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# Protecting Mental Disability Rights: A Success Story in the Inter-American Human Rights System

by Alison A. Hillman

ON DECEMBER 17, 2003, the Inter-American Commission on Human Rights (Commission) granted precautionary measures, a type of emergency relief, to protect the lives and physical, mental, and moral integrity of 460 individuals detained in the state-run Neuro-Psychiatric Hospital in Paraguay. This decision was historic. It was the first time that the Commission called for immediate, life-saving measures to combat ongoing abuses in a psychiatric institution.

Mental Disability Rights International (MDRI) and the Center for Justice and International Law (CEJIL) filed a petition before the Commission on behalf of two teenage boys, Julio and Jorge, who had been detained in six-by-six foot isolation cells, naked and without access to bathrooms, for over four years. While documenting the conditions for Julio and Jorge, MDRI investigators discovered that the conditions and treatment for the other 458 individuals detained in the institution differed little from the dehumanizing and abusive circumstances of Julio and Jorge's detentions. Accordingly, MDRI and CEJIL attorneys framed the petition to document not only the egregious human rights violations that Julio and Jorge suffered, but the abuses inflicted upon all 460 individuals detained in the institution.

Since December 2003, MDRI and CEJIL (petitioners) have worked through the Commission, achieving an extension of the precautionary measures in July 2004. Their efforts have paid off, as the petition before the Commission regarding Paraguay's Neuro-Psychiatric Hospital has become one of the foremost successes of precautionary measures in the history of the inter-American human rights system.

## BACKGROUND AND FINDINGS FROM MDRI'S INITIAL INVESTIGATION INTO ABUSES IN THE NEURO-PSYCHIATRIC HOSPITAL

IN OCTOBER 2003, AFTER RECEIVING REPORTS of horrendous abuses in Paraguay's Neuro-Psychiatric Hospital, MDRI sent a mission to Paraguay to document Julio and Jorge's situation. The boys were frighteningly thin and locked naked in tiny isolation cells. Holes in the cell floors designed to be latrines were crammed and caked over with excrement. The cells reeked of urine and feces, and the cell walls were smeared with excrement. Each boy was infested with lice, covered with scars, and spent approximately four hours every other day in an outdoor pen, which was littered with human excrement, garbage, and broken glass.

During a two-day investigation, MDRI documented atrocious treatment and conditions for all 460 people detained in the institution, which has a stated capacity of 350. These conditions included exceptionally poor hygiene among patients—their hands, arms, and bodies caked in filth—which guaranteed the spread of germs and disease. Detainees urinated and defecated in public

patios, while others knelt to drink from standing pools on the same patios. Showers, sinks, and toilets were non-functional and lacked soap and towels. Existing toilets were little more than filthy holes in the floor. Some individuals were compelled to sleep in close proximity to these excrement-encrusted holes. The stench of open sewage and rancid garbage permeated the buildings inside and out.

The institution suffered from dangerously low levels of staffing, giving rise to near-universal neglect and resulting in actual harm. The low staff-to-patient ratio placed more vulnerable patients at risk of aggression from other patients and self-harm. Available staff members were unable to render active treatment (the organized effort to develop the skills, behaviors, and attitudes essential to independent living). Treatment interactions between staff and patients were largely limited to the distribution of medications from the opposite side of a wall of locked bars. Insufficient staffing also created the inevitability of locked buildings, the use of isolation cells, and chemical restraint (large doses of sedating medications to render patients docile and listless).

The entire facility was a prison-like setting with almost no recognition of the individuals' mental health needs, and representing little more than sub-custodial warehousing. Although large numbers of patients slept in barred isolation cells, often with padlocked cell doors, no written orders or policies existed to mandate or guide the use of seclusion. A survey of medical records revealed that little relationship existed between the use of medications and actual psychiatric diagnoses. Only four of thirteen patient records surveyed even contained a diagnosis. Medical records were disorganized and lacked case histories, family contacts, evaluations, treatment and discharge plans, and medication histories.

Investigators also documented the detention of children side-by-side with adults, in contravention of international standards, and the lack of any viable community-based mental health services. Concluding the two-day inspection, investigators determined that the hospital posed an immediate health hazard to those who were detained in or employed by the institution.

## PETITION FILED FOR PRECAUTIONARY MEASURES WITH THE INTER-AMERICAN COMMISSION

MDRI AND CEJIL FILED A PETITION for precautionary measures with the Inter-American Commission on December 9, 2003. Precautionary measures are an instrument within the inter-American human rights



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Jorge in an isolation cell (October 2003).

