Human Rights & Mental Health in Peru

A report by:

MENTAL DISABILITY RIGHTS INTERNATIONAL

&

ASOCIACIÓN PRO DERECHOS HUMANOS

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Human Rights & Mental Health in Peru

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MENTAL DISABILITY RIGHTS INTERNATIONAL

Mental Disability Rights International (MDRI) is an advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. MDRI documents human rights abuses, supports the development of mental disability advocacy abroad, assists advocates seeking legal and service systems reforms, and promotes international oversight of the rights of people with mental disabilities in the United States and abroad. Drawing on the skills and experience of attorneys, mental health professionals, human rights advocates, people with mental disabilities and their families, MDRI is forging an alliance to challenge discrimination and abuse of people with mental disabilities worldwide.

ASOCIACIÓN PRO DERECHOS HUMANOS

APRODEH is a collective of people committed to the struggle for the respect of human rights in Peru, organized as a non-profit civil society association. APRODEH was founded in 1983 to support legislative work responding to the growing human rights violations in the context of Peru's armed internal conflict. Over the years, APRODEH has broadened its vision of the human rights situation. APRODEH's work of denouncing human rights violations in defense of victims, and proposing alternatives to violence, has gained recognition from diverse sectors as well as national and international attention.

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Acknowledgments

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Marcel Velásquez Landmann painstakingly translated numerous versions of this report into Spanish. He also contributed valuable insights and observations throughout the report drafting process, as well as substantial emotional support. Marcel's commitment to exposing the abuses against people with mental disabilities in Peru far predates his involvement in this report, with his prior studies and video documentary exposing conditions in a psychiatric facility in Cusco contributing to his voluminous background knowledge on the situation of persons with mental disabilities in Peru.

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Executive Summary

Human Rights & Mental Health in Peru presents the findings of a joint investigatory mission of Mental Disability Rights International (MDRI) and the *Asociación Pro Derechos Humanos* (APRODEH, Association for Human Rights) in October 2002 and February 2003 on the human rights of people with mental disabilities[1] in Peru. During these investigations, the research teams met with a broad array of non-governmental advocacy groups, including human rights organizations, mental disability rights groups, family organizations, the Association of Psychiatrists, communities displaced by political violence, and government representatives. Investigation teams also visited facilities for people with psychiatric and developmental disabilities, a prison ward, the psychiatric units in a social security and a police hospital, and general health services in a rural community. This report assesses Peru's compliance with national and international standards for the treatment of persons with mental disabilities, highlights successful community-integrated programs in Peru, and provides recommendations for reform of mental health and social service systems.

MDRI and APRODEH find a number of serious human rights violations against people with mental disabilities, including: inhuman and degrading treatment in institutions; discrimination in the provision of health and social services; failure to ensure informed consent; and violations of the right to community integration, among others. These violations are the product of several factors, including non-compliance with laws and standards protecting the rights of people with mental disabilities; near-pervasive discrimination, prejudice, and lack of opportunities for people with mental disabilities; insufficient government financing for mental health and social services; and the historical failure to include people with mental disabilities in services planning. While there are a few impressive programs, primarily privately funded and organized initiatives, the government has largely failed to take responsibility for the most basic concerns of people with mental disabilities.

Historically, there has been a dearth of government planning and financing to accommodate the needs of people with mental disabilities in Peru. Available psychiatric care has been institution-based and necessary support services in the community have not existed. The result has left people with psychiatric disabilities either segregated in institutions or abandoned and unable to participate in the economic and social life of their communities. While the great majority of people with mental disabilities are capable of working and establishing a measure of economic independence, they may be unable to do so without essential support systems in the community. Some individuals with intellectual disabilities are also segregated in institutions, while those who remain with their families are largely excluded from schools and denied opportunities for vocational development and work training programs. Individuals with psychiatric disabilities who are denied essential treatment and social supports in the community may not be able to

[1] In this report, the term "mental disabilities" includes: individuals with psychiatric disabilities; individuals with intellectual or developmental disabilities; individuals with no disability who may be subject to discrimination based upon the perception that they have a mental illness or disability; and those who may be subject to discrimination based upon a record or prior history of mental disability.

maintain jobs for which they are otherwise capable. This situation leads to economic and social dependence on families, as well as a risk of homelessness, long-term institutionalization, and increased risk of suicide.

Tremendous potential support exists among Peruvian families of people with mental disabilities. While families are the mainstay for most individuals with mental disabilities, without government support many of these families are left impoverished and socially marginalized. There are several family support groups in Peru for families of persons with mental disabilities. With a small investment, these groups could be a tremendous and low-cost resource for community support and advocacy.

In any population, a sub-class of individuals with mental disabilities will be unable to live with their families. Particularly for people who have experienced physical or sexual abuse at home, it may be dangerous for these individuals to remain dependent on their families. In Peru, there are almost no community-based services that allow people to live independently. People estranged from their families are at a particularly high risk of homelessness and long-term institutionalization, and community-based alternatives must be developed to accommodate these individuals.

In Peru, investigators found that health and social services available to the population at large do not accommodate the special needs of individuals with mental disabilities, leaving these individuals excluded from some of the basic benefits of society accorded to other Peruvian citizens. Public health clinics that have medications for somatic disorders are not equipped with psychotropic medications. Benefits through social security hospitals are arbitrarily limited for people with mental disabilities in a manner that they are not for individuals with other health concerns. Children with mental disabilities are excluded from public education.

Despite the enormous challenges detailed in this report, Peru is a promising country for mental health reform. The Peruvian government has taken steps toward promoting reform, and sectors of Peru's vibrant civil society movement have been organizing in a Coalition for Human Rights in Health to participate actively in this process. In January 2004, the Ministry of Health published new "Guidelines for Action in Mental Health." With the publication of these guidelines, the Ministry of Health endorsed valuable new policies, and entrusted the Mental Health Unit of the General Direction of Health Promotion with their implementation.[2] The Guidelines represent a major step forward as a matter of government policy and an important commitment to mental health reform.

As this report describes, actual practice in the mental health system falls far short of these valuable Guidelines. Along with legal reforms and the creation of human rights oversight and enforcement mechanisms, full implementation of the Guidelines would be an important step toward remedying many of the human rights violations documented in this report. While legal reforms and human rights enforcement will cost little, full

[2] Ministry of Health of Peru, General Direction of Promotion of Health, *Guidelines for Action in Mental Health* (2004) [hereinafter *Guidelines for Action in Mental Health*].

implementation of the Guidelines will require new funding. It is imperative that the government of Peru demonstrate its political will for reforming its mental health services, and dedicate the funding necessary to implement these reforms.

With appropriate supports and services, people with mental disabilities around the world have been successfully integrated into the community and live and work in integrated settings. Under these circumstances, people with mental disabilities have become economically independent, or have made important financial contributions to their own support. It is our sincere hope that the information and recommendations contained in this report will serve to assist policymakers, service providers, stakeholders, and non-governmental organizations to accommodate the needs of people with mental disabilities, and transform Peru into a more inclusive society.

Recommendations

Based on the joint MDRI-APRODEH fact-finding investigations, we issue the following recommendations to the government of Peru:

I. **Create an implementation plan for the *Guidelines for Action in Mental Health*** proposed by the Ministry of Health that includes a timeline for specific steps to be taken by designated government agencies. The plan should also include a detailed budget that will realistically permit effective program implementation. The government of Peru should allocate the resources necessary for the implementation of this plan.

II. **Create a core minimum of services** for people with mental disabilities, in consultation with stakeholders, as part of the public mental health and social service systems. A core minimum of services should include:

A. Community-based family support programs to provide assistance to families of individuals with mental disabilities who are unable to work. In any society, family support is one of the least expensive and most practical ways to support community integration. In Peru, given the strength of family ties, this is a particularly important place to start. Such assistance should be sufficient to support people with mental disabilities and their care-givers with funds needed for adequate:

1. medical care—mental health services should be available to the same extent that physical health services are available, including access to psychotropic medications and subsequent medication management;
2. respite care—a system whereby caretakers of persons with mental disabilities receive needed time to attend to personal business or rest;
3. disability pensions for individuals who cannot work; and
4. cash assistance for caretakers of people with mental disabilities.

Allocating funds to implement article 4 of national Law 27050, which pledges support for families of persons with disabilities,[3] would begin to address some of these needs.

B. Support for the creation and training of consumer or family controlled peer-support programs. In the past decade, programs emphasizing non-professional peer support and focused on a "recovery model" have been an effective and low-cost way to provide an important component of community services to many people with mental disabilities.[4]

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[3] General Law of the Person with Disability, No. 27050 (1998) [hereinafter Law 27050], art. 4.

[4] *See* William Anthony, "Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s," 16 PSYCHOSOCIAL REHABILITATION J. 21 (1993). *See also* Laurie Ahern and Daniel Fisher, Personal Assistance in Community Existence, National Empowerment Center (2003).

C. Accommodations needed to ensure that people with mental disabilities and family members have access to the same medical, social, and educational services available to other Peruvian citizens; this access may include:

1. Assistance with transportation, such as a reduced fare disability bus pass;
2. Volunteer assistive services established through the Offices on Disability in the municipalities to help people with disabilities gain access to basic medical and social services;
3. Access to psychotropic and other psychiatric medications that are not taxed at higher rates than other medications and medications that are subsidized or provided free-of-charge by the government to the extent possible.

D. A system of placement with extended family or foster care for children who are subject to abuse within their own families, or who are abandoned by their families. Foster care, while a necessary alternative, should be used as a last resort, after other options for placement with extended family have been exhausted.

E. Supported living arrangements for persons with mental disabilities who cannot live with their families, or who have been abandoned by their families, or who for whatever reason do not wish to live with their families.

III. Work toward enforcing the right to community-integrated mental health services.

A. Develop community mental health services in existing community health centers, where individuals with mental disabilities can be served in an integrated community setting.

B. Shift care of inpatients able to be served in the community to outpatient clinics and community health centers.

C. Plan for the closure of long-term psychiatric institutions, which segregate people with mental disabilities from the community and inhibit rehabilitation and recovery. As appropriate out patient services and community supports are created, shift resources that had supported these individuals in institutionalized settings to community services.

D. Provide acute care for persons with psychiatric disabilities in general hospitals throughout the country.

E. Provide national identity documents to individuals detained in psychiatric facilities without these documents. Investigators received

reports that there are 180 individuals detained in Victor Larco Herrera Hospital without national identity documents.

IV. End human rights abuses in institutions. Internationally accepted standards for protections of people with mental disabilities in institutionalized settings should be followed to protect against inhuman and degrading treatment.

