

BEHIND CLOSED DOORS:

Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centers of Turkey

A REPORT BY MENTAL DISABILITY RIGHTS INTERNATIONAL

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Mental Disability Rights International

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Mental Disability Rights International (MDRI) is an advocacy organization dedicated to the human rights and full participation in society of people with mental disabilities worldwide. MDRI documents human rights abuses, supports the development of mental disability rights advocacy, and promotes international awareness and oversight of the rights of people with mental disabilities. MDRI advises governments and non-governmental organizations to plan strategies to bring about effective rights enforcement and service system reform. Drawing on the skills and experience of attorneys, mental health professionals, and people with disabilities and their families, MDRI challenges the discrimination and abuse faced by people with mental disabilities worldwide.

MDRI is based in Washington, DC and has an office in Prishtina, Kosovo. MDRI has investigated human rights conditions and assisted mental disability rights advocates in Argentina, Armenia, Azerbaijan, Bulgaria, the Czech Republic, Estonia, Hungary, Kosovo, Lithuania, Macedonia, Mexico, Paraguay, Poland, Peru, Romania, Russia, Serbia, Slovakia, Slovenia, Turkey, Ukraine, and Uruguay. MDRI has published the following reports: *Human Rights & Mental Health: Peru* (2004); *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo* (2002); *Human Rights & Mental Health: Mexico* (2000); *Children in Russia's Institutions: Human Rights and Opportunities for Reform* (2000); *Human Rights & Mental Health: Hungary* (1997); *Human Rights & Mental Health: Uruguay* (1995).

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Executive Summary

Behind Closed Doors describes the findings of a two-year investigation in Turkey by Mental Disability Rights International (MDRI) and exposes the human rights abuses perpetrated against children and adults with mental disabilities. **Locked away and out of public view, people with psychiatric disorders as well as people with intellectual disabilities, such as mental retardation, are subjected to treatment practices that are tantamount to torture.** Inhuman and degrading conditions of confinement are widespread throughout the Turkish mental health system. This report documents Turkey's violations of the European Convention for the Prevention of Torture (ECPT), the European Convention on Human Rights (ECHR), the UN Convention on the Rights of the Child (CRC) and other internationally accepted human rights and disability rights standards.

There is no enforceable law or due process in Turkey that protects against the arbitrary detention or forced treatment of institutionalized people with mental disabilities. There are virtually no community supports or services, and thus, no alternatives to institutions for people in need of support. As a result, thousands of people are detained illegally, many for a lifetime, with no hope of ever living in the community. Once inside the walls of an institution, people are at serious risk of abuse from dangerous treatment practices. In order to receive any form of assistance, people must often consent to whatever treatment an institution may have to offer. For people detained in the institution, there is no right to refuse treatment. The prison-like incarceration of Turkey's most vulnerable citizens is dangerous and life-threatening.

Some of the most egregious human rights violations uncovered by MDRI include:

Psychiatric Institutions

- **Arbitrary detention of every person** – In the absence of any enforceable law or procedures for independent judicial review of commitment, every person in Turkey's psychiatric facilities are detained arbitrarily and in violation of international law;
- **The inhumane and pervasive use of electroconvulsive or “shock” treatment (ECT) without the use of muscle relaxants, anesthesia, and oxygenation (referred to as “unmodified” ECT) in state-run institutions** – ECT is a psychiatric treatment whereby electricity is administered to the brain and is thought to alleviate certain conditions that do not respond to more conventional treatment. However, in its unmodified form, it is extremely painful, frightening and dangerous and violates the European Convention for the Prevention of Torture. The World Health Organization (WHO) has called for an outright ban on unmodified ECT.

I only had ECT one time. It was the first and the last time. They hold you down, they hold your arms, they hold your head and they put cotton in your mouth. I

heard them say 70 to 110 volts. I felt the electricity and the pain, I felt like dying.
– 28-year-old former Bakirköy psychiatric patient

- **The use of ECT as punishment** - The director of the ECT center at Bakirköy Psychiatric Hospital, one of the largest institutions in the world, told MDRI investigators that they do not use anesthesia because “patients with major depression feel that they need to be punished.” Patients cannot refuse this treatment and they are frequently lied to and told they are getting an x-ray. Terrorized people are commonly dragged into the ECT room in straitjackets and are forcibly held down by staff during the procedure. ECT without the use of anesthesia and muscle relaxants violates all internationally accepted medical standards. Other psychiatrists observed that, because there are no standards on the use of ECT in Turkey, ECT is abused and used as punishment.

We use ECT for people with major depression. Patients with major depression feel that they need to be punished. If we use anesthesia the ECT won't be as effective because they won't feel punished. – Chief of ECT Center, Bakirköy

- **The use of ECT on adolescents and children** – The WHO has stated that there are no clinical indications for the use of ECT (even with anesthesia) on children and the practice should be banned in all cases. Psychiatrists report that ECT is regularly administered to adolescents and on rare occasions on children. **In Turkey, children as young as nine years old are administered ECT without anesthesia.**
- **Over-use of ECT** – ECT is massively overused in Turkish psychiatric facilities in cases for which there is no clinically proven justification. ECT is used for the convenience of institutional authorities when more appropriate services in the community are unavailable. The over-use of ECT exposes thousands of people to unnecessary, frightening and dangerous experiences and violates the Turkish government's own public commitments to the European Committee for the Prevention of Torture.

Rehabilitation Centers and Orphanages

I love my daughter, but I hope she dies before I do. I do not know what will happen to her after I die and can't take care of her any longer. I do not want her ever to have to live in the institution.