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system that allows the Commission to address promptly compelling human rights violations. Article 25.1 of the Commission's Procedural Rules states that the Commission may issue precautionary measures "[i]n serious and urgent cases, and whenever necessary according to the information available . . . to prevent irreparable harm to persons." The Inter-American Court on Human Rights (Inter-American Court or Court) has applied the "irreparable harm" standard through the use of the analogous "provisional measures" to cases in which a petitioner faces a serious threat to his or her physical, psychological, or moral integrity. "[I]rreparable harm" may also be shown by demonstrating the existence of a serious risk to life or personal integrity.

Petitioners argued that Paraguay's detention and confinement of Julio, Jorge, and the other 458 individuals held in the hospital in inhuman and degrading conditions presented a grave and urgent risk to their lives. Based upon the egregious nature of the human rights violations encountered, petitioners requested the Commission's immediate intervention to protect the lives and the physical, mental, and moral integrity of all those detained in the institution. Through a review of medical records, interviews, and video and photographic evidence, MDRI investigators documented clear violations of the rights to life, humane treatment, liberty and freedom from arbitrary or prolonged detention; equality before the law; fair trial and due process guarantees; and violations of the rights of the child.

all forms of discrimination against persons with disabilities and to promote their full integration into society." Discrimination against people with disabilities is defined as "any distinction, restriction, or exclusion based on a disability" having "the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise . . . of . . . human rights and fundamental freedoms." States Parties to the Disability Convention commit to facilitating or promoting "the independence, self-sufficiency, and total integration into society of persons with disabilities, under conditions of equality."

In the hospital, poor conditions and the lack of treatment negated the promotion of the individual's full integration into society. Detention within the facility undermined the mental health of patients and limited opportunities for future community integration. The absence of any identifiable active treatment, treatment plans, and discharge plans doomed patients to a sub-human existence in conditions that were an affront to their dignity. Not only was detention in these conditions unsuitable for the needs of any individual, much less an individual perceived to have a mental disability, but they did not represent care standards identical to those received by other ill persons in the country. Taken together, petitioners argued, the improper segregation from society and the poor conditions in the facility represented discriminatory treatment against people with mental disabilities.

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“The substantial changes in mental health practice and policy accomplished by this advocacy is one of the foremost successes in the use of precautionary measures in the inter-American human rights system.”

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#### DISCRIMINATION & VIOLATION OF THE RIGHT TO COMMUNITY INTEGRATION

Petitioners argued that Paraguay's treatment of individuals detained in the hospital constituted grave and urgent violations of international human rights laws ensuring equality before the law and anti-discrimination. Articles 1.1 and 24 of the American Convention on Human Rights (American Convention) contain anti-discrimination clauses and provide the right to equal protection, as does Article 2 of the Convention on the Rights of the Child (CRC). Further, Principle 8.1 of the UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles) establishes the right of every patient to receive health and social care suitable to his or her needs at standards identical to the care received by other ill persons.

Petitioners further argued that Paraguay's obligations of non-discrimination toward those detained in the hospital should also be examined under the Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities (Disability Convention), ratified by Paraguay in 2002. The Disability Convention's purpose is to "prevent and eliminate

#### VIOLATION OF THE RIGHT TO LIFE

Article 4 of the American Convention establishes that "[e]very person has the right to have his life respected." The Inter-American Court has interpreted this provision broadly, recognizing a state's duty not only to refrain from arbitrarily depriving an individual of life, but also to take affirmative measures to guarantee life and life opportunities. The Court extended this principle in *Villagrán Morales*, a case from Guatemala regarding state action in the killings of five street children. Petitioners noted that *Villagrán Morales* extended the right to life to a state's affirmative obligations to "provide the measures required for life to develop under decent conditions" with regard to abandoned children and other defenseless persons, arguing that this standard includes those abandoned in psychiatric institutions.

#### VIOLATION OF THE RIGHT TO HUMANE TREATMENT

In addition, petitioners argued that Paraguay's confinement of people detained in the hospital in inhuman conditions presented an urgent risk of grave and irreparable harm to their right to be free from cruel, inhuman, and degrading treatment. Article 5 of the American Convention provides that "[n]o one shall be sub-

jected to torture or to cruel, inhuman, or degrading punishment or treatment,” and that everyone deprived of liberty “shall be treated with respect for the inherent dignity of the human person.”

