women are re-victimized by their institutionalization. Laura Prescott, founder of Sister Witness International, and a trauma survivor herself, notes that tying women to beds and using other physical restraints can mimic the circumstances of a

previous sexual assault. As a result of these episodes of re-traumatization, female trauma survivors often are improperly diagnosed with major psychoses, leading to even longer psychiatric institutionalization. Additionally, in a number of countries women face gender-based violence and exploitation by patients and professional staff within institutions; yet women do not have legal recourse against perpetrators or the institutions that fail to protect them.

Children also are particularly vulnerable to abuse. In Russia, MDRI found that 400,000 to 600,000 children are institutionalized, many of whom are mentally or physically disabled or at risk of becoming disabled due to their confinement. Under the Russian discipline of defectology, children are seen as having defects that need to be corrected rather than disabilities that should be accommodated within their communities. Officials report that at least 20 percent of institutionalized children with mental disabilities are permanently confined with physical restraints to their beds in “lying down” rooms and given no treatment. Furthermore, children are severely undernourished and either over-medicated or not provided with needed medication.

### **The Application of the MI Principles in Mexico**

There is no UN human rights convention specific to the rights of people with disabilities. As a result, MDRI reports utilize UN General Assembly resolutions as guidelines for assessing conditions in institutions. In a 1993 law review article, MDRI Executive Director Eric Rosenthal and Physicians for Human Rights Executive Director Leonard S. Rubenstein argued that the 1991 UN General Assembly’s resolution MI Principles should be used as the standard to interpret the general protections against “inhuman and degrading treatment” and “arbitrary detention” as established in the International Covenant on Civil and Political Rights (ICCPR), the European Convention on Human Rights, and the American Convention on Human

Rights (American Convention). Rosenthal and Rubenstein also suggested that failure to meet the MI Principles may violate the right to the highest attainable standard of physical and mental health established in the International Covenant on Economic, Social, and Cultural Rights (ICESCR).

In 1996, the UN Committee on Economic, Social, and Cultural Rights declared in General Comment No. 5 on the ICESCR that the MI Principles should be the basis for interpreting the responsibilities of governments to people with mental disabilities under the Covenant. In particular, the Committee found the failure to provide the opportunity for community integration constitutes a form of discrimination under the ICESCR. General Comment No. 5 also recognized the “Standard Rules on Equalization of Opportunities for Persons with Disabilities” (Standard Rules), adopted by the UN General Assembly in 1993, as a guide for interpreting the ICESCR. The Standard Rules are a significant instrument since the rules recognize the right of people with disabilities to participate at all levels of government in planning, policymaking, and the development of legislation to enact rights

enforcement for people with disabilities. At the UN, international disability groups have pointed to the Standard Rules to demand an increased role in the future development of international human rights law.

Recent developments stemming from MDRI’s investigation of psychiatric institutions in Mexico serve as a case study of the application of the MI Principles and existing conventions, and demonstrate the importance of oversight by regional human rights bodies. MDRI’s report, “Human Rights and Mental Health: Mexico,” brought extensive international attention to the human rights of people with mental disabilities, and in an unprecedented move in March 2000, the Inter-American Commission on Human Rights (IACHR) held hearings on the treatment of people with mental disabilities in Mexico. The hearings addressed the application of international human rights law as it affects people with mental disabilities, including mental illness and developmental disabilities. This marked the first time the IACHR held hearings regarding the treatment of people with mental disabilities within a country’s entire mental health system, demonstrating the barriers that people with mental disabilities, especially those who are institutionalized, face in seeking protection of their human rights.

Following the press attention to MDRI’s findings and the IACHR hearings, the Mexican government agreed to implement significant changes in its mental health system. In November 2000, Mexico closed the Ocaranza Psychiatric Facility, one of its most abusive institutions. With the assistance of MDRI’s adviser, Dr. Robert Okin, Chief of Psychiatry at San Francisco General Hospital, Mexico established some of its first publicly-funded homes allowing people with mental disabilities to live with dignity in an environment integrated into the community. MDRI’s work in Mexico demonstrates how recognition of the

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human rights of a vulnerable population can set the stage for major changes in public and legal understanding of a problem, as well as genuine improvements in the lives of mentally disabled persons.