A. End the use of seclusion and restraint such as that documented at Noguchi Institute. Seclusion and restraint should never be used as a form of discipline or coercion, for staff convenience, or as a substitute for adequate staffing or active treatment.[5] As established in MI Principle 11(11), physical restraint or involuntary seclusion shall be used "only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period strictly necessary for this purpose."[6]

B. End the use of unmodified electroconvulsive therapy (ECT) such as that documented at Noguchi Institute. The administration of ECT without anesthesia and muscle relaxants is no longer considered acceptable in modern psychiatric practice. The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment states, "Apart from the risk of fractures and other untoward medical consequences, the process as such is degrading for both the patients and the staff concerned."[7]

C. Do away with regimented conditions in psychiatric wards that deny basic autonomy, such as those witnessed in Victor Larco Herrera Hospital. Conditions in institutions should be as unrestricted as possible and should maximize opportunities for individual choice about basic aspects of daily life.

D. Plan for the closure of Larco Herrera's mental retardation ward. In the interim, hire an expert in developmental disabilities for the mental retardation

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[5] "Active treatment" as a concept in mental health care refers to:

> an aggressive and organized effort to maximize each client's fullest developmental potential. It requires an integrated, individually tailored plan of services directed to achieving measurable, behaviorally stated objectives. It requires an environment approximating everyday life in mainstream society. The goal is the development of those skills, behaviors, and attitudes essential to independent living in contemporary society . . . .

MICHAEL TRUE, AN INTRODUCTION TO ACTIVE TREATMENT (2003).

[6] *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 119, U.N. GAOR, 46th Sess., No. 49, Annex, at 188-92, U.N. Doc. A/46/49 (1991) [hereinafter *MI Principles*], Principle 11(11).

[7] European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, *The CPT Standards: "Substantive" sections of the CPT's General Reports*, CPT/Inf/E (2002) 1 - Rev. 2003 [hereinafter *The CPT Standards*] *at* http://www.cpt.coe.int/en/documents/eng-standards.doc.

ward at Larco Herrera to provide basic habilitation and occupational therapy, and train staff in providing active treatment for residents, while finding placements in the community.

V. Establish human rights oversight and monitoring for mental health services, both in institutions and in the community.

A. Develop independent oversight and accountability to monitor compliance with national legislation and international human rights principles for persons with mental disabilities, including a system to investigate allegations of abuse that would protect the privacy and safety of victims and witnesses.

B. Create a complaint mechanism, whereby people with disabilities can report abuse in mental health services without fear of reprisals.

VI. Ensure the inclusion of stakeholders in the planning and implementation of medical, mental health, and social services for people with mental disabilities.

A. Reform article 6 of Law 27050, regarding the composition of the National Council for the Integration of Persons with Disability (CONADIS), to include representation of persons with psychiatric disabilities.[8]

B. Fund stakeholder advocacy so that people with mental disabilities and family members have the resources necessary to fully participate in the planning and policy-making process, particularly regarding policies that concern them.

VII. End discrimination in funding and access to health services and education for persons with mental disabilities.

A. Reform the law of Integral Health Insurance to include coverage for mental health services, as called for by the *Guidelines for Action in Mental Health*.

B. Establish parity between social security benefits provided persons with physical ailments and assistance needs, and people with mental health care needs.

[8] Law 27050, *supra* note 3, art. 6. While article 6 of Law 27050 was amended on January 9, 2004 through Law 28164 to include "a representative selected from members of family associations for persons with conduct disabilities," this language does not adequately address persons with psychiatric disabilities. Law Modifying Diverse Articles of Law No. 27050, General Law of the Person with Disability, No. 28164 (2004) [hereinafter Law 28164] art. 6(l). Furthermore, international standards emphasize the importance of self-advocacy by people with disabilities. *See Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, G.A. Res. 96, U.N. GAOR, 48th Sess., U.N. Doc. A/Res/48/96 (1993) [hereinafter *Standard Rules*].

C. **Eliminate policies barring persons with psychiatric disabilities from the Center for Rehabilitation and Professionalism** and other centers and facilities.

D. **Provide inclusive and appropriate education** for children with intellectual disabilities. Integrating children with mental disabilities in mainstream classrooms will require training for teachers, and teachers' aides may be necessary in some classrooms. Peru's educational system should also provide programs in speech pathology, physical therapy, and mental health services to enable children with disabilities to benefit from an education.

VIII. **Provide support for survivors of violence in a manner that includes people with mental disabilities**. There appears to be the greatest consensus in Peru for assisting individuals subject to violence. In part, this stems from an acceptance of the principle that society owes these individuals reparations for their suffering. As a political matter, this consensus may make it possible to build a coalition for the support of services for this population. Practically, the needs of this population have much in common with those of individuals with mental disabilities throughout Peruvian society. A low-cost, culturally-appropriate model for community services should be created for this population.

A. **Create necessary accommodations in community-based trauma counseling programs** to include people with psychiatric and developmental disabilities, instead of referring them to institutions.

B. **Include employment programs and micro enterprise projects** in reparations to promote the economic independence of populations affected by the political violence. Employment is an important component of psychosocial rehabilitation.[9] Employment programs for violence-affected populations would not only help with their economic and social reintegration, but also contribute to the Peruvian economy.

C. **Ensure that mental health programs are trauma-informed and develop trauma-sensitive mental health services** by training health care professionals to recognize trauma and provide appropriate treatment. With Peru's history of armed internal conflict and the prevalence of intra-family violence, health service providers should assume that many people seeking mental health treatment have been subject to trauma. Service providers should be trained to avoid practices that may be retraumatizing for individuals accessing their services.

[9] Psychosocial rehabilitation consists of the joining of a number of forces and programs directed at employing an individual's maximum potential for personal growth toward helping him or her overcome or diminish disadvantages or disabilities in the principal aspects of his or her daily life. *See e.g.,* ORGANIZACIÓN PANAMERICANA DE LA SALUD, REESTRUCTURACIÓN DE LA ATENCIÓN PSIQUIÁTRICA: BASES CONCEPTUALES Y GUÍAS PARA SU IMPLEMENTACIÓN, MEMORIAS DE LA CONFERENCIA REGIONAL PARA LA REESTRUCTURACIÓN DE LA ATENCIÓN PSIQUIÁTRICA, CARACAS, VENEZUELA, 11 AL 14 DE NOVIEMBRE DE 1990, 65 (1991) [hereinafter REESTRUCTURACIÓN DE LA ATENCIÓN PSIQUIÁTRICA].

X. **Support human rights and disability awareness training** for health care professionals and others serving people with mental disabilities through the implementation of Law 27741, which establishes an education policy in human rights and creates a National Plan for its diffusion and teaching.[10] The goals of such training should be to:

A. Combat stigma and prejudice such as that encountered in interviews with mental health services providers and in publications distributed by mental health institutions;

B. Promote recognition of potential for recovery and community integration in the planning and delivery of mental health services;

C. Introduce principles of human rights and patients' choice in the planning and delivery of mental health services.

[10] Law Establishing Education Policy in Human Rights and Creates a National Plan for Diffusion and Teaching, Law No. 27741 (2002) [hereinafter Law 27741]. Art. 3 establishes, "Compulsory education in human rights and international humanitarian law should cover the enforcement and strict compliance with international agreements and conventions; as well as the protection of fundamental rights in the national and international arenas."

Preface: Goals and Methods of this Report

This report documents the treatment of people with mental disabilities in public mental health and social service systems in Peru. The report analyzes this treatment through the lens of Peruvian law and international human rights standards to which Peru has binding obligations, with particular attention to the American Convention on Human Rights (American Convention),[11] the International Covenant on Economic, Social and Cultural Rights (ICESCR),[12] the Convention on the Rights of the Child (CRC),[13] and the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities.[14] This report also examines human rights enforcement through specialized standards adopted by the United Nations General Assembly, such as the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles),[15] the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (the Standard Rules),[16] and the Declaration on the Rights of Mentally Retarded Persons (MR Declaration).[17] Peru's compliance with regional standards such as the Declaration of Caracas[18] and the Recommendation of the Inter-American Commission on Human Rights for the Promotion and Protection of [Persons with Mental Disabilities][19] is also analyzed. Based on this analysis, the report

[11] American Convention on Human Rights, Nov. 22, 1969, 1144 U.N.T.S. 123, O.A.S.T.S. No. 36, at 1, OEA/Ser.L/V/II.23 doc. Rev. 2, 9 I.L.M. 673 (1970) [hereinafter American Convention]. Peru ratified the American Convention on July 28, 1978.

[12] International Covenant on Economic, Social and Cultural Rights, Dec. 16, 1966, 993 U.N.T.S. 3, *entered into force* Jan. 3, 1976 [hereinafter ICESCR]. Peru ratified the ICESCR on July 28, 1978.

[13] Convention on the Rights of the Child, G.A. Res. 44/25, U.N. GAOR, 44th Sess., Supp. No. 49, at 166, U.N. Doc. A/44/25 (1989) [hereinafter CRC]. Peru ratified the CRC on September 5, 1990.

[14] Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities, June 7, 1999, AG/RES. 1608, *entered into force* Sept. 14, 2001 [hereinafter Inter-American Convention on Disability]. Peru ratified the Inter-American Convention on Disability on August 30, 2001.

[15] *MI Principles*, *supra* note 6.

[16] *Standard Rules*, *supra* note 8.

[17] *Declaration on the Rights of Mentally Retarded Persons*, G.A. Res. 2856, U.N. GAOR, 26th Sess., Supp. No. 29, at 99, U.N. Doc. A/8429 (1971) [hereinafter *MR Declaration*].

[18] *Declaration of Caracas* (1990), reproduced in RODRIGO JIMÉNEZ, LOS DERECHOS HUMANOS DE LAS PERSONAS CON DISCAPACIDAD 186 (1996) [hereinafter *Declaration of Caracas*]. In 1990, the Pan American Health Organization (PAHO/WHO) convened mental health organizations, associations, professionals and jurists to the Regional Conference on Restructuring Psychiatric Care in Latin America, held in Caracas, Venezuela. The Declaration of Caracas was adopted in the framework of that Conference.

[19] *Recommendation of the Inter-American Commission on Human Rights for the Promotion and Protection of the Mentally Ill* [sic], INTER-AM. COMM. H.R., 11th Sess., Apr. 4, 2001 [hereinafter *IACHR Recommendation*]. The official English translation of the title of the IACHR Recommendation is incorrect. The Spanish original is entitled "*Recomendación de la Comisión Interamericana de Derechos Humanos Sobre la Promoción y Protección de los Derechos de las Personas con Discapacidad Mental*," which translates as "*Recommendation of the Inter-American Commission on Human Rights for the Promotion and*

details recommendations to bring Peru's mental health and social service system into compliance with international human rights standards. In so doing, the report draws from international experience and local expertise to recommend strategies to complement and build on the resources available in Peru.

The goal of this report is not to cast blame on the numerous mental health care workers in Peru's service system committed to working with people with mental disabilities. Investigators met many compassionate and caring staff who are dedicated to delivering quality services to people with mental disabilities. Further, investigators recognize that conditions in institutions that are harmful to persons with mental disabilities are also harmful to the staff employed there. The need for increased funding for mental health services and social supports, oversight to enforce human rights protections, and enhanced training will benefit staff as well as those receiving services.