– Director of a private school for children with mental disabilities

- **Starvation and dehydration** – MDRI observed bedridden children, unable to feed themselves due to their disability, left inadequately fed and without assistance by staff. **Investigators observed children emaciated from starvation. Staff reported children dying from starvation and dehydration.**

Many of the children could not feed themselves. Some were struggling to hold onto or reach the bottles and much of the contents spilled out onto beds or wasn't eaten. A little girl, who looked to be about 2 years old, was crying and squirming in her crib. A full bottle of formula was lying in the corner of her crib, just out of reach. I watched for over an hour, and no one came to feed her. She would have had nothing if I hadn't eventually helped her.

Over the course of a number of feedings, I watched as staff came quickly into the room, dropped off bottles, and then picked up the bottles as they left the room. If a child could not pick up the bottle to eat or drink, she starved.

– MDRI investigator

- **Lack of rehabilitation and medical care** – There is a broad lack of rehabilitation and physical therapy for children and adults with disabilities detained in orphanages and rehabilitation centers. Left to languish for years in a state of total inactivity, placement in these facilities is likely to contribute to a person's disability. Children's arms, legs, and spines become contorted and atrophy from the lack of activity or physical therapy. The effect of living without loving care-takers or any form of stimulation causes some children to become self-abusive. Rehabilitation centers offer no assistance for self-abusive children other than to tie them down. According to staff at one facility, children with the most severe physical and mental disabilities are denied medical care when they become ill and are left to die.

Nurses come to the units and stand in the doorway. They ask workers if there are any sick children, they just yell in. The workers always say no even if the children are very ill. When children get sick, they are no longer bathed and are not allowed to be taken out of bed. They are tied into their beds at times. If children are not taken care of, they do die. One is dying now.

– Saray staff

- **The use of physical restraints and seclusion on both children and adults** – MDRI observed children tied to cribs and beds, some of them permanently restrained. Four point restraint, that is, legs and arms tied to the four corners of the crib or bed, is also used. Children who scratch or hurt themselves – a reaction to the mind-numbing boredom they are forced to endure – were found with plastic bottles permanently duct taped over their hands. MDRI investigators also found a young child locked in a tiny room alone. At another institution we observed a small seclusion room with no toilet, reeking of urine.

Personnel get cut in half on the weekends. On some of the units, children are restrained. If you let them go, they go after the quiet children. They are just bored and frustrated. So they are restrained all the time. [The children] are between 7 and 15 years old.

– Saray staff

Lack of community care

- **People with mental disabilities and families are abandoned** – Community-based care and supports are almost entirely unavailable for people with mental disabilities. Throughout the world, it has been demonstrated that community programs can help people with mental disabilities (either psychiatric or intellectual) live fully as part of society, to enjoy relations with family members and friends, and to take advantage of educational opportunities, work and cultural life. Without such support, people with mental disabilities in Turkey are often segregated from society in institutions or their own homes. People with mental disabilities may have no choice but to depend on families for a life-time. Without adequate support, family members often become overwhelmed and impoverished.

Conclusions

In the absence of an enforceable mental health law, everyone detained in Turkey's institutions is illegally and arbitrarily detained as a matter of the European Convention on Human Rights (ECHR). Within institutions, Turkey subjects its citizens with mental disabilities to a broad range of serious human rights violations. The use of unmodified ECT is the most common and dangerous human rights violation documented by MDRI. Even for children and adults who do not receive ECT, detention in a public psychiatric facility or a rehabilitation center is a degrading and dangerous experience. The lack of active treatment and rehabilitation at these facilities for thousands of children and adults with mental disabilities leaves them segregated from society with no hope of returning to normal life. The total inactivity and social isolation experienced in these facilities presents a threat to their development and psychological well-being. Such custodial detention violates the right to health of all people so detained.

The lack of community-based mental health services creates enormous pressures on in-patient psychiatric facilities and undermines the treatment and care they can provide. By unnecessarily filling inpatient beds with "chronic" patients, there is a shortage of resources for people in need of acute care throughout the system. Large state facilities throughout Turkey are overwhelmed. As a result, people most in need of treatment – individuals undergoing an acute psychiatric crisis – are often deprived of the attention and care they need. Staff at two state psychiatric facilities reported that ECT is commonly used because it appears to produce a quick alleviation of symptoms and patients can be returned to the community. Yet the provision of ECT in 20-40% of acute cases is totally inappropriate. Its efficacy for a wide variety of indications is unproven or contra-indicated by internationally accepted standards of psychiatry. Many patients reported to MDRI that they would do or say anything to be discharged to avoid being subjected to ECT.

For people subject to the most extreme abuses – the long-term use of physical restraints, the coerced use of unmodified ECT, the lack of protection against violence, and the denial of medical care – detention in a facility can be painful, dangerous and life threatening. Such practices constitute the most extreme forms of inhuman and degrading

treatment prohibited by international law. People subjected to unmodified ECT as a form of punishment are being subjected to torture.

The structure of Turkey’s public mental health and social service system segregates people with mental disabilities from society and puts large numbers of its citizens with mental disabilities at risk of these abuses. The sole reliance on long-term custodial facilities is contrary to internationally accepted human rights standards as well as widely recognized best practices in mental health. At a gathering of European governments convened by the WHO in January 2005, Ministers of Health of the member states for the European Region affirmed their commitment to “develop community-based services to replace care in large institutions for those with severe mental health problems.”¹ They also agreed to adopt mental health legislation to protect against discrimination and “end inhumane and degrading care.”² **European governments have committed themselves to “offer people with mental health problems choice and involvement in their own care, sensitive to their needs and culture.”³ Turkish mental health services do not meet these standards.**

As Turkey applies for membership in the European Union, it is under an obligation to take action to harmonize its laws and policies to meet European standards and to protect basic human rights of its citizens with disabilities. A major new commitment is urgently needed on the part of the government of Turkey to enforce these human rights — to protect people with mental disabilities against abuses within institutions and to develop positive programs to ensure their full integration into Turkish society.