MDRI's Mexico report was the result of close collaboration between MDRI investigators and grassroots mental disability rights advocates. During its three-year investigation, MDRI and local advocates visited psychiatric institutions in Mexico City and the states of Hidalgo and Jalisco. The MDRI report documented degrading and substandard living conditions, abuse of physical restraints, inadequate staffing, denial of basic medical care, and a lack of legal oversight mechanisms for independent monitoring of abuses and enforcement of rights in institutions. For example, in Ocaranza, a number of patients froze to death due to neglect.

MDRI investigators not only documented extensive examples of inhuman and degrading treatment but also observed that arbitrary detention without due process was the rule for most people confined in these facilities.

Thousands of individuals are detained and subjected to filthy conditions without any privacy. The majority of these individuals will spend their entire lives in isolated institutions, far from their families and friends, despite the fact that even the directors of these institutions report that up to 60 percent of those currently detained in institutions could survive in the community with appropriate support. Families under severe financial burden with no access to respite care, day treatment, professional advice, or consumer groups feel they have no choice but to abandon relatives to live in remote institutions.

MDRI documented especially inhumane conditions at a children's psychiatric facility near Guadalajara. Living in barren rooms furnished only with beds or mattresses on the floor, children were held in restraints for hours at a time—ostensibly to prevent self-abuse—putting them at risk of infection, muscle atrophy, and eventual amputation. Access to physical therapy was insufficient, and as a result, many of the restrained children lost the use of their arms and legs. Left covered in their own urine and feces, and without water in some institutions, both children and adults were susceptible to disease.

Having documented these inhumane conditions, MDRI investigators and local advocates concluded that Mexico's mental health system violates the American Convention, the ICCPR, and numerous sections of the MI Principles. If there are no alternative services in the community, a country such as Mexico is in violation of MI Principle 3, "Every person with a mental illness shall have the right to live and work, as far as possible, in the community," and in violation of MI Principle 7, which establishes the right to treatment in the community. The detention of people in psychiatric institutions due to the lack of community services violates MI Principle 16, which states that individuals may be detained involuntarily in a psychiatric institution only if "[due to mental illness] there is a serious likelihood of immediate or imminent harm to that person

or to other persons." In violation of the MI Principles, the Mexican mental health system relies almost entirely on long-term institutions for the care of its mentally disabled citizens.

These conditions constitute "inhuman and degrading treatment" prohibited by Article 7 of the ICCPR and Article 5 of the American Convention. MDRI investigators also documented the involuntary commitment of individuals to institutions without independent review in violation of MI Principle 17, which holds that no individual shall be involuntarily committed to an institution without the review of an "independent and impartial body." Failure to perform such review also violates Article 13 of the ICCPR and Article 7 of the American Convention prohibiting arbitrary detention.

In response to the international attention focused on Mexico, significant changes have taken place. The closing of the Ocaranza Psychiatric Facility and the creation of community services for its former residents is a model that can be replicated throughout Mexico and other Latin American countries. Mexico's struggle to provide humane treatment for people with dis-

abilities is only one example of the growing movement to end the discrimination undermining the fair treatment and care of people with mental disabilities.

### Shortcomings and Improvements in the Application of International Conventions to the Rights of People with Mental Disabilities

MDRI has called for oversight, reform, and the use of existing international conventions and law to enforce the rights of people with mental disabilities. The Organization of American States recently adopted a new Inter-American Convention on the Elimination of Discrimination against People with Disabilities. This Convention has not yet garnered the requisite ratifications to enter into force. Even without such a specialized convention, grassroots activists have demonstrated the effectiveness of using existing universal human rights documents to argue for more humane treatment of people detained in psychiatric institutions and the right to treatment in the community.

The travesty is that international laws have not been enforced in the case of people with mental disabilities. Even though existing human rights instruments do apply to people with disabilities, the absence of specific references to people with disabilities in general international conventions creates major limitations. States Parties to these conventions are not specifically required to report on the treatment of people with mental disabilities. For instance, lack of specific mention of the rights of people with disabilities has contributed to the impression that these are matters of purely domestic concern. Unfortunately, there is still no binding mechanism requiring countries to report their progress in meeting the standards for the treatment of persons with mental disabilities created by either the MI Principles or the Standard Rules.