MDRI traveled to Peru to help conduct this investigation at the request of APRODEH in October 2002 and February 2003. Members of the October 2002 investigation team included: Alison A. Hillman, Dr. Robert Okin, Liliana Peñaherrera, Mario Rios, Eric Rosenthal, and Alicia Yamin. In February 2003, Hillman, Okin, Peñaherrera, and Rosenthal were joined by Anne Meadows to complete the fact-finding. This report is based on observations from visits to state-run psychiatric hospitals, government-funded social services, community clinics, trauma programs, and primarily privately-funded community-based initiatives for persons with mental disabilities. Investigative teams were unable to visit all mental health programs, and this report is not intended to be an assessment of all such programs. Rather, the report underscores some of the areas for concern in the programs and services visited, lessons from which can be applied to similar programs throughout the country and the continent.

MDRI and APRODEH request that any factual errors or additional relevant information be brought to our attention, including comments, responses, or suggestions for future work. Such comments may be directed to:

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This report has been translated into Spanish. MDRI and APRODEH appreciate any comments regarding or corrections to the translation. If there are any disparities in the contents of the English and Spanish versions, the English language text should be recognized as the official version of the report.

Protection of Persons with Mental Disabilities." This is an important distinction, not only because the English translation disregards the "people first" language of the disability rights movement, but substantively because the identifier "persons with mental disabilities" incorporates a broader array of individuals, not just those diagnosed with a mental illness, as discussed in *supra* note 1.

I. Introduction

Peru is a country with a population of approximately 28 million. During twenty years of armed internal conflict, from 1980-2000, constituting "the most intense, extensive and prolonged episode of violence in the entire history of the Republic,"[20] more than 69,000 Peruvians were killed, leaving thousands more widowed and orphaned.[21] Approximately 5,000 people were forcibly disappeared[22] and 60,000 internally displaced. The region of Ayacucho was particularly hard hit during these two decades, experiencing more than 40% of the reported deaths and disappearances.[23] In 1982, the government declared a state of emergency in Ayacucho and ordered the armed forces to combat subversives throughout the region. As a result, the population was placed virtually under military control, and the government severely curtailed civil and political rights while massive human rights violations were carried out on the population.[24]

In 1990, President Alberto Fujimori was elected to his first term of office and imposed a financial austerity program weeks after assuming the presidency. According to independent information, resulting increases in prices, unemployment, and currency devaluation fueled the insurgency movement, leading to an increase in violence. In April 1992, Fujimori declared an auto-coup, dissolving the legislature, suspending the Constitution, and persecuting opposition politicians. During the repression, a strong independent advocacy movement sprouted in Peru, emphasizing an expanded role for civil society in shaping government policy and human rights enforcement.

Today, Peru's government is in a transition toward democracy, emerging in November 2000 from a decade of authoritarian rule under former President Fujimori. In July 2001, Alejandro Toledo was sworn in as president. Despite Peru's transition toward democracy, the country's economic development has stagnated due to pervasive corruption and the government's failure to address issues of social and economic disparity.[25] High unemployment and underemployment continue, along with a highly

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[20] TRUTH AND RECONCILIATION COMMISSION OF PERU, FINAL REPORT—GENERAL CONCLUSIONS, para. 1 (2003) [hereinafter TRC REPORT] *available at* http://www.aprodeh.org.pe/sem_verdad/informe_final/english/conclusions.pdf.

[21] *Id.* para. 2.

[22] APRODEH, EL RETO DE LA VERDAD Y LA JUSTICIA, PERÚ: 1980-2000, 17 (2001) [hereinafter EL RETO DE LA VERDAD].

[23] TRC REPORT, *supra* note 20, para. 4.

[24] EL RETO DE LA VERDAD, *supra* note 22, at 10.

[25] BBC News UK Edition, *Country Profile: Peru*, (June 30, 2004) *at* http://news.bbc.co.uk/1/hi/world/americas/country_profiles/1224656.stm.

disparate income distribution, in which the poorest 20% of the population receives less than 5% of the national income.[26]

II. Right to Health

A. The right to health in national law

Both national legislation and international human rights standards ratified by Peru contain the right to health for persons with disabilities. Nationally, article 7 of the 1993 Constitution of Peru provides everyone with the right to the protection of health.[27] Article 7 also states that persons with disabilities have the right to respect of their dignity and to legal protections of their rights.[28] Peru's General Health Law, Law 26842, establishes in article II of the introduction, that the protection of health is in the public interest, and that the State has a responsibility to regulate, safeguard, and promote health. Article IV of the introduction states that public health is the primary responsibility of the State, while article V specifically recognizes the State's responsibility to safeguard and attend to problems of mental health and the health of disabled persons, among others, in situations of social abandonment.[29]

In 1998, Peru adopted the General Law of the Person with Disability, Law 27050, which created the National Council for the Integration of Persons with Disability (CONADIS, *Consejo Nacional para la Integración de la Persona con Discapacidad*).[30] The law establishes legal protections, with attention to health, work, education, rehabilitation, social security, and prevention, so that persons with disabilities achieve social and economic development and cultural integration, as provided by article 7 of the

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[26] Economist.com, *Country Briefings: Peru, Workforce and unemployment* (Aug. 16, 2004), *at* http://www.economist.com/countries/Peru/profile.cfm?folder=Profile%2DEconomic%20Structure.

[27] PERU CONST. (1993), art. 7.

[28] *Id.*

[29] General Health Law of Peru, Law No. 26842 (1997) [hereinafter Law 26842], in the preliminary section, note V states: "It is the responsibility of the State to safeguard, prevent and attend to the problems of malnutrition and mental health of the population, environmental health, as well as the health problems of people with disabilities, children, adolescents, mothers and the elderly in situations of social abandonment."

[30] Law 27050, *supra* note 3, art. 5. Law 27050 defines a person with disability as one who:

> has one or more evident deficiencies with a significant loss of one or more physical, mental, or sensory functions, that manifest in the decrease or absence of the capacity to carry out an activity inside margins considered normal, limiting the performance, function or exercise of activities and opportunities to participate equally in society.

Art. 2.

1993 Constitution of Peru.[31] Several articles of Law 27050 specifically provide a right to access health services for people with disabilities. Article 16 provides persons with disabilities a right to access the health services of the Ministry of Health, and specifies that medical, professional, assistant and administrative personnel provide special attention to facilitate the treatment of persons with disabilities.[32] Article 20 addresses health services in State facilities for persons with disabilities, asserting that the purpose of treatment is recovery.[33] Article 21 concerns inclusion in Social Security, and provides that CONADIS will coordinate a special regimen of health benefits, to be assumed by the State, for persons with severe disabilities and in situations of extreme poverty.[34]

In its final provisions, Law 27050 states that norms of international conventions signed by Peru on rights and obligations pertaining to persons with disabilities form part of Law 27050 and its regulations, to the extent that these obligations are consistent with Peru's constitution.[35] Based on these rights established through national legislation, and the fundamental rights guaranteed to all human beings in international human rights conventions, as described below, Peru is not meeting its obligations to its citizens with mental disabilities.

B. The right to health in international instruments

Peru has also ratified international instruments providing a right to health. Article 12 of the ICESCR provides "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[36] This "right to health" has been interpreted as an obligation that governments implement public health policies that provide "equality of opportunity for people to enjoy the highest attainable level of health"[37] through progressive realization of the right to health, meaning "that States parties have a specific and continuing obligation to move as expeditiously and effectively

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[31] *Id.* art. 1. PERU CONST. of 1993, art. 7 reads:

> Everyone has the right to the protection of their health, the health of their family and of the community, as well as the duty to contribute to its protection and defense. Persons incapacitated, either physically or mentally, have the right to respect of their dignity and to a legal regime of protection, attention, re-adaptation and security.

[32] Law 27050, *supra* note 3, art. 16.

[33] *Id.* art. 20.

[34] *Id.* art. 21.

[35] *Id.* 1ª disposición final. S*ee, e.g.*, ICESCR, *supra* note 12, art. 12. Inter-American Convention on Disability, *supra* note 14. CRC, *supra* note 13, art. 23, § 2-3.

[36] ICESCR, *supra* note 12, art. 12

[37] Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, 22nd Sess., U.N. Doc E/C.12/2000/4 (2000) [hereinafter *General Comment No. 14*], para. 8.

as possible towards the full realization" of the right to health.[38] Despite Peru's economic hardships, the UN Committee on Economic, Social, and Cultural Rights has recognized that the obligation of governments to protect their most vulnerable populations takes on increased importance in times of economic difficulties.[39]

The Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights,[40] also known as the "Protocol of San Salvador," establishes the right to health in article 10.[41] Similar to the language of the ICESCR, the Protocol states that the right to health is "understood to mean the enjoyment of the highest level of physical, mental and social well-being."[42] To ensure the exercise of the right to health, States Parties agree to adopt measures to guarantee access to primary health care, health services, universal immunization, prevention and treatment of disease, health education, and the fulfillment of the health needs of vulnerable groups.[43] Article 18 of the Protocol, addressing the situation of persons with disabilities, provides that persons with disabilities are entitled to "special attention" designed to help them achieve their greatest possible personal development.[44]

The Convention on the Rights of the Child (CRC) likewise provides that special assistance be afforded children with disabilities and their families.[45] This assistance should, whenever possible, be available free of charge, and should ensure that children with disabilities have "effective access to and receive[s] education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the *fullest possible social integration* and individual development, including his or her cultural and spiritual development."[46]

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[38] *Id.* para. 31.

[39] Committee on Economic, Social and Cultural Rights, *General Comment No. 5, Persons with disabilities,* 11th Sess., Supp. No. 2, U.N. Doc E/C.12/1994/13 (1994) [hereinafter *General Comment No. 5*], para. 10.

[40] Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, Nov. 17, 1988, O.A.S.T.S. No. 69 (1988), 28 I.L.M. 156 (1989), *entered into force* Nov. 16, 1999 [hereinafter Protocol of San Salvador], *available at* http://www.cidh.org/Basicos/basic5.htm, *reprinted in* BASIC DOCUMENTS PERTAINING TO HUMAN RIGHTS IN THE INTER-AMERICAN SYSTEM 65, OAS Doc. OEA/Ser.L.V/I.4, rev.8 (2001) [hereinafter BASIC DOCUMENTS]. Peru ratified the Protocol of San Salvador on June 4, 1995.

[41] *Id.* art. 10.

[42] *Id.* art. 10(1).

[43] *Id.* art. 10(2).

[44] *Id.* art. 18.

[45] CRC, *supra* note 13, art. 23, § 2-3.

[46] *Id.* art. 23 § 3 [emphasis added].