In *Victor Rosario Congo*, the Commission found that Ecuador had violated Article 5 by placing Congo in an isolation cell and denying him proper medical attention. The Commission further stated that, as Congo had a mental illness, he was in “a particularly vulnerable position,” making the state’s violation of his right to physical integrity even more egregious. Petitioners argued that Julio, Jorge, and the others detained in Paraguay’s Neuro-Psychiatric Hospital were in such a vulnerable position, making



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A men’s ward in Paraguay’s Neuro-Psychiatric Hospital (July 2004).

the threats to their physical integrity particularly serious. This seriousness was further compounded in the case of Julio and Jorge given their status as minors. Their conditions of confinement clearly constituted cruel, inhuman, and degrading treatment, particularly for persons with a mental disability. In some cases, petitioners argued, such conditions may rise to the level of torture.

#### VIOLATIONS OF THE RIGHT TO PERSONAL LIBERTY

Petitioners argued that Paraguay’s ongoing, unreviewed detentions of Julio and Jorge represented grave and urgent violations of the right to liberty, protected by Article 7 of the American Convention. Under Article 7, the right to liberty entails the exercise of physical freedom, which includes the right to be free from institutionalization. Although this right is not absolute, it only permits restrictions of an individual’s liberty according to procedures established by law. As recognized in *Congo*, the MI Principles can provide a guide to the Convention’s requirements for people with mental disabilities. The MI Principles set forth both substantive standards and due process protections against the arbitrary deprivation of liberty. Under MI Principle 17, admissions must be reviewed by independent and impartial review bodies “at reasonable intervals as specified by domestic law.” This guarantee parallels Article 7 of the American Convention, which the Commission has found to be violated where domestic procedures fail to provide for detention reviews at reasonable intervals.

#### VIOLATIONS OF THE RIGHTS OF THE CHILD

The petitioners argued that Paraguay’s treatment of Julio, age 17, Jorge, age 18, and other children detained at the hospital

represented grave and urgent violations of their right to special protections as children, afforded by Article 19.1 of the CRC. Article 19 establishes a state’s affirmative obligation to protect children from “physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse. . . .” These obligations are heightened when a child is in state custody. In such circumstances, the state becomes directly responsible for the health and wellbeing of the child. The Court has clarified that a state’s obligation to take protective measures includes special assistance for children deprived of a family environment, including “the social rehabilitation of all children who are abandoned or exploited.” Julio and Jorge were abandoned children who had been deprived of a family environment for more than a decade.

Petitioners maintained that Paraguay had engaged in a number of flagrant violations of the Rights of the Child, particularly when the American Convention is read in conjunction with the CRC. Article 23 of the CRC specifically addresses the rights of children with disabilities, recognizing that they “should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.” Children with disabilities have a right to “special care” and assistance to ensure their effective access to “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. . . .” Article 20.2 maintains that states should ensure “alternative care” for a child deprived of a family environment. This care could include adoption, placement with a foster family, or, if necessary, placement in a facility suitable for the care of children.

Petitioners argued that Paraguay’s Neuro-Psychiatric Hospital should not be responsible for the care and protection of children, notwithstanding the fact that Julio, Jorge, and other children were detained there. The institution had no experience in safeguarding the rights of children and no one on staff could speak to the best interests of the child. Contrary to being an adequate facility for the protection of the child, petitioners argued, the hospital did not conform to minimum standards of health and safety. The hospital employed a dangerously insufficient number of suitable staff, which prevented active treatment and practically assured abuse and neglect. Children detained in the institution lived in wards with an adult population, which was a matter of special concern due to the high risk of abuse.

#### RESULTS OF THE PRECAUTIONARY MEASURES PETITION

ON DECEMBER 17, 2003, THE INTER-AMERICAN Commission approved urgent measures to protect the lives and physical, mental, and moral integrity of people detained in a psychiatric institution. The Commission requested that Paraguay comply with the following recommendations: (1) adopt all necessary measures to protect the lives, health, and the physical, mental, and moral integrity of the 460 people detained in the institution, with special attention to the situation of women and children; (2) adopt necessary measures to improve hygiene in the hospital; and (3) restrict the use of isolation cells to situations and circumstances that follow international protocols and safeguards.

MDRI brought the issue to worldwide attention by collaborating with *CNN en Español* on a follow-up story and streaming

the video over the MDRI website. After this publicity, Paraguay's President and Minister of Health personally visited the hospital, fired the hospital's director, and created a commission to investigate abuses.