Summary of Recommendations

MDRI recommends that the government of Turkey take immediate action to end conditions that are dangerous and life-threatening. Practices that constitute torture or inhuman or degrading treatment must be immediately terminated. The government of Turkey should:

- Ban the use of unmodified ECT in all circumstances;
- Establish guidelines to ensure that ECT is only used with appropriate medical safeguards, is only used in limited circumstances and within internationally accepted and proven indications for its use, and is never used without the free and informed consent of the individual subject to the treatment;
- Stop the use of restraints and seclusion as a substitute for rehabilitation and lack of staff;
- Ensure the availability of adequate food, staffing, and medical care to protect the basic health and safety of everyone detained in an institution;
- Create oversight mechanisms to ensure that physical and sexual abuse in institutions is terminated;
- Create a system of family support and supported foster care to ensure that all children with disabilities remain in a family-like environment rather than an institution; as soon as such programs are created, there should be

no new admissions of children to orphanages or rehabilitation centers in Turkey; and

- Adopt an enforceable mental health law consistent with international human rights standards. This law must provide a right to independent review of any decision to detain a person in an institution.

The Government of Turkey must make a commitment to the full inclusion of people with mental disabilities in all aspects of Turkish society. This includes all people with psychiatric as well as intellectual disabilities. Fulfilling its human rights obligations toward this population will require the development of a comprehensive system of community-based mental health and social services. MDRI recommends that Turkey establish a public commission to begin immediate planning for the creation of a community-based mental health and social service system that will permit people with psychiatric and intellectual disabilities to live, work, and receive treatment in the community.

MDRI has provided detailed recommendations at the end of this report about steps that can be taken to end abuses in institutions and plan for the creation of an effective and comprehensive community-based system of mental health and social services.

Turkey's International Legal Obligations

The government of Turkey has ratified the European Convention on Human Rights (ECHR),⁴ the European Convention for the Prevention of Torture (ECPT),⁵ the International Covenant on Civil and Political Rights (ICCPR),⁶ the International Covenant on Economic, Social, and Cultural Rights (ICESCR),⁷ and the Convention on the Rights of the Child (CRC).⁸

Turkey is under an immediate obligation to adopt enforceable legal protections against arbitrary detention.⁹ As the European Court of Human Rights has made clear, the protection against arbitrary detention entails a right to independent judicial review of every detainee in a psychiatric facility.¹⁰ Individuals subject to psychiatric commitment also have a right to counsel to assist them in the commitment hearing.¹¹

Torture, as well as inhuman and degrading treatment, is strictly prohibited by these conventions under all circumstances.¹² Lack of funding does not excuse these human rights violations. In its recent summary of international human rights law, the World Health Organization stated that:

The lack of financial or professional resources is not an excuse for inhuman and degrading treatment. Governments are required to provide adequate funding for basic needs and to protect the user against suffering that can be caused by a lack of food, inadequate clothing, improper staffing at an institution, lack of facilities for basic hygiene, or inadequate provision of an environment that is respectful of individual dignity.¹³

The structure of Turkey's service systems that segregate people with mental disabilities from society constitute discrimination prohibited by the ICESCR.¹⁴ The lack of community-based services violates the right to live, work, and receive treatment in the community as recognized by the UN's Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) and other international disability rights norms.¹⁵

Turkey's practice of segregating children with mental disabilities from society in orphanages and rehabilitation centers is a particularly serious problem. As described further in this report, research has shown that for young children, institutions are particularly dangerous. Thus, international law now takes a strong stand against congregate care for children in institutions. Article 23(1) of the CRC recognizes that "a mentally or physically disabled child 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."¹⁶

In addition to its obligations under the ECHR, future accession to the EU would require major changes in Turkish law and policy to bring the country's mental health and social service system into conformity with policies established by the EU. The European Parliament of the EU has called for Member States to provide people with mental disabilities with education, community services, and opportunities for living and working in the community.¹⁷ The European Parliament has recognized that people with mental disabilities have the right to live independently and participate fully in society.¹⁸

Preface: Goals & Methods of this Report

Behind Closed Doors: Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centers of Turkey describes the findings of a two-year investigation in Turkey by Mental Disability Rights International (MDRI) on the human rights of people with mental disabilities (this is a broad term that includes people with a diagnosis of mental illness and people with an intellectual disability such as mental retardation). We investigated public psychiatric facilities under the authority of the Ministry of Health as well as orphanages and rehabilitation centers under the authority of the Directorate for Social Services and Child Protection (SHCEK). The report also examines the human rights implications of health and social policies affecting people with mental disabilities in the community. This work is the product of five fact-finding investigations by inter-disciplinary teams of Turkish and US investigators that took place between September 2003 and July 2005. A short version of the report is also available from MDRI in video format at www.MDRI.org.

Behind Closed Doors assesses Turkey's enforcement of international human rights law pertaining to people who are detained or receive treatment through the public mental health and social service system. The goal of this report is to provide the information necessary for a full public understanding and debate about matters of fundamental importance to millions of Turkish individuals with disabilities and their families. It is our hope that this assessment will assist the Turkish government and Turkish citizens in promoting the reforms necessary to bring laws and practices in the mental health and social service systems into conformity with international human rights law. The report includes detailed recommendations for reform.