C. Increased funding for health needed

Despite the fact that Peru has committed to guaranteeing the right to health through its constitution, legislation, and the ratification of international human rights treaties, in practical terms the government has not followed through on this commitment. As recognized by the United Nations Special Rapporteur for Health, "In recent years spending in health has decreased in real terms, as a percentage of the national budget and as a percentage of the GDP."[47] Peru's annual health expenditures are also below the average health budgets of the other countries in the region.[48] Investigators found that few, if any, Peruvians with mental disabilities have access to the health services and supports guaranteed through Peru's national laws and international treaty obligations. Meanwhile, the government invests a considerable amount of its limited public resources in institution-based care, resources that could be used to establish community-integrated programs, which would help bring Peru into compliance with international human rights standards. MDRI and APRODEH join the Special Rapporteur in his emphatic recommendation that the government attack the decrease in health spending, and invest significant financial resources for health policies directed toward the poorest Peruvians. Such resources for health care should be administered based in principles of equality, and should be fully accessible to and inclusive of people with mental disabilities.

III. Human Rights Abuses

MDRI and APRODEH investigators documented egregious abuses against people with mental disabilities in Peru's psychiatric institutions, including inhuman and degrading conditions such as: the improper use of seclusion; the dangerous use of unmodified electro-convulsive therapy; the failure to ensure informed consent; and detention in bleak, barren wards where people are kept in total inactivity for years.

A. Segregation in Institutions

There are three government-supported psychiatric hospitals in Lima: Victor Larco Herrera Hospital (Larco Herrera), Hermilio Valdizán Hospital (Valdizán), and the National Institute of Mental Health "Honorio Delgado – Hideyo Noguchi" (Noguchi Institute). These hospitals have combined annual budgets of more than 15 million US dollars. The directors of these hospitals informed investigators that the average stays for "acute" patients range from 30-45 days. At both Larco Herrera and Valdizán hospitals, "chronic" patients receive what amounts to custodial care: psychotropic medications, limited in-hospital activities, and almost no chance of discharge. As a result, many chronic patients remain institutionalized for life.

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[47] Relator Especial de Naciones Unidas sobre el derecho de toda persona al disfrute del más alto nivel posible de salud física y mental, Resumen de recomendaciones provisionales, Misión al Perú, 7-15 junio 2004 [hereinafter Rapporteur's Provisional Recommendations], para. 18.

[48] *Id.*

1. Victor Larco Herrera Hospital

Victor Larco Herrera Hospital, founded in 1918, is the largest and oldest psychiatric hospital in Lima. During the MDRI-APRODEH October 2002 visit, Larco Herrera had 580 inpatients. According to psychiatrist Dr. Jose Ortiz, the hospital has 600 new admissions a year, and conducts approximately 3,200 consultations. The hospital has an annual budget of close to 10 million US dollars.[49] According to a pamphlet published in 1999 describing the institution, Larco Herrera has 800 employees, including psychiatrists, psychologists, nurses, social workers and administrative personnel.[50]

Larco Herrera's psychiatric services are divided into two departments, with wards for "acute" and "chronic" patients.[51] The "acute" patients, comprising approximately 40% of the patient population, are generally people who enter the hospital in crisis and stay "no longer than six weeks."[52] "Chronic" patients are those who have more protracted hospitalizations, many of whom have lived at the hospital ten, twenty, thirty years, or longer.[53]

Investigators toured both acute and chronic wards, and found conditions in the acute ward to be appreciably better than those in the chronic ward visited. In the women's acute ward, there were on average ten beds to a room, with cabinets to store personal belongings. Bathrooms were clean, and bathroom stalls had doors. There was music playing and some people dancing in one room, while others wandered the halls or lay in bed. Investigators observed one woman tied to a bed; psychiatrists claimed that she was aggressive.

In the men's chronic ward visited, conditions were stark, the bathrooms filthy, and severe regimentation denied patients' basic autonomy. Upon arrival, all 80 patients were seated along opposite sides of the corridor on long wooden benches. The approximately 40 patients down the left side of the wall were wearing identical grey sweat suits with the number four spray painted on the hip and chest. Spray painting the ward number on clothing is a common way for institutions to identify to which ward communal clothing needs to be returned.

Contrary to article 5 of the American Convention on Human Rights, guaranteeing the Right to Humane Treatment, bathrooms in this ward were filthy and the stench of raw

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[49] Interview with Dr. Jose Ortiz, Psychiatrist at Larco Herrera Hospital (Oct. 18, 2002) [hereinafter Interview with Dr. Ortiz].

[50] HOSPITAL VICTOR LARCO HERRERA, BREVE RESEÑA HISTORICA DEL HOSPITAL "VICTOR LARCO HERRERA" 1918-1999 (1999).

[51] Interview with Dr. Jose Ortiz, *supra* note 49. Dr. Ortiz informed MDRI investigators that this division is "an administrative concept."

[52] *Id.*

[53] *Id.*

sewage permeated the air. There was excrement and urine on the floors of the bathrooms and in and around the "stalls"—stations with holes in the floor. In contravention of the Right to Privacy under article 11 of the American Convention and MI Principle 13, bathrooms lacked doors or other means of ensuring privacy. The common showers also had no doors or other means of safeguarding privacy. The ward's rooms likewise afforded no modicum of privacy. Most rooms were large, stark, and barren, consisting only of two long rows of beds with twenty-two or twenty-five beds to a room. There was no other furniture or place to store personal items in these rooms.

During a 45-minute tour of the ward, patients were left sitting on the benches, exactly as they had been when investigators entered. When investigators asked why the patients were sitting idly, Dr. Ortiz said that they were seated there to enable the investigators to ask them questions.[54] When investigators requested that they be allowed to resume their normal activities, the men were marched, single file, to the dining room, where they washed their hands, one by one, in a regimented fashion, before sitting down to eat lunch.

Investigators observed little rehabilitation taking place at Larco Herrera. Dr. Ortiz claimed that if he discharges twelve patients a year he considers it a victory.[55] According to participants in a Pan American Health Organization (PAHO) workshop in Lima on Mental Health and Human Rights in October 2002, there are 180 people interned at Larco Herrera without national identity papers.[56] With no identity documentation, these individuals are destined to remain institutionalized for the remainder of their lives and unable to receive the types of supports that could help them transition to the community.

a. Institutionalization of people with cognitive disabilities

In Larco Herrera's ward for persons with mental retardation, MDRI and APRODEH investigators witnessed pervasive neglect and a lack of any habilitative programming. Institutionalization is particularly inappropriate for persons with cognitive disabilities, as these individuals can frequently be supported to live a safe and dignified life in the community. Further, the dangers of institutionalization are especially great for this population as they are the most vulnerable to abuse and neglect. Investigators witnessed conditions in Larco Herrera's "mental retardation ward" that illustrated vividly this neglect. In the ward's concrete patio, five individuals lay on their backs, rolling from side to side, one naked from the waist down. Another individual lay in the corridor of the main building in a puddle; three others were rolled into fetal positions, lying on the lawn; two more sat rocking in wheelchairs against a wall, their pants wet. Patients' clothing in this ward was also substandard. Investigators observed patients with clothing rotting off their bodies, pants in tatters, and shirts with gaping holes in the sleeves. In an hour-long

[54] *Id.*

[55] *Id.*

[56] Information from participants in the PAHO workshop, "Promoción y Protección de los Derechos Humanos y Libertades Fundamentales de las Personas con Discapacidades mentales y sus Familias," October 25-26, 2002.

interview with the ward psychiatrist and the hospital's director, investigators never obtained a clear answer regarding the habilitative activities offered by the hospital. Attempting to explain the lack of habilitation, the treating psychiatrist stated that the individuals in wheelchairs were incapable of any habilitation, and that there was nothing to do but leave them against the wall in their wheelchairs.[57]

The institutionalization of people with cognitive disabilities in Larco Herrera's mental retardation ward violates international human rights principles. The MI Principles state that individuals may only be detained in a mental health facility if they are diagnosed with a mental illness[58] "in accordance with internationally accepted medical standards."[59] The MR Declaration and the Declaration on the Rights of Disabled Persons state that persons with mental retardation should live with their own families, or with foster families, whenever possible.[60] In the event that living with families could be deemed not possible for those individuals detained in Larco Herrera's mental retardation ward, the inhuman and degrading conditions and lack of habilitative treatment clearly violate principles established in these declarations for an environment and conditions 'as close as possible to normal life.'[61]

2. Hermilio Valdizán Hospital

Hermilio Valdizán Hospital was opened in 1961, with 20-25 chronic patients transferred from Larco Herrera to "found" the hospital.[62] According to Valdizán's director, Dr. Jaime Jiménez Hernández, the hospital operates with 250 beds, which, at the time of MDRI's February 2003 visit, were 90% occupied. Dr. Jiménez informed investigators that the average stay for inpatients is between 30 and 45 days, with the average stay in the emergency clinic between two to three days.[63] Approximately 85% of the patients admitted to the emergency clinic are interned for a 30-45 day stay.[64]

The facility appeared clean but most patients seem to have succumbed to the pervasive inactivity in the hospital, wandering aimlessly around the grounds, or sitting on

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[57] Interview with psychiatrist in mental retardation ward, Larco Herrera Hospital (Oct. 2002).

[58] *MI Principles*, *supra* note 6, principle 16.

[59] *Id.* principle 4(1).

[60] *MR Declaration*, *supra* note 17, principle 4. *Declaration on the Rights of Disabled Persons,* G.A. Res. 3447, U.N. GAOR, 30th Sess., Supp. No. 34, at 92, U.N. Doc. A/10,034 (1975) [hereinafter *Declaration on the Rights of Disabled Persons*], art. 9.

[61] *Id.*

[62] Interview with Dr. Jaime Jiménez Hernández, Director, Hermilio Valdizán Hospital (Feb. 12, 2003) [hereinafter Interview with Dr. Jiménez].

[63] *Id.* Dr. Jiménez noted that, five to ten years ago, the average stay was closer to 90 days.

[64] *Id.*

benches, while technicians and nurses crowded around nurses' stations, talking among themselves. As investigators toured the grounds, some technicians attempted to remove patients from the patches of grass where they were lying. Dr. Jiménez admitted that the hospital's department of rehabilitation is "limited," and that, in reality, the programs are just an attempt to keep patients occupied. Programs where real rehabilitation and therapy take place, he said, "are just a dream."[65]

Dr. Jiménez explained that the hospital does not give any medications to a patient until a social worker has conducted an economic assessment that the family cannot afford to pay for medications. "In principle, every patient receives medication," he stated, "if not, we would just be a hotel."[66] The hospital has no budget to provide medicines to patients once they are discharged, and Dr. Jiménez admitted that the lack of support for patients to afford medications on an out-patient basis is one of the causes of relapse, which turns the hospital into a revolving door.[67]

Valdizán has no program for appropriate outplacement of discharged patients. When MDRI and APRODEH investigators asked Dr. Jiménez where patients go when they are released from the hospital, he responded, "I have no idea."[68] During a meeting with the Peruvian Psychiatric Association in October 2002, one psychiatrist reported that 40% of the patients at Valdizán Hospital are "*abandonados*"—individuals abandoned by their families—and "do not need to be hospitalized."[69]

The environment at both Larco Herrera and Validizán is unsuitable for rehabilitation and not conducive to recovery. The social isolation that is a byproduct of institutionalization results in a breakdown of ties to family and the community.[70] The MI Principles emphasize that individuals treated at mental health facilities "shall have the right to return to the community as soon as possible,"[71] and that treatment "shall be directed towards preserving and enhancing personal autonomy."[72] The Declaration of Caracas recognizes that psychiatric hospitals, as the sole response to mental illness, hinder the achievement of effective mental health care, as they:

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[65] *Id.*

[66] *Id.*

[67] *Id.*

[68] *Id.*

[69] Meeting with the Peruvian Psychiatric Association (Oct. 22, 2002).