#### **WORKING FOR CHANGE THROUGH THE INTER-AMERICAN COMMISSION**

Since December 2003, petitioners have worked through the Commission to address the institution's life-threatening conditions and to ensure that Paraguay develops a system of community-based mental health and social services that will guard against the repetition of such abuses in the future. In January 2004, the Paraguayan government began a series of reforms when Paraguay's President, Nicanor Frutos Duarte, appointed a new hospital administration. This administration began working immediately to address the abusive conditions and treatment surrounding Julio and Jorge's detention. Nevertheless, during return trips to Paraguay in the spring and summer of 2004, MDRI documented that Julio and Jorge continued to be segregated within the institution and lacked treatment plans focusing on their habilitation and eventual reintegration into the community. Moreover, investigators documented that hospital conditions continued to threaten the lives and health of the other 458 institution detainees.

In July 2004, MDRI and CEJIL filed a petition to extend the precautionary measures. This petition focused on the plight of the hundreds of other people detained in the institution in similarly inhuman and degrading conditions with no active treatment, no rehabilitative services, and no hope of returning to life in the community. On August 9, 2004, the Commission granted the petitioners' request to extend the precautionary measures for an additional six months.

On October 26, 2004, in a meeting before the Commission, petitioners provided further evidence of continuing perilous conditions in the hospital. Although the Paraguayan government had taken steps to improve the situation of Julio and Jorge, it had done little to address the inhuman and degrading treatment endured by the other 458 detainees. MDRI expressed concern that Paraguay was investing resources in rebuilding the institution, when the state could not guarantee even the most basic hygienic conditions within the hospital. Commission President José Zalaquet encouraged petitioners and the government to forge a collaborative relationship, as both sides wanted to improve the available mental health services and alternatives to institution-based care in Paraguay. Petitioners and the Paraguayan government agreed to talks around implementing a plan for community integration for people detained in the institution and for reforming the country's mental health services.

In December 2004, MDRI returned to Paraguay to forge a more collaborative relationship. The MDRI team observed that although the physical facilities and hygiene had improved, patients remained improperly segregated from society. The hospital still had not implemented meaningful treatment or rehabilitation to help people return to their communities. Furthermore, the hospital's budget for the following year did not reflect the increased funding necessary to undertake the substantial improvement in treatment or community programs to which the government had already committed.

Petitioners and the Paraguayan government entered into negotiations to respond to the underlying problem: the lack of community-based services leading to the improper detention of

people in the psychiatric facility. Through this process, the Paraguayan government agreed to establish a plan, timeline, and funding for a process of deinstitutionalization and the establishment of community-based mental health services in the country.

#### **HISTORIC ACCORD SIGNED: TRANSFORMATION TO COMMUNITY-BASED SERVICES**

In late February 2005, petitioners signed a groundbreaking accord with the Paraguayan government, requiring the state to develop a plan for deinstitutionalization and the creation of community-based mental health services, along with the guarantees of funding for such a plan by Paraguay's President and Minister of Health. As part of the plan, Paraguay has committed to undertake a full-scale restructuring of its mental health services with the technical assistance of MDRI and the Pan American Health Organization (PAHO). This restructuring would provide for a decrease of at least 70 percent of the hospital's current population, while expanding and strengthening community-based mental health and support services within the next one to five years.

#### **CONCLUSION**

THE SUBSTANTIAL CHANGES IN MENTAL HEALTH PRACTICE and policy accomplished by this advocacy is one of the foremost successes in the use of precautionary measures in the inter-American human rights system. The Inter-American Commission was instrumental in facilitating the process between petitioners and the Paraguayan government which led to the signing of the groundbreaking accord and paved the way for substantive mental health reform. Since December 2003, the Paraguayan government has taken significant steps to address life-threatening conditions in its Neuro-Psychiatric Hospital. The govern-



*Courtesy of author*

Jorge now lives in a home in the community (February 2005).

ment has also taken steps to reintegrate people with mental disabilities into community life. Today, Jorge, one of the boys detained in a feces-filled isolation cell just 14 months ago, lives in a home in the community.

As this article goes to press, MDRI, CEJIL, and PAHO are providing technical assistance for and monitoring of the implementation of this historic accord. If reforms continue in Paraguay as planned, this accord may herald a new age of mental health services in South America, one respectful of the rights of people with mental disabilities, allowing them to be self-determined advocates of their own lives and active participants in helping shape the policies that affect them.

*HRB*