MDRI has published similar reports on human rights conditions in Hungary, Mexico, Peru, Russia, Uruguay, and the United Nations administration of Kosovo. In each report, we use a framework of international human rights law to provide a fair and consistent standard of assessment.

This is the first report in which MDRI has identified a practice – the use of ECT without anesthesia – that rises to the level of torture. It is important to note, however, that this practice was used in the United States and elsewhere in the 1940s. In historical perspective, the human rights abuses documented in this report are not fundamentally different from similar problems experienced in the United States and Europe over the last fifty years. The human rights abuses we document in this report should not be tolerated in any country. Yet, unfortunately, these human rights abuses are almost inevitable in any country without strong legal protections for people with mental disabilities – providing them protections against discrimination and abuse, as well as positive rights to participate fully in society. These abuses are also inevitable in any country that, like Turkey, segregates children or adults with mental disabilities behind closed doors of institutions, be they psychiatric facilities, rehabilitation centers, or orphanages. Out of sight and out of mind, the public can forget that a significant percentage of its population

will need support, assistance, and other accommodations to participate fully in society. When people are separated from society, dangerous stereotypes and stigma take hold—that people with mental disabilities are frightening, inherently bad, incapable, sick, or unable to make decisions about their lives. Placed in institutions in a position of dependence and vulnerability, these stereotypes may become self-fulfilling.

Given an opportunity to live as part of society, people with disabilities have shattered stereotypes and demonstrated that they are capable of living full and meaningful lives. In every country of the world, major changes have only taken place when users and former users of mental health and social service systems take charge of their own destiny. It is ultimately the goal of this report to encourage the government of Turkey to provide people with disabilities the opportunity to participate in determining their own future.

In the United States, Europe, Latin America, and other parts of the world, the process of mental health system reform began when the public learned about abuses in institutions and demanded change. And despite many important reforms in these countries, the abuse of this vulnerable population is an ongoing challenge everywhere. This is why strong oversight mechanisms are needed to shine the spotlight of public attention regularly and systematically on the treatment of people with mental disabilities.

This report is not intended to place blame on mental health professionals as a group. Many mental health professionals we encountered, as well as staff at institutions, work under difficult circumstances and would not continue to work except out of their professional dedication and care for the individuals they serve. It is generally our experience that, when resources are provided to improve care for people with mental disabilities, the working environment of mental health professionals and staff also improves dramatically. When legal systems create mechanisms for accountability, staff who are abusive must be removed from positions of power and authority. The result is a safer, more therapeutic, and more empowering environment for everyone. MDRI would like to thank the many public officials, mental health professionals, and staff who contributed their time and insights to our work.

A number of our sources took risks in speaking out about abuses they observed. Staff expressed fears that they could be “exiled” by having their jobs moved to remote parts of the country. Former patients who might be returned to institutions for treatment told MDRI that they were afraid of reprisals. To protect them, we have not used the names of any of our sources in this report. We have provided as much identifying information as we can to explain the perspective and basis for which a source provides information.

At every institution we visited, we attempted to be as thorough as we could in understanding the human rights situation of people living or receiving treatment at the facility. We asked to visit all parts of the institutions. We interviewed institutional authorities, staff, and patients. During each site visit, MDRI teams brought a video camera to record observations. To the extent that we could, we took photographs in each

institution. It is our experience that photo and video documentation is tremendously helpful in corroborating our observations and helping the public to understand the reality of life in an institution. We generally find that people within institutions are amenable or eager to have their photographs taken.

We did experience some important limitations on our ability to document human rights conditions. In many institutions our access was limited. We were often prohibited from taking photographs or video. We were denied entry to a number of institutions. In many cases, institutional authorities expressed their willingness to help but stated that they did not have permission from authorities in Ankara to grant us access. On one visit to Saray, however, we were denied access despite prior approval of the visit by higher authorities at the Directorate for Social Services & Child Protection (SHCEK). This would have been a more comprehensive report if we had been granted greater access.

We are acutely aware of the limitations of understanding any society from the outside. This report is, therefore, the product of collaboration between US and Turkish citizens who have each brought valuable personal and professional experience to this project. The US citizens who participated in this investigation are all experienced in fighting against human rights abuses within the United States and in other countries of the world. It is our belief that lessons learned in other countries are of direct relevance to Turkey. Turkey can draw on these experiences – and avoid mistakes made in the United States and elsewhere. Mental health service reform has taken half a century in the United States and there is a long way to go to provide the most effective and humane services. It is our belief that Turkey can protect the rights of its citizens and bring about their full participation in society through a much quicker process of reform.

Turkey is a large country, and there are inevitably differences in the mental health and social service systems in different regions and within the sites that we visited. There are no doubt valuable programs – as well as serious abuses – that we were not able to include in our report. We acknowledge these limitations of our work. We have made every effort to provide as accurate and comprehensive an analysis of the major human rights issues as we were able to understand them. The observations and conclusions reached in this report represent the position of the authors and of MDRI alone. If any reader identifies errors or omissions in the report, we encourage you to contact MDRI at mdri@mdri.org. We intend to publish updates of this report, as well as corrections, on our website at www.MDRI.org.

This report was originally written in English. While we have made every effort to provide an accurate translation, there are inevitably differences in technical meaning or nuance. If there is any question about a discrepancy between the two versions, please refer to the English original.