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As the international community begins to acknowledge the universal human rights of people with mental disabilities, governments are also learning that community-based care is both more affordable and more humane. In fact, the Inter-American Convention on the Rights of People with Disabilities acknowledges the principle that community integration is an internationally recognized human right. Furthermore, the right to services that would permit community integration has already been established for children with disabilities under Article 23(3) of the UN Convention on the Rights of the Child. A number of non-binding UN General Assembly resolutions also support a right to integration in the community.

Regional organizations have also begun to promote the rights of people with mental disabilities. In 1990, the Pan American Health Organization (PAHO) was the first to establish principles to guide the application of international human rights conventions to persons with mental disabilities. Legislators, mental health professionals, human rights leaders, and disability rights activists from North and South America adopted the 1990 Declaration of Caracas, which states that complete reliance on institutions “imperil[s] the human and civil rights of patients.” The Declaration urges governments and nongovernmental organizations (NGOs) to “promote alternative service models that are community-based and integrated into social and health care networks.”

The development of internationally accepted standards has made it possible for regional bodies to interpret binding international human rights conventions with regard to people detained in psychiatric institutions. In March 1999, the IACHR found in *Victor Rosario Congo*, its first decision regarding mental disability rights, that the MI Principles function as an authoritative guide to the interpretation of the American Convention in the absence of a specialized convention on the rights of people with mental disabilities. In Ecuador, “Mr. Congo, a person with a mental disability, died of ‘dehydration’ in pre-trial detention after he was beaten by a guard, placed in isolation, and denied adequate medical and psychiatric care.” The IACHR held that Congo was subjected to neglect and inhuman and degrading treatment, which violated Article 5 of the American Convention, finding that, “Ecuador’s failure to provide appropriate care for Mr. Congo violated its duty to protect his life under Article 4(1).”

In 2001, the IACHR for the first time conducted a site visit to psychiatric facilities as part of its regular oversight activities, observing conditions in psychiatric institutions in Panama with the assistance of mental health experts from the PAHO. During its visit to National Psychiatric Hospital in Panama, the IACHR documented that more than half the patients in the institution were hospitalized involuntarily. In their June 2001 press release, the IACHR reported that “[t]here were . . . no legal or other entities that were trained, independent, and impartial, nor were there any effective procedures for reviewing the involuntary admission of patients or determining whether the conditions or circumstances for their involuntary admission still existed.” The IACHR’s statement supports MDRI’s findings that human rights violations in psychiatric facilities are common throughout the Americas. The fact that IACHR has conducted a visit to a psychiatric institution as part of its regular oversight activities

is a significant indicator of the incipient increase in international human rights oversight for people with mental disabilities.

### Disability Rights Organizations Call for a UN Convention

In April 2000, the UN Human Rights Committee adopted Resolution 2000/51, calling on all governments to report on the enforcement of the human rights of people with disabilities under existing UN human rights conventions. Although many activists in the disability rights field are encouraged by this development, there is a growing consensus that the rights of people with disabilities will never get the attention they need until a specialized convention on the rights of people with disabilities is established. The International Disability Alliance, a group that represents the six major world disability groups, has called for such a convention. The U.S. National Council on Disabilities, a federal advisory body, also is advocating for a convention. In May 2001, UN High Commissioner for Human Rights Mary Robinson held an open meeting to hear from disability rights activists about the need for improved protections under international human rights law. Developments over the last few years demonstrate that there have been major changes in international thinking regarding the rights of people with mental disabilities. As Rosenthal commented, “[o]ver the last few years, the belief that countries should protect the rights of people with disabilities has gained greater acceptance. And now, the disability rights movement is starting to mobilize at the international level. That changes everything. People with disabilities will not rest until there is a UN convention to protect their rights.”

### Conclusion

Representing over 500 million people worldwide, disability rights organizations are gaining power at the international level. Full recognition of the rights of people with mental disabilities is still emerging as one of the newest goals of the international human rights movement. The importance of such oversight mechanisms and increased advocacy for enforcing the rights of people with mental disabilities cannot be overstated. The work of MDRI and other NGOs demonstrates both the power of utilizing existing international human rights law to press for change and the great need for improved international protections. As advocacy increases and oversight mechanisms improve, there is growing hope that the rights of people with mental disabilities will be more fully protected, and more people with mental disabilities will be able to live and thrive as full participants in their communities. 🌐

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