[70] This social isolation is described in ERVING GOFFMAN, ASYLUMS: ESSAYS ON THE SOCIAL SITUATION OF MENTAL PATIENTS AND OTHER INMATES (1961).

[71] *MI Principles*, *supra* note 6, Principle 7(2).

[72] *Id.* Principle 9(4).

(a) isolate the patient from society, creating greater social disability;
(b) create unfavorable conditions that put the human and civil rights of the patient at risk;
(c) absorb the bulk of financial and human resources allotted mental health care; and
(d) fail to provide professional training that is adequately geared to the mental health needs of the population, the general health services, and other sectors.[73]

The Declaration also notes that traditional psychiatric services do not allow for objectives compatible with mental health attention that is community-based, decentralized, participatory, integral, continuous, and preventative.[74]

3. Noguchi Institute

Noguchi Institute, founded in 1982, has services for both adults and children, although children are treated strictly on an outpatient basis. The Institute, serving a population of approximately three million, treats an average of 200 outpatients a day, and the adult ward treats 150 inpatients. According to the hospital's Director, Dr. Héctor Tovar Pacheco, Noguchi has a policy of "no institutionalization," although five percent of the patients remain "long term." The average stay at the hospital is 45 days.[75]

Noguchi Institute, in contrast to Larco Herrera and Valdizán, appeared clean and well-staffed, with a noteworthy occupational therapy program. One of the successes of this program is that it integrates inpatients and outpatients, allowing those being treated in the hospital to interact and socialize with their peers who live in the community. Such integration provides hope to inpatients that community reintegration is possible, and develops vital peer support links between inpatients and outpatients. While Noguchi's occupational therapy programming is noteworthy, it would be even more effective if it were integrated into the community, and not on the grounds of the institution. Noguchi Hospital operates seven community outreach clinics in Lima, and three psychiatrists rotate to serve these seven clinics. The clinics provide counseling and psychotropic medications, but are not connected with a broader array of community services and supports.

Noguchi also has a limited rehabilitation program. The program is capable of serving seven patients at a time for a period of three months. While the small number of patients ensures individual attention, three months' rehabilitation may be insufficient to ensure that an individual who has experienced an emotional crisis is ready to return to the demands of daily life. Elena Sabán, a member of ALAMO, a combined family and user

[73] *Declaration of Caracas, supra* note 18, introductory note 2.

[74] *Id.* introductory note 1.

[75] Interview with Dr. Héctor Tovar Pacheco, Executive Director, Noguchi Institute (Oct. 18, 2002) [hereinafter Interview with Dr. Tovar].

support group, informed investigators that many patients, upon graduation from the program, relapse for lack of continued community supports.[76] Many of those being treated as inpatients at Noguchi appeared to be high functioning and could be treated effectively in the community, if appropriate services and supports were created.

a. Dangerous use of seclusion

Investigators documented inappropriate use of seclusion rooms at Noguchi Institute. A patient detained in one of the seclusion rooms appeared over drugged, his eyelids heavy and drool dripping from his mouth. He was banging a plastic cup against the seclusion room door and pleading, almost incoherently, for water. Investigators informed staff at the nursing station a few feet away, and within sight, that the individual in detention wanted water. Staff responded that they would get to it, and continued talking among themselves. Dehydration is a real danger for individuals placed in long-term seclusion. A psychiatrist in the acute ward at Noguchi informed investigators that patients spend an average of one week in seclusion for aggressive behavior. When an MDRI investigator expressed concern that detaining patients for a week in seclusion contravenes international standards, the psychiatrist revised his answer, stating that patients spend an average of two days in isolation, and a week at the longest.[77]

The MI Principles provide that physical restraint or involuntary seclusion:

> [S]hall not be employed except in accordance with the officially approved procedures of the mental health facility and only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose.[78]

The MI Principles require that "all instances" of seclusion and restraint be documented in a patient's medical record, as well as the reasons for, nature, and extent of usage, so that strict controls may be established. Seclusion and restraint should never be used as a form of discipline or coercion, for staff convenience, or as a substitute for adequate staffing or active treatment.[79] Given the dangers associated with the use of improper seclusion and restraint, including the risk of serious injury or death, retraumatization of people who have a history of trauma, and loss of dignity and other psychological harm,[80] the implementation of these safeguards is essential.[81]

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[76] Interview with Elena Sabán (Feb. 2003).

[77] Interview with treating psychiatrist, Noguchi Institute (Oct. 18, 2002).

[78] *MI Principles*, *supra* note 6, Principle 11(11).

[79] National Association of State Mental Health Program Directors, *Position Statement on Seclusion and Restraint* (visited Nov. 24, 2003) *at* http://www.nasmhpd.org/posses1.htm.

[80] *Id. See also* Wanda K. Mohr, et al., *Adverse Effects Associated with Physical Restraint*, 48 CAN. J. PSYCHIATRY 5 (2003).

b. Improper use of ECT

Investigators also documented improper use of electroconvulsive therapy (ECT) as a substitute for medications where the medications were deemed too expensive. The treating psychiatrist at Noguchi Institute informed investigators that unmodified ECT—without anesthesia or muscle relaxants—was substituted for medications two or three times per week.[82] According to the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), the administration of ECT without anesthesia and muscle relaxants is no longer considered acceptable in modern psychiatric practice. The CPT states, "Apart from the risk of fractures and other untoward medical consequences, the process as such is degrading for both the patients and the staff concerned."[83] While administering ECT in accordance with appropriate safeguards is a recognized treatment for severe depression, it is potentially dangerous, and frequently causes short term memory loss. ECT's use should be restricted to situations in which its efficacy has been clearly demonstrated and always in accordance with appropriate protocols (anesthesia and muscle relaxants).[84]

B. Failure to ensure informed consent

Peru's General Health Law, No. 26842, establishes the right to informed consent. Article 15 maintains that consumers of health services have the right, "To be informed of all of the necessary information to ensure informed consent, before any procedure or treatment, as well as the right to deny such treatment."[85] Complete and continuous information should be provided in comprehensible terms about the procedure, including the diagnosis, prognostic, and treatment alternatives, as well as the risks, necessary precautions, and warnings of the medications that are prescribed and administered.[86]

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[81] The World Health Organization has published a useful reference, *Guidelines for the Promotion of Human Rights of Persons with Mental Disorders*, which includes the text of the MI Principles, "immediately followed by a series of relevant questions intended to guide those interested in verifying the extent to which each Principle is applied." WHO, *Guidelines for the Promotion of Human Rights of Persons with Mental Disorders*, at vi, WHO/MNH/MND/95.4 (1996) [hereinafter *WHO Guidelines*] *available at* http://whqlibdoc.who.int/hq/1995/WHO_MNH_MND_95.4.pdf. For Guidelines on the use of physical restraint and involuntary seclusion, *see id.* pp. 26-27.

[82] Interview with treating psychiatrist, Noguchi Institute (Oct. 18, 2002).

[83] *The CPT Standards*, *supra* note 7.

[84] *Id. See also* AMERICAN PSYCHIATRIC ASSOCIATION, THE PRACTICE OF ELECTROCONVULSIVE THERAPY: RECOMMENDATIONS FOR TREATMENT, TRAINING AND PRIVILEGING 133-34 (2nd ed. 2001). *See also* Christopher Hummel, Electroconvulsive Therapy (ECT) procedure and consequences of unmodified treatment (Jan. 2003) (unpublished article on file with author).

[85] Law 26842, *supra* note 29, art. 15(h).

[86] *Id.* art. 15(g).

There is a common misperception in Peru, even among human rights advocates, that family members are appropriate persons to make treatment decisions for individuals with mental illness. In many instances, the family is seen as the spokesperson and guardian of rights for their family members with psychiatric diagnoses. A representative from the disability office within the Human Rights Ombudsman's office commented that persons with mental disabilities "do not need independent rights; they have their families to speak for them."[87]

Valdizán Hospital has a policy of not treating individuals who do not arrive with a family member. Valdizán's director, Dr. Jiménez, explained that "the law forbids us" from attending to people who arrive without family.[88] In the emergency clinic there is a sign displayed prominently in the entrance, "Note: Remember that all new patients should come to the appointment with a family member. Thank you."

Noguchi Institute also has a policy that those seeking treatment must arrive with a family member or someone responsible for them.[89] Testimonials published in a diagnostic study of the mental health programs operated by Noguchi give insight into this policy. The study points out that mental health personnel place greater credence in information provided by family members than that provided by patients and that this is the reason that family involvement in the consultations is such an important element in treatment.[90] At Noguchi, investigators also documented that ECT was being used as a treatment for a 16 year-old young woman who had complained of sexual abuse by her grandfather. Family members, who did not believe her allegations, had authorized her to receive ECT.[91]

From a human rights perspective, with emphasis on the importance of autonomy and self-determination, consent by family members for treatment is insufficient. While it is perfectly acceptable if the individual receiving treatment decides to rely on family members for support in making decisions, autonomy requires that it be the individual's desires that prevail and not those of the family. The MI Principles state that an individual's family members cannot consent to treatment or to the waiver of any of an individual's rights. Under principle 1(6), a personal representative may be appointed for an individual who lacks capacity for a certain decision, only after a hearing before an

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[87] Conversation with Human Rights Ombudsman's attorney from the office on disability (Oct. 17, 2002).

[88] Interview with Dr. Jiménez, *supra* note 62. According to attorneys in Congressperson Javier Diez Canseco's office, there is no national legislation requiring persons with psychiatric disabilities to be accompanied by a family member at appointments; they surmised that this was an internal policy of Valdizán Hospital.

[89] *See* Serie: Monografías de Investigación No. 8, Diagnostico Situacional de la Salud Mental en el Distrito de Independencia (2000), at 166, 171 [hereinafter Diagnostico Situacional].

[90] *Id*. at 171.

[91] Information gathered by investigators during visit to Noguchi Institute (Oct. 18, 2002).