I. Abuses in Psychiatric Institutions

MDRI investigators visited three large state hospitals (Bakirköy and Erenköy in Istanbul and Manisa near Izmir) as well as three university hospitals (in Ankara, Marmara, and Dokuz Eylül in Izmir). The largest psychiatric facility in the country (and perhaps the largest in Europe) is Bakirköy in Istanbul, with 2970 beds.¹⁹ At Manisa Hospital, there are 400 beds for 500 in-patients. There are at least six large state psychiatric facilities in Turkey spread out over the country (five regional facilities plus the Erenköy institution formerly dedicated to the care of state workers). There are smaller psychiatric units at university and general hospitals, as well as forensic units of prisons. In addition, the Turkish military operates psychiatric facilities that include many people undergoing evaluation of fitness for military service (we were not able to visit any of these facilities). We received varying estimates of the number of people detained in psychiatric facilities. The five regional psychiatric facilities are reported to have approximately 5,500 beds.²⁰ In 2003, the Vice President of the Turkish Psychiatric Association reported to MDRI that there are a total of 9,000 inpatient beds in the public mental health system.

As described in Section III of this report, the mental health system of Turkey does not provide adequate services or support systems for people with mental disabilities who wish to remain living in their homes in the community. As a result, people with a psychiatric disability in need of services may have no choice but to seek treatment as an inpatient. The lack of community-based alternatives creates enormous pressures on inpatient facilities and undermines the treatment and care they can provide. By unnecessarily filling inpatient beds, there is a shortage of resources for people in need of acute care throughout the system. A small number of university hospitals are able to provide a full range of care to the few people able to gain access to their services. Large state facilities throughout Turkey, however, are overwhelmed. As a result, people most in need of treatment – individuals undergoing an acute psychiatric crisis – are often deprived of the attention and care they need. The assistant director of Manisa stated that, due to these pressures, no treatment other than medications and electroconvulsive therapy (ECT) is available.

A. Electroconvulsive therapy (ECT) without anesthesia

The most widespread and serious human rights violation MDRI observed in Turkey's mental health system is the common practice of using electroconvulsive therapy (ECT) in its "unmodified" form without anesthesia, muscle relaxants, or oxygenation.

The practice of unmodified ECT creates a climate of fear that pervades public psychiatric facilities and makes many people afraid to seek any form of psychiatric treatment or care.

I only had ECT one time. It was the first and the last time. They hold you down, they hold your arms, they hold your head and they put cotton in your mouth. I heard them say 70 to 110 volts. I felt the electricity and the pain, I felt like dying.

– 28-year-old former Bakirköy psychiatric patient, subjected to "unmodified" ECT

I went to Bakirköy because I was very depressed. I got medications. I had no idea what ECT was. I knew nothing except electricity was given to the brain. The doctors gave me no information. I had it nine times and I feared a lot while they were giving me ECT. They put cotton in my mouth. My eyes were opened and I saw everything. They put metal bars on both sides of my head. The moment they touched my head I saw a white light, like from a florescent light, very bright. It was very cold and I experienced a kind of pain, a different pain than I ever experienced before.

I saw someone else after they received ECT. He was trembling very much. I saw saliva on his mouth. And I thought that this cannot be a good thing whatever it is. It looked like torture. He opened his eyes wide as if he was fixed on some object. I was curious as to what it [ECT] looked like. I opened the door and saw. So finally I understood why they were hiding it.

– 26 year-old former Bakirköy patient

Under any circumstances, subjecting people to extreme forms of pain and suffering constitutes “inhuman and degrading treatment” under the ECHR. The European Committee for the Prevention of Torture has ruled that the practice of unmodified ECT violates the European Convention against Torture.²¹ The practice of unmodified ECT in Turkish psychiatric facilities involves the intentional infliction of severe pain or fear of such pain on people who have committed no crime, are theoretically detained for their own protection and treatment, and are likely to be particularly vulnerable due to the emotional distress of their personal circumstances. At minimum, the practice of unmodified ECT constitutes inhuman and degrading treatment in violation of the ECPT and the ECHR. To the extent that ECT is used as a form of punishment – or is held over patients as a threat of punishment – the practice rises to the level of torture under these international human rights conventions.

We use ECT for people with major depression. Patients with major depression feel that they need to be punished. If we use anesthesia the ECT won't be as effective because they won't feel punished. – Chief of ECT Center, Bakirköy

Electroconvulsive therapy with appropriate medical safeguards, such as anesthesia and muscle relaxants, is an accepted psychiatric treatment whereby a controlled electric current is passed through the brain to induce a seizure. Even with safeguards, ECT can have dangerous side effects, such as heart complications, prolonged seizures, apnea, and even death.²² Common side effects include headache, muscle soreness, and nausea.²³ The most significant side effects are potentially severe cognitive impairments, such as amnesia and deficits in concentration and attention.²⁴ While side effects for some people may be short term, “patients vary considerably in the extent and severity of their cognitive side effects following ECT.”²⁵ For some people, cognitive deficits may be persistent,²⁶ sometimes lasting years,²⁷ and can be frightening and extremely disruptive to a person’s life.²⁸

Despite the risks involved, mainstream mental health professionals believe that the combination of the electrical current and the ensuing seizure combine to provide short-term relief of symptoms of certain specific conditions.²⁹ The normal course of ECT involves a series of treatments, from 6 to 21 sessions (three times a week for two to seven weeks).³⁰ According to the American Psychiatric Association's 2001 guidelines, the primary indications for ECT are severe major depression, acute mania, mood disorders with psychotic features, and catatonia.³¹ ECT may be a secondary treatment for a broader array of conditions that do not respond to other forms of treatment.³² In Europe, standards for the use of ECT are generally stricter than in the United States. The British National Institute for Clinical Excellence recommends, for example, that ECT be used "only to achieve rapid and short-term improvement of severe symptoms after an adequate trial of other treatment options has proven ineffective and/or when the condition is considered to be potentially life-threatening, in individuals with severe depressive illness, catatonia, or severe manic episodes."³³

Since the 1950s, the use of general anesthesia, muscle relaxants and oxygenation during the administration of ECT treatments has become standard medical practice. Thus, there has been almost no research and no documentation of the dangers of unmodified ECT for almost half a century (and Turkish psychiatric facilities have never monitored these side effects). As one modern ECT researcher remembers:

When it was first introduced, electroshock was given without anesthetic, and patients approached each treatment with anxiety, dread, and panic. Some patients sustained fractures; some died. Anesthesia, muscle relaxation and hyperoxygenation were answers to the problems, but they were not accepted as routine measures until the mid-1950s, after 20 years of unmodified ECT. Unmodified treatments did harm memory, so much so that memory loss came to be seen as an essential part of the treatment.³⁴

Much of the danger of unmodified ECT is caused by the lack of a muscle relaxant (which cannot be administered unless anesthesia is also present). ECT produces a generalized tonic-clonic seizure,³⁵ meaning that electrical stimulation from the brain to the muscles stimulates the muscles to contract and relax repeatedly with great force.³⁶ Such forceful contractions will put the patient at risk for any type of musculoskeletal injury, including bone fractures, joint dislocations and damage to skeletal muscle, tendons, and ligaments. In fact, it was the observation of such musculoskeletal injuries that led to the introduction of muscle relaxants to convulsive therapy in 1941.³⁷ Prior to the use of muscle relaxants during convulsive treatment, the main risk to the patient was spinal fracture.³⁸ In addition, several other injuries which can be greatly reduced by administration of muscle relaxants have been reported, including hip fractures,³⁹ hip dislocations,⁴⁰ shoulder fractures, shoulder dislocations, bronchospasm,⁴¹ neck strain,⁴² headaches,⁴³ and generalized muscle soreness.⁴⁴

The lack of oxygenation is another danger of unmodified ECT. Professional standards for ECT include the use of oxygenation during the seizure.⁴⁵ In Turkey, psychiatrists report that oxygen is available following the seizure if there an interruption

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in breathing, but oxygen is not usually provided during the seizure itself. Thus, there is an interruption of oxygen reaching the brain inherent in this form of unmodified ECT. Research has shown that oxygenation before, during, and after the ECT seizure reduces cognitive deficits.⁴⁶

Some psychiatrists in Turkey claim that individuals subject to unmodified ECT do not feel pain because of the seizure caused by the electrical stimulus to the brain. Yet it is well established that there may be a delay of 20-40 seconds between the time electricity is administered and the time of the seizure.⁴⁷ The sensation of an electric shock during this time can be extremely painful. In addition, some people may not go into a seizure at all when even after they are subject to electric shock.⁴⁸ The amount of electricity required to cause a seizure varies widely from one individual to another. When anesthesia is used, it is standard practice to start with a low voltage of electricity and slowly increase (or “titrate”) the shock to use the minimum of electricity required to induce a seizure. For a person without anesthesia, this process would be extremely painful.

Given these dangers, the World Health Organization has called for the “practice of using unmodified ECT [to] be stopped.”⁴⁹ The Council of Europe’s Bioethics Committee also has called for unmodified ECT to be strictly prohibited.⁵⁰ In October 1997, the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) visited Bakirköy and Samsun Hospitals and criticized their use of unmodified ECT, finding it “degrading for both the staff and patients concerned.”^a

In its 1997 visit to Turkish psychiatric facilities, the use of unmodified ECT was the most serious concern raised by the CPT. The CPT called on Turkey to terminate the use of this practice immediately. The CPT also expressed alarm at the extremely high percentage of acute patients receiving ECT. The Ministry of Health of Turkey, in its response to the CPT findings, promised to support changes at Bakirköy. They stated that because Bakirköy possesses a neurosurgery department, they are prepared with both the personnel and equipment to provide anesthesia during ECT treatments. The Ministry also said they would work to ensure that the “new, state-of-the-art ECT centre,” under

^a “The CPT is seriously concerned by the current procedures for the administration of ECT observed in the Bakirköy and Samsun Hospitals, and in particular by the frequent recourse to this treatment in its unmodified form (i.e. without anaesthetic and muscle relaxants). Admittedly, ECT is a well-established and scientifically valid form of treatment. However, the application of unmodified ECT can no longer be considered as acceptable in modern psychiatric practice. Apart from the risk of fractures or other untoward medical consequences, the process as such is degrading for both the staff and patients concerned. . . . In light of the above remarks, **the CPT recommends that the practice of unmodified ECT (i.e. without anaesthetic and muscle relaxants) be discontinued in the Bakirköy and Samsun Hospitals as well as in any other psychiatric establishment in Turkey where this method is currently employed.**” (underline and bold in original). European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, REPORT TO THE TURKISH GOVERNMENT ON THE VISIT TO TURKEY CARRIED OUT BY THE EUROPEAN COMMITTEE FOR THE PREVENTION OF TORTURE AND INHUMAN AND DEGRADING TREATMENT OR PUNISHMENT (CPT) FROM 5 TO 17 OCTOBER 1993 (Feb. 23, 1999), para. 178, at <http://www.cpt.coe.int/documents/tur/1999-02-inf-eng.htm#II.C.3>.

construction at Bakirköy and due to open in July of 1999, would perform a “leadership function for other hospitals” and would eliminate the barriers “which prevent ECT from being practiced in a modern and scientific manner.” Additionally, the Ministry reiterated that the indications for the use of ECT “are being steadily restricted worldwide” and should only be used for: (1) serious suicidal and homicidal psychotic patients; (2) psychotic patients exhibiting catatonic motor behavior; (3) psychotic patients refusing nourishment; and (4) depressive patients for whom medication remains ineffective.⁵¹

Despite a clear mandate set forth by the European Committee for the Prevention of Torture, the Council of Europe’s Bioethics Committee, and established “best practice” guidelines on the use of ECT, MDRI’s investigation finds that the practice of unmodified ECT persists unabated at Bakirköy, Erenköy, and Manisa psychiatric facilities – and likely throughout Turkey’s public mental health system.