"independent and impartial tribunal," at which a patient has a right to counsel.[92] Informed consent requires that patients receiving psychiatric treatment be informed about their diagnoses, as well as the purpose, method, likely duration, and expected benefits of the proposed treatment.[93] Patients must also be made aware of available alternatives to, and possible side effects of, the proposed treatment.[94] Patients have the right to refuse treatment. Although this right under the MI Principles is not absolute, it can only be limited by review of an independent authority, which must find the person lacks capacity to consent, and determine that the "proposed plan of treatment is in the best interest of the patient's health needs."[95] Furthermore, the MI Principles provide that patients have the right to an individualized treatment plan that they must be able to discuss with a qualified member of the treatment staff.[96]

C. Human rights oversight and monitoring

People detained in psychiatric institutions and other facilities are particularly vulnerable to human rights abuses as they are dependent upon these institutions for their basic needs and medical care, and these facilities control their access to the outside world. These factors make it difficult for people detained in institutions to report abuses, both because of issues of access and because they may fear reprisals for speaking out. When they do speak out, they are usually seen as lacking credibility because of their psychiatric diagnosis. Thus, as documented in this report, human rights abuses can go undocumented and unaddressed for years, and human rights oversight and monitoring is needed to ensure the protection of the rights of people detained in institutions.

International human rights standards require that the state ensure the safety and well-being of those in detention.[97] MI Principle 22 requires that:

> States shall ensure that appropriate mechanisms are in force to promote compliance with these Principles, for the inspection of mental health facilities, for the submission, investigation and resolution of complaints and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient.[98]

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[92] *MI Principles*, *supra* note 6, principle 1(6).

[93] *Id.* principle 11(2).

[94] *Id.*

[95] *Id.* principle 11(6)(c).

[96] *Id.* principle 9(2).

[97] American Convention, *supra* note 11, article 1 (requiring that states ensure treaty-based rights).

[98] *Id.* principle 22.

The Inter-American Commission on Human Rights (IACHR) also recommends that States undertake initiatives through the Human Rights Ombudsman's office to protect the human rights of people with mental disabilities.[99] The IACHR calls on States to "Support the establishment of organs that supervise compliance with human rights norms in all psychiatric care institutions and services."[100] Such organs should involve consumers, family members, representatives of consumers, and mental health workers.[101]

In the provisional recommendations from his trip to Peru in July of 2004, the UN Special Rapporteur for Health, Paul Hunt, likewise recommends that independent mechanisms of monitoring and oversight for mental health services be implemented, including efficient mechanisms for receiving patient complaints.[102] "The development and launching of these mechanisms should include the participation of consumers and family representatives," Hunt recommends, adding, "An oversight board should be established to undertake periodic inspections of mental health facilities, including patient interviews. The monitoring mechanisms should likewise include an independent, regular, and systematic revision of cases of admission and involuntary treatment."[103]

IV. Right to Community Integration

A. International standards on the right to community integration for persons with mental disabilities

Community integration is an internationally recognized right of persons with mental disabilities. The Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities states that the Convention's objectives are "to prevent and eliminate all forms of discrimination against persons with disabilities and to promote their full integration into society."[104] Article IV, section 2(b), specifies that the States parties are to collaborate in "[t]he development of means and resources designed to facilitate or promote the independence, self-sufficiency, and total integration into society of persons with disabilities, under conditions of equality."[105]

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities specify that "Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need

[99] *IACHR Recommendation*, *supra* note 19, para. 5.

[100] *Id.* para. 7.

[101] *Id.*

[102] Rapporteur's Provisional Recommendations, *supra* note 47, para. 34.

[103] *Id.*

[104] Inter-American Convention on Disability, *supra* note 14, art. II.

[105] *Id*. art. IV, § 2.

within the ordinary structures of education, health, employment and social services." [106] The MI Principles provide that "Every person with a mental illness shall have the right to live and work, as far as possible, in the community."[107]

The Declaration on the Rights of Mentally Retarded Persons states that a person with a cognitive disability "should live with his own family or with foster parents and participate in different forms of community life."[108] The Declaration on the Rights of Disabled Persons provides, "Disabled persons have the right to live with their families or with foster parents and participate in all social, creative or recreational activities."[109] Both the MR Declaration and the Declaration on the Rights of Disabled Persons state that if care in a specialized setting is indispensable, then the environment and conditions of such a setting shall be "as close as possible" to those of "normal life."[110]

The Declaration of Caracas, which establishes standards for protecting human rights and mental health, also recognizes the right to community integration.[111] Article 1 provides, "[t]hat the restructuring of psychiatric care on the basis of Primary Health Care and within the framework of the Local Health Systems Model will permit the promotion of alternative service models that are community-based and integrated into social and health care networks."[112] Article 3(c) provides, "That the resources, care and treatment that are made available must . . . strive to ensure that patients remain in their communities."[113]

Despite these international standards, for the vast majority of individuals with mental disabilities in Peru the right to community integration remains an unfulfilled principle. MDRI and APRODEH investigators observed hundreds of people with mental disabilities who have been detained in psychiatric institutions for years, improperly segregated from society. Investigators also observed people with mental disabilities living with their families, but effectively segregated from society. Without services or supports for families and individuals with mental disabilities in the community, people with mental disabilities have no meaningful opportunity to participate in society.

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[106] *Standard Rules*, *supra* note 8, Introduction, para. 26.

[107] *MI Principles*, *supra* note 6, Principle 3.

[108] *MR Declaration*, *supra* note 17, art. 4.

[109] *Declaration on the Rights of Disabled Persons*, *supra* note 60, *art*. 9.

[110] *Id. MR Declaration, supra* note 17, art. 4.

[111] *Declaration of Caracas*, *supra* note 18.

[112] *Id,* art. 1.

[113] *Id.* art. 3(c).

V. Implementing the Right to Community Integration

A. Community integration and the role of the family

Families can play an important role in achieving community integration, but without appropriate services and supports families will be unable to facilitate the effective community integration of their family members with disabilities. Peru's General Law of the Person with Disability (Law 20750) pledges an array of supports to families of persons with disabilities.[114] Article 4 identifies the family as playing an essential role toward achieving the objectives of the law, and establishes that the state will offer the family integrated training in education, sports, health, and incorporating family members with disabilities into the labor force.[115] Despite Law 27050, families of persons with disabilities receive little or no government support. Families could benefit greatly from training in facilitating the rehabilitation of and care for their family members with disabilities, as well as provisions for respite care, and other services, as called for by article 4.

B. Alternatives to the family needed

Notwithstanding the care and support provided by many families for their family members with disabilities, alternatives to the family must be created to ensure that those who cannot live with their families, or who have been abandoned by their biological families, also have opportunities to live in the community. The nature of mental illness itself may sometimes contribute to the alienation of the individual with the illness from the family. In any society, some individuals with mental disabilities experience abuse and neglect within their families, contributing to their illness. Peru has an alarming rate of intra-family violence.[116] Alternatives must be created so that individuals experiencing violence at home, or leaving a mental health treatment facility, are not placed back into the home where violence or sexual abuse contributed to the deterioration of the individual's mental health.

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[114] Law 27050, *supra* note 3, art. 4, regarding the Role of the Family and the State reads:

> The family plays an essential role in achieving the actions and objectives of this Law. The State will offer the family integral training (in the areas of education, sports, health, and incorporation into the workforce, etc.) to attend to the presence of some disability in one or various family members.

Not official translation.

[115] *Id.* art. 4.

[116] According to one study conducted of metropolitan Lima, 52.3% of parents admitted to physically abusing their children, while 77.7% admitted to subjecting their children to constant verbal abuse. Silvia Ponce García, Estudio epidemiológico sobre maltrato infantil en la población escolarizada de Lima Metropolitana y Callao (1995), *cited in* Dr. Federico Infante Lembcke, *Indicadores de Salud Mental para una Política de Salud Mental* 23-26 (Sept. 2001) [hereinafter Lembcke].

Peru has no foster care or extended family support system that officially places individuals experiencing violence in the home in alternative care settings. Whenever possible, individuals should be placed with extended family, but as the Convention on the Rights of the Child (CRC) requires, "alternative care" must be provided for those unable to remain with their biological families.[117] One alternative could be the development of a foster care or extended family support system, whereby caring families provide a home for people who have been abandoned by or abused in their nuclear families. Foster care, while a necessary alternative, should be used as a last resort, after other options for placement with extended family have been exhausted.

C. Access to psychotropic medications

Barriers to adequate community-integrated mental health services are also created by the government, through its taxation of atypical neuroleptic medications. The average cost of atypical neuroleptics is more than two to three times the basic monthly salary in Peru, while the cost for generic medications is approximately twelve dollars a month.[118] Psychiatrists informed investigators that the price differential between atypical and generic medications is also due to an 18% import tax, in addition to government tariffs, which comprise 20-30% of the medications' overall cost to the consumer.[119] Mental health workers, family members, and people with psychiatric disabilities told investigators repeatedly that the high cost of medication made it virtually impossible for people to afford medications and remain in the community.

The quality of psychotropic medications also varies widely. A psychiatrist at one of the Social Security hospitals, Dr. José Cabrejos, told investigators that there are several brands of Fluoxetine, but that they range drastically in price and effectiveness.[120] Dr. Cabrejos explained that he must prescribe three to four times the amount of less expensive medications to achieve the same effectiveness of more expensive strains.[121] The less expensive medications also have more debilitating side effects, for which other medications must be prescribed. As a result, there is little difference in the ultimate cost of atypicals and less expensive generic medications, and, according to Dr. Cabrejos, use of the cheaper, less effective medications leads to patients becoming ill repeatedly, and to their tendency to develop into chronic patients.[122]

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[117] CRC, *supra* note 13, art. 20.

[118] Meeting with Peruvian Psychiatric Association (Oct. 22, 2002).

[119] *Id.*

[120] Comments of Dr. José Cabrejos (Feb. 18, 2003).

[121] *Id.*

[122] *Id.*

Under article 10 of the Protocol of San Salvador, Peru has committed to ensuring the right to health through "prevention and treatment of endemic, occupational and other diseases,"[123] as well as "satisfaction of the health needs of the highest risks groups and of those whose poverty makes them vulnerable."[124] Furthermore, under General Comment No. 14 interpreting the right to health in article 12 of the ICESCR, the government of Peru has an ongoing obligation "to move as expeditiously and effectively as possible towards the full realization" of the right to health.[125] Toward implementing the right to health for people with mental disabilities in Peru, the government could provide increased accessibility to psychotropic and other psychiatric medications by lowering the taxes on these medications, and subsidizing or providing free of charge to the extent possible, these needed medications.

D. Impressive community-integration models

Investigators visited several impressive community-integrated program models serving people with mental disabilities. One model is a group home for persons with developmental disabilities run by Graciela Hurtado Alva, a former staff psychologist in Larco Herrera's mental retardation ward. With the help of international financing, and the commitment of Larco Herrera to support the home with a portion of its budget, Ms. Hurtado purchased a house and established a group home in the community. In 1994, Ms. Hurtado opened the home for six individuals, between the ages of 18 and 35, many of whom had been detained in Larco Herrera's mental retardation ward their entire lives. The home has a family environment, in which attention is given to the residents' needs for individual development, recreational activities, privacy, and personal space. At the home, investigators observed a well-trained, caring, and dedicated staff engaged in habilitative activities with residents, one of whom has a job at an integrated workplace in the community. Essential support is provided through an agreement with Larco Herrera, in which the hospital pays the salaries of six technicians who work at the home, and covers the expenses for food, electricity, telephone, and water. The Association for Habilitation and Normalization of the Person with Mental Retardation (HANOPREM) directs the administrative aspects of the home, and plans the objectives and goals to facilitate the personal and social development of the home's residents.

Residents of the home also receive support in the form of scholarships to attend the Ann Sullivan Center of Peru, another promising model of community integration for persons with developmental disabilities. In 1979, the director of the Ann Sullivan Center, Liliana Mayo, began working with eight children with developmental disabilities in her parents' garage. Today, the Center is a fully accessible education facility serving 350 students with severe mental retardation, autism, and emotional and behavioral difficulties, and their families. The theory behind the Center is to train parents and family

[123] Protocol of San Salvador, *supra* note 40, art. 10(2)(d).

[124] *Id.* art 10(2)(f).

[125] *General Comment No. 14*, *supra* note 37, para. 31.

members to work with their children. Ms. Mayo noted, "If teachers are the only ones involved [in the students' lives], change doesn't happen."[126] Thus, the Center requires that families attend 90 hours of parent education annually, ensuring that the instruction provided in the Center's setting is reinforced at home. MDRI and APRODEH investigators witnessed parents working alongside their children, helping to teach them essential life skills including cooking and doing laundry. The Center also provides a continuing education and service program for students and their families throughout the student's life, and helps place students in community-integrated jobs. At the time of our visit, 40 students from the Center were working in integrated job settings in the community; for some, this is the only income for their families.

In Villa El Salvador, investigators observed two successful community mental health programs, the Parochial Mental Health Center and the Community Mental Health Center. These programs not only provided psychotropic medications, counseling, and social support, but, more importantly, involved families actively in this support. In so doing, these services helped individuals obtain supports needed for effective community integration. These programs are funded by private donors from abroad and within Peru, and the Catholic Church. Each of these programs reaches out to the local community for essential support.

The group home, the Ann Sullivan Center, and the programs in Villa El Salvador demonstrate that community integration for people with mental disabilities is a viable alternative to institutionalization. These successful models should be supported, studied, and replicated, so that others with mental disabilities can move from institution-based care to community-integrated settings.

VI. Consumer Advocacy

A. Lack of a consumer movement

Peru has no established consumer advocacy movement of persons with mental disabilities. There are family support organizations that incorporate persons with mental disabilities, such as ALAMO, and that are doing tremendous work with few resources, but there are no independently organized consumer advocacy groups. While families can be an important component of an advocacy movement, persons with mental disabilities often have their own ideas and priorities that need to be heard in planning and policy making. Full respect for the rights of persons with mental disabilities requires that they have a voice in policy making. Failure to include the independent participation of persons with mental disabilities in the public policy debate will continue to foster dependence, and families will continue to be perceived as the sole spokespersons for their relatives with mental disabilities.

[126] Interview with Liliana Mayo, Director, Ann Sullivan Center (Oct. 24, 2002).

B. Disability rights advocacy: national legislation and international standards

Peru's national legislation recognizes the importance of self-advocacy for persons with disabilities. Article 6(j) of Law 27050, regarding the composition of CONADIS, amended by Law 28164, specifies that the council should be comprised of "Three representatives, selected from members of the associations of persons with physical disabilities, hearing and language disabilities, and visual disabilities, legally constituted and registered with the National Registry of Persons with Disability."[127] Article 6(k) provides that one member of the council will be a representative from among the legally constituted associations of families of persons with developmental disabilities,[128] while article 6(l) allows for "a representative selected from members of family associations for persons with conduct disabilities."[129] None of these articles adequately address the importance of self-advocacy for persons with psychiatric disabilities. Self-advocacy by persons with psychiatric disabilities may not have been contemplated when article 6 was drafted or amended, as investigators noted no legally constituted groups of persons with psychiatric disabilities operating in Peru. Law 27050, article 6 should be reformed so that representation within CONADIS is also available to persons with psychiatric disabilities.

Internationally, the UN Standard Rules are unambiguous that people with disabilities themselves have a right to participate in public policy-making and that mere token representation without actual participation in policy planning by persons with disabilities is insufficient.[130] The Standard Rules emphasizes throughout the importance of self-advocacy for persons with disabilities in local, national, and international arenas. The Standard Rules characterize as being of "utmost importance,"[131] the participation of persons with disabilities in the development of government programs, policy-making and planning, economic policies, information gathering, personnel training, the monitoring and evaluation of disability programs, and the planning for development programs concerning persons with disabilities. PAHO also recognizes the important role played by users of mental health services in determining policy. PAHO identifies four categories of actors who intervene in the execution of mental health policy, noting that, "In first place are the people (patient, client, user) around whom all policy should be structured."[132]

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[127] Law 28164, *supra* note 8, art. 6(j).

[128] *Id.* art. 6(k).

[129] *Id.* art. 6(l).

[130] *See Standard Rules*, *supra* note 8, Rules 13-22.

[131] *Id.*

[132] REESTRUCTURACIÓN DE LA ATENCIÓN PSIQUIÁTRICA, *supra* note 9, at 67.

C. Funding stakeholder advocacy

The Standard Rules call on governments to "encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates."[133] Funding stakeholder advocacy, a practical first step in any larger advocacy campaign, costs little to implement and sustain, and is an investment in the development of political allies who will be critical in any future campaign. There is an emerging combined family support and consumer movement in Peru that is taking its place within the disability working group of the Coalition for Human Rights in Health. With government support, groups such as this one could help ensure the participation of individuals with psychiatric disabilities in public policy making.

There are models of consumer involvement in South America from which Peru could draw. Brazil is a country where consumers have been involved more effectively in public policy decision making than in other Latin American countries. According to one study, reform in Brazil's health system was created through a participative forum that contributed to the democratization in health sector decision making at a municipal level.[134] Through these participative fora, social and labor movement representatives gained greater influence over decisions regarding allocation of public sector resources, had greater access to information, could ensure quality control of services rendered, and were able to influence policy formulation to favor the social sectors that they represented.[135]

VII. Discrimination in Services

A. Non-discrimination as a principle of international human rights law

Non-discrimination is a basic tenet of international human rights instruments, and States parties to the ICESCR have an *affirmative obligation* to eliminate discrimination against people with disabilities.[136] General Comment 5 specifies:

> [I]n so far as special treatment is necessary, States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability.[137]

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[133] *Standard Rules*, *supra* note 8, Rule 18.

[134] Vargas Cortes SM, Conselhos Municipais de Saúde: a possibilidade dos usuários participarem e os determinantes da participação. Ciência a Saúde Colectiva 1998; III (1): 5-17.

[135] *Id.*

[136] *See General Comment No. 5, supra* note 39, § 3, paras. 15-18 [emphasis added].

[137] *Id.* para. 5.

Investigators observed near-pervasive discrimination against people with mental disabilities in almost every aspect of Peru's health care system, including mental health and other public services. Investigators noted ubiquitous discrimination in access to insurance coverage, social security benefits, and government-operated rehabilitation programs. As underscored by United Nations Special Rapporteur for Health, Paul Hunt, services and facilities for mental health care, "including community care, rehabilitation services, and family support services" must be available "to persons with whatever type of mental disability or psychological problem."[138]

B. Discrimination in health insurance coverage

The Protocol of San Salvador provides a right to social security in article 9, stating, "Everyone shall have the right to social security protecting him from the consequences of old age and of disability which prevents him, physically or mentally, from securing the means for a dignified and decent existence."[139] In Peru, mental health is not covered under the law of Integral Health Insurance (*Seguro Integral de Salud*, SIS), which was designed to attend to populations with the fewest resources and without other health insurance coverage.[140] Social Security does not cover needs of individuals following suicide attempts, and private insurance does not include mental health in its coverage. Health insurance that excludes mental health coverage is blatantly discriminatory against people with mental disabilities, and has profound effects for people with mental illness, producing consequences that endanger their lives. Dr. Jose Cabrejos, a psychiatrist in a Social Security hospital, reported that medical and social services are cut off to individuals with mental disabilities with long-term needs once they are released from the hospital, while individuals with long-term physical assistance needs continue to receive benefits.[141] Such policies have real detrimental consequences for people with mental illness, many of whom, unable to afford medications and without access to vital community supports, are at an increased risk of social marginalization, homelessness, suicide, and institutionalization.

C. Discrimination in the provision of rehabilitation services

The Center for Rehabilitation and Professionalism (CERP), in la Victoria, Lima, financed by social security, runs rehabilitative programming for persons with a range of disabilities. The center's atmosphere is warm and inviting, with a fully accessible pool, basketball courts, and a recreation hall. Investigators were impressed with the quality of

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[138] Rapporteur's Provisional Recommendations, *supra* note 47, para. 34.

[139] Protocol of San Salvador, *supra* note 40, art. 9.

[140] According to the *Guidelines for Action in Mental Health*, made public by the Ministry of Health in January 2004, SIS will include "essential attention in mental health and will progressively include other mental health problems in accordance with the possibilities of financing." *Guidelines for Action in Mental Health*, *supra* note 2, guideline 3.

[141] Interview with Dr. Jose Cabrejos (Oct. 2002).

the facility, the dedicated and caring staff, and the variety of programs available to persons with disabilities. Persons with psychiatric disabilities, however, are excluded from the center's programs. The director justified this exclusion, claming it was necessary because center staff feared that persons with psychiatric disabilities would stop taking their medications, and that all the work invested in rehabilitating them would be lost.

International human rights law requires that reasonable accommodations[142] be made to ensure that people with disabilities can contribute to society and benefit from being included members of the community.[143] Within its definition of discrimination under the ICESCR, the Economic and Social Committee includes the "denial of *reasonable accommodation* based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights."[144] Under the ICESCR, the right to reasonable accommodation is strongest where it impacts on the right to health.[145] Anti-discrimination language in the Standard Rules also requires that governments provide rehabilitation services in the local community "on the principles of full participation and equality."[146]

D. Discrimination in access to education

Persons with developmental disabilities are denied equal access to education in Peru. Investigators visited the Center for Special Education No. 1, a school for persons with developmental disabilities in Lima. Children at this school are excluded from

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[142] Under the Americans with Disabilities Act, 'reasonable accommodation' may include:

> (A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities and (B) job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment of modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities.