On MDRI’s 2005 visit to Bakirköy, investigators toured the “state-of-the-art ECT centre,” which opened in 1999. While psychiatrists at the main administration building informed us that all ECT performed at the center that day had been administered with anesthesia, the psychiatric resident who administered the ECT that day reported that no anesthesia had been used. Indeed, the resident said that ECT was *only* applied with anesthesia when a patient has a bone fracture or dislocated jaw. As this resident described:

We only give anesthesia to patients with bone fractures or dislocated mandibles. We gave ECT to 16 patients today without anesthesia. Patients are always nervous and afraid. Three staff is used to hold down the patient. When they give ECT on the wards, they use straightjackets. Anesthesia may lessen pre-ECT anxiety and it may be more ethical, but the patients don’t feel any pain.

– Physician on duty at
Bakirköy ECT center

Mental health professionals at university hospitals report that the use of unmodified ECT has been terminated because of negative experiences with its use. Many Turkish university hospital psychiatrists have taken a strong stand against unmodified ECT because of its dangers. Staff at all three university hospitals we visited reported that they discontinued the use of unmodified ECT because of the dangers they observed in patients subject to this treatment. The impact of the seizure without muscle relaxants leads to bone fractures and dislocated joints. At Manisa hospital, where unmodified ECT is still used, the assistant director reported that dislocated jaws are common. “We usually avoid [fractures] because we know how to hold the patient down,” the assistant director stated, “but when it happens, we know how to snap it back.” A psychiatrist at Ankara University Hospital described her experience with unmodified ECT before the practice was banned at her hospital, saying, “**I remember one case where it cured the patient’s depression – but left the man in traction for six months when he fractured his spine.**” A psychiatrist from Marmara University explained that without oxygenation, ECT can be life-threatening.

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Despite these dangers, authorities at Bakirköy, Manisa, and Erenköy reported to MDRI that they all continue to administer unmodified ECT. When MDRI asked for exact numbers or information about the side effects of unmodified ECT, we learned that none of these hospitals keep track of how often dangerous complications occur. Nor were the authorities at any of these institutions aware of the Turkish government's pronouncements to the European Committee for the Prevention of Torture about limitations on the use of ECT. At each of these facilities, authorities reported that there were no official rules or regulations, controlling standards, or guidelines on the use of ECT. Yet psychiatrists at each facility expressed that they are aware that Turkish practices are not in conformity with international medical standards.

In every professional meeting on ECT, I raise this issue. So it is still alive. I teach students here about the dangers of unmodified ECT Everyone knows our views. I attend most psychiatric conferences. Many other psychiatrists share our view, but they make little effort to change things. They are passive. – Professor Psychiatry, Marmara University

ECT with or without anesthesia causes short-term amnesia. According to authorities at Bakirköy, the use of ECT among young people is particularly disruptive because they often lose a full year of their education. The amnesia caused by ECT also makes it difficult to document the pain caused by its administration without anesthesia. Many people subjected to this treatment cannot remember the experience. Amnesia is not universal, however, and it was not hard for MDRI investigators to identify individuals who could remember the experience. These individuals reported feeling the electricity in their bodies and experiencing tremendous pain.

While some people feel that ECT benefits them, many others are terrified by the experience and wish to avoid it. The practice of unmodified ECT is of particular concern because it is usually administered without informed consent. Authorities at Bakirköy claim that they always obtain informed consent for ECT, and specialized informed consent forms exist at Bakirköy – yet these forms permit family members to consent on behalf of relatives (indeed, the forms provided to MDRI investigators at Bakirköy did not even have a place where the patient could sign). No legal procedure is required to empower a family member to make such a decision and no process exists to inform the patient or his or her family of the risks inherent in unmodified ECT use (see further discussion on the lack of legal protections in part IV of this report). At Bakirköy, psychiatrists report that they often have to bring patients into the ECT room in a straight jacket. At both Manisa and Erenkoy hospitals, staff report that they routinely misinform patients, telling them that they are going to get an x-ray or other medical procedure to get them into the ECT room.

During the administration of ECT, three people are used to hold down the patient. The fear of the entire patient population is magnified greatly by watching or hearing other patients subjected to ECT. At Manisa and Bakirköy, ECT is administered on the ward with other patients watching or hearing what is going on (despite the creation of an ECT center at Bakirköy, ECT is also still administered on the ward). At Manisa and Erenköy,

patients reported to MDRI that they are forced to hold down others receiving ECT. One patient from Manisa reported to MDRI that he was ordered to hold down more than 200 patients for ECT:

Each time they called my name, I was terrified that it would be my turn next. I lived in constant fear of getting ECT. But holding down other patients was maybe more horrible. I was in the hospital because of my own crisis and I did not want to hurt other people. But I felt I could not say no to the staff. They could do anything to me if I said no.

– Former psychiatric patient at Manisa

A psychiatrist at Marmara University explained that before unmodified ECT was abolished at his facility, he would try unsuccessfully to cover up the screams of patients. “I introduced music so other patients would not hear it. But people cried out nonetheless and there was no way to stop other patients from hearing,” he explained.

B. Over-use and misuse of ECT

With or without anesthesia, ECT is overused and misused in Turkish psychiatric facilities because of a lack of other forms of treatment. This practice exposes thousands of people to unnecessary, potentially dangerous, and frightening experiences. Turkish psychiatric facilities also use ECT in cases for which there is no evidence of its efficacy or where it is specifically contra-indicated. Under the UN’s Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (the MI Principles), psychiatric care may only be provided if it is “appropriate to his or her health needs” – and not for the administrative convenience of the institution. Furthermore, “[e]very patient shall be protected from harm, including unjustified medication . . . or other acts causing mental distress or physical discomfort.”⁵²

The use of ECT for any condition for which there is no clinically proven record of efficacy is a form of inhuman and degrading treatment and a violation of the right to health. This is true for any form of ECT – even with anesthesia and other modern medical safeguards. In addition to the known risks of ECT, there are inherent dangers to the use of any unproven medical practice. The use of an inherently risky medical procedure for unproven benefits constitutes a form of “medical experimentation” which violates article 7 of the International Covenant on Civil and Political Rights.⁵³

In 1997, the European Committee for the Prevention of Torture (CPT) expressed concern that up to 20% of the patients at Bakirköy were receiving ECT.⁵⁴ During MDRI’s 2003-5 investigation, psychiatrists at Bakirköy, Erenköy, and Manisa informed MDRI that 20-33% of acute patients at hospitals receive ECT at any one time. At Dokuz Eylül University Hospital, authorities reported to MDRI in July 2005 that 40% of inpatients receive ECT at any one time.

According to the CPT, Turkish authorities claimed in 1997 that they used such a high level of ECT because of “the shortage of alternative treatment facilities.”⁵⁵ During

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MDRI's investigation, psychiatrists at Bakirköy and Manisa stated that ECT is frequently used because of a lack of beds in the institution and the need to move people out quickly.^b At Manisa, the assistant director said that ECT is often used because the facility is chronically understaffed:

We only have a quarter of the nurses we need. ECT is supposed to be used when a patient is suicidal. But how can psychiatrists know when a patient is suicidal without enough nurses? We give ECT (unmodified) when we don't know just to be sure.

– Assistant director of Manisa

Official policy at Bakirköy is that ECT is used when medications prove ineffective. A psychiatrist at the Bakirköy admission unit explained that in practice, however, ECT is frequently used when there is a shortage of beds and there is insufficient time to assess the impact of medications. While some psychiatrists claim to use medications as the first line of treatment, they do not always leave time to assess the impact of medications. One psychiatrist at Bakirköy explained that he only waits three or four days to see if a person responds to medications before he administers ECT. "I have great experience in this, so I can usually tell in three days," he said. This assertion is not credible. It is well established in the psychiatric literature that the effects of most psychotropic medications for major mental disorders cannot be evaluated before a patient has received them for at least 10-14 days. This is the time it takes to evaluate one medication, though most accepted treatment protocols for the use of ECT require that at least two alternatives should be tried before ECT is administered.

There is no law or professional standard in Turkey governing the practice of ECT or restricting hospitals from its misuse. In its response to the European Committee for the Prevention of Torture, however, the Turkish government claimed that ECT should be used only to treat four limited conditions. The chief psychiatrist at the Bakirköy ECT told MDRI investigators in July 2005 that "Psychiatrists make the decision about who gets ECT. We do not go by any Turkish Ministry standards." The list of indications he provided MDRI were much broader than what was promised to the CPT. A substantially similar list was provided to MDRI independently by a psychiatric resident in charge of the ECT center when we visited in April 2005. According to them, ECT is used for:

- depression or bipolar disorder
- schizophrenia
- eating disorders, such as anorexia
- epilepsy (if anti-epilepsy medication doesn't work)
- obsessive-compulsive disorder

^b When used as a treatment for certain accepted indications, such as major depression, ECT may bring about a much quicker (though temporary) alleviation of symptoms than do most psychotropic medications. When administered inappropriately on individuals for which there is no clinical justification, we can only speculate as to why the use of ECT clears beds quickly. Given the high levels of fear of the procedure reported to MDRI, it is likely that some people will behave in any way necessary to convince mental health authorities that they are ready to be discharged.

- borderline patients with psychotic episodes
- people with neuroleptic malignant syndrome who cannot take neuroleptics^c
- elders (because they may not tolerate medications)
- pregnant women with depression (because they cannot take all psychiatric medications)
- children 12 to 18 years of age (at least once every day at Bakirköy, occasionally on children as young as 9 years old)
- very aggressive patients
- Alzheimer's with depression
- Parkinson's disease
- Post-partum depression (ECT is considered the best line of treatment for this and is used before medications are tried)
- People with mental retardation with affective disorders or self-abuse
- delirium tremens due to alcoholism
- personality disorders, such as schizoid personality disorder

There is no clinical evidence of efficacy for many of these indications – such as personality disorders or substance abuse problems.⁵⁶ A number of the above conditions are specifically contraindicated. The British National Institute for Clinical Excellence, for example, states that “[t]he risks associated with ECT may be enhanced during pregnancy, in older people, and in children and young people, and therefore clinicians should exercise particular caution when considering ECT treatment for these groups.”⁵⁷

Widely different rationales are used to explain the rate of ECT use at different institutions. At Dokuz Eylül, a psychiatrist explained that ECT makes medications more effective. At Manisa, the assistant director explained that he is more likely to use ECT for patients who come from long distances and will not have access to medications after they leave the facility. The psychiatrist at Bakirköy said that ECT is used more and with higher voltages of electricity for black people from the southern part of Turkey.

Even when used with anesthesia, precautions are not taken that could reduce side effects of ECT. According to the American Psychiatric Association standards, “ECT treatment technique is a major determinant of the percentage of patients who develop delirium characterized by continuous disorientation.”⁵