American with Disabilities Act of 1990, 42 U.S.C. § 12111(9). While US law is "not an authoritative interpretation of the ICESCR's protection of the right to reasonable accommodation . . . the growing jurisprudence in the countries that have adopted similar legislation provides extensive guidance that can be used to develop effective protections." Eric Rosenthal & Clarence Sundram, *The Role of International Human Rights in National Mental Health Legislation*, DEPARTMENT OF MENTAL HEALTH AND SUBSTANCE DEPENDENCE, WORLD HEALTH ORGANIZATION 42 (2004) [hereinafter Rosenthal & Sundram] *available at* http://www.mdri.org/pdf/WHO%20chapter%20in%20English_r1.pdf. For a practical discussion on the right to reasonable accommodations for people with mental disabilities, *see* ROBERT M. LEVY AND LEONARD S. RUBENSTEIN, THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES 159 (1996).

[143] *See generally* Rosenthal & Sundram, *supra* note 142.

[144] *General Comment 5*, *supra* note 39, para. 15.

[145] Rosenthal & Sundram, *supra* note 142, at 42-43.

[146] *Standard Rules*, *supra* note 23, Rule 3.

mainstream education and segregated in classrooms where they sit idly at desks. In the highland village of Tambillo, Ayacucho, investigators met with a mother and her 13 year-old daughter who has a developmental disability and uses crutches. When the girl was five, the mother carried her daughter on her back to Ayacucho, an hour's bus ride away, where there was a special education school. The girl attended the school for two months, until her mother could no longer afford to take her. In those two months, the mother reported that she saw signs of progress in the girl's condition. The mother attempted to enroll her daughter at the primary school in the village, a few hundred feet from her house, but the teacher refused to accept her daughter in the classroom.

These realities contravene Peru's Law 27050, article 23.1, which provides:

> The education of persons with disabilities is directed toward their integration and social, economic, and cultural inclusion. Toward this end, Regular and Special Education Centers should incorporate persons with disabilities, taking into account the nature of the disability, the aptitudes of the person, as well as the individual and/or family possibilities and interests.[147]

Article 23.2 continues, "Access to an educational center cannot be denied for reasons of physical, sensory, or mental disability, neither can an individual be withdrawn or expelled for this reason. Any act based in discriminatory motives that affect by whatever manner the education of a person with disability, is null."[148]

International human rights law endorses the right of equal access to education for all persons. General Comment 13 of the ICESCR proclaims that, "educational institutions and programs have to be accessible to everyone, without discrimination,"[149] enabling "all persons to participate effectively in a free society[.]"[150] Paragraph 1 of General Comment 13 states:

> Education is both a human right in itself and an indispensable means of realizing other human rights. As an empowerment right, education is the primary vehicle by which economically and socially marginalized adults and children can lift themselves out of poverty and obtain the means to participate fully in their communities.[151]

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[147] Law 27050, *supra* note 3, art. 23.1.

[148] *Id.* art. 23.2.

[149] Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 13*, U.N. Doc, E/C.12/1999/10, 21st Sess., para. 6(b).

[150] *Id.* para. 4.

[151] *Id.* para. 1.

The CRC specifies that persons with disabilities have a right to education "in a manner conducive to the child's achieving the fullest possible social integration and individual development."[152] The Standard Rules also specify that states should ensure integrated education opportunities for persons with disabilities.[153]

Inclusive and appropriate education should be provided for all children with disabilities. Integrating children with mental disabilities in mainstream classrooms will require training for teachers, and teachers' aides may be necessary in some classrooms. Peru's educational system should also provide programs in speech pathology, physical therapy, and mental health services to enable children with disabilities to benefit from an education.

VIII. Support to Survivors of Violence

As a result of Peru's armed internal conflict, the Truth and Reconciliation Commission has found that "broad sectors of the population affected by the violence suffer from one or another form of effects on their mental health, which weakens their ability for self-development and for overcoming the wounds of the past."[154] While there has been increasing worldwide attention to individuals who have been subject to political violence, MDRI has found through its work in other countries that these programs may leave out persons with mental disabilities. Counseling programs for people exposed to violence may not address the needs of the most vulnerable populations, although individuals with mental disabilities are at greater risk in situations of political violence. Circumstances surrounding exclusion from these programs may "retraumatize" individuals, leading to a worsening of psychiatric symptoms. In a society experiencing social disruption, the lack of social supports is particularly dangerous for individuals with mental disabilities.

A. Inclusive trauma counseling needed

Investigators visited two trauma counseling programs in marginalized communities displaced by the political violence. While the programs' participants considered the counseling valuable, investigators observed that individuals with mental disabilities were not included. During investigators' meeting with the participants in one program, a man who had attempted suicide on two occasions came and sat with the group, but did not speak. When he left, participants told investigators that they felt they could not help him.[155] Programs that accommodate individuals with more intensive needs are essential. These individuals will require a much more extensive system of community support services than the broader population, and more funding should be dedicated to

[152] CRC, *supra* note 13, art. 23 § 3.

[153] *Standard Rules, supra* note 8, Rule 6.

[154] TRC REPORT, *supra* note 20, para. 159.

[155] Meeting with members of trauma counseling group, Cantogrande, Lima (Oct. 2002).

these programs, as existing funds are probably insufficient to cover the needs of this population.

B. Economic revitalization needed

To aid in the social and economic reintegration of persons affected by trauma, a system of micro credit should be extended to populations that have been displaced by political violence, enabling them to develop micro industries.[156] This would be one approach to help these populations toward economic self-sufficiency, while alleviating symptoms of depression and post traumatic stress disorder. As PAHO recognizes, employment is an important component of psychosocial rehabilitation.[157]

Investigators met with groups of women in two communities displaced by the political violence, now living in marginalized communities on the outskirts of Lima. Both groups described their most pressing needs in economic and social terms, expressing that they needed jobs, clean water, and access to education and health care. Any reparations for those affected by Peru's armed internal conflict should be developed in close consultation with those affected directly by the political violence, so that the most appropriate remedies are provided.

C. Creating trauma-informed services

Given Peru's history of armed internal conflict and the prevalence of intra-family violence,[158] health providers should expect a high percentage of those seeking mental health services to be exposed to trauma. While there is little systematic evidence regarding how to address the psychosocial effects of violence,[159] health care services can better serve violence-exposed individuals by creating services that are "trauma-informed." Services that are "informed about trauma" are not only informed about the consumer's history of prior and ongoing abuse—permitting holistic, integrated treatment planning—but also are aware of the role that violence plays in the lives of those it serves.[160] Such services are designed to meet the specialized needs of trauma survivors,

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[156] In the SUMMARY OF THE COMPREHENSIVE REPARATIONS PLAN, the TRC recommends similar reparations. *See* TRC, SUMMARY OF THE COMPREHENSIVE REPARATIONS PLAN, para. 3.6 (2003) [hereinafter TRC REPARATIONS PLAN] *available at* http://www.aprodeh.org.pe/sem_verdad/informe_final/english/reparations_plan.pdf.

[157] REESTRUCTURACIÓN DE LA ATENCIÓN PSIQUIÁTRICA, *supra* note 9.

[158] *See* Lembcke, *supra* note 116.

[159] Joop T. V. M. de Jong, *Public Mental Health, Traumatic Stress and Human Rights Violations in Low-Income Countries: A Culturally Appropriate Model in Times of Conflict, Disaster and Peace*, *in* TRAUMA, WAR, AND VIOLENCE: PUBLIC MENTAL HEALTH IN SOCIO-CULTURAL CONTEXT 1 (Joop de Jong, ed., 2002).

[160] Maxine Harris and Roger D. Fallot, *Envisioning a Trauma-Informed Service System: A Vital Paradigm Shift, in* 89 NEW DIRECTIONS IN MENTAL HEALTH SERVICES: USING TRAUMA THEORY TO DESIGN SERVICE SYSTEMS 4 (Spring 2001).

and "facilitate consumer participation in treatment."[161] As the Truth and Reconciliation Commission recommends, service providers should be trained in methodologies to address trauma[162] as well as how to avoid practices that may be retraumatizing for individuals accessing their services.

IX. Human Rights and Disability Awareness Training

Human rights and disability awareness training should be provided for health care professionals, teachers, and others serving persons with mental disabilities. Law 27741 establishes an education policy in human rights and creates a National Plan for its diffusion and teaching.[163] Article 3 of Law 27741 establishes that, "Compulsory education in human rights and international humanitarian law should cover the enforcement and strict compliance with international agreements and conventions; as well as the protection of fundamental rights in the national and international arenas."[164]

In regional standards, the IACHR recommends public awareness campaigns and other actions targeted at combating stigmatization and discrimination against people with mental disabilities.[165] Such training could inform service providers of the rights of people with mental disabilities, and safeguard against discrimination and abuses. This training could also help to combat stigma and prejudice, such as the views expressed in interviews with mental health service providers and in publications distributed by mental health institutions.

Investigators observed examples of prejudice against persons with psychiatric disorders within the psychiatric profession. Investigators noted several health care professionals, including the director of a psychiatric institution, refer to individuals receiving mental health treatment in condescending, diminutive terms, calling them "little patients" or "little crazy ones."[166] Evidence of this prejudice is also documented in a diagnostic study of the mental health services offered by Noguchi Institute, in which a mental health professional is quoted as saying that psychiatric patients "lie" and "manipulate," as justification for a policy which requires that individuals with a diagnosis of mental illness have a "responsible" party accompany them to appointments.[167] Such broad generalizations are harmful to individuals diagnosed with mental illness who do not lie and manipulate. A thorough review of such policies should be made to avoid

[161] *Id.*

[162] TRC, Summary of the Comprehensive Reparations Plan, 3.2 Health-oriented reparations, *available at* http://www.aprodeh.org.pe/sem_verdad/informe_final/english/reparations_plan.pdf.

[163] Law 27741, *supra* note 10.

[164] *Id.* art. 3.

[165] *IACHR Recommendation*, *supra* note 19, rec. 8.

[166] Interview with Dr. Jiménez, *supra* note 62.

[167] Diagnostico Situacional, *supra* note 89, at 171.

blanket generalizations that classify and stigmatize persons diagnosed with mental illness.

X. Conclusion

International human rights law and Peru's national legislation require broad-scale reform of health and social services to enforce the rights of people with mental disabilities in Peru. Coordinated planning, financing, and implementation of community-integrated approaches are needed to address the myriad human rights abuses documented in this report. As emphasized by the UN Special Rapporteur for Health, Peru must attack the under-funding of its health budget through a greater investment of financial resources.

The Ministry of Health can provide leadership in bringing Peru's mental health system into compliance with international human rights standards. In adopting the *Guidelines for Action in Mental Health*, the Health Ministry has made an important endorsement of the need for reform. Nonetheless, the authority to address all of the concerns raised in this report goes beyond the scope of the Health Ministry. Other branches of the Peruvian government, particularly those entrusted with education and employment policies, must also join the battle to ensure full respect for the rights of persons with mental disabilities. Now is a crucial moment when the government of Peru can lend support to an historical process that has benefited from wide-spread civil society participation and take concrete steps to fulfill its obligations under national and international human rights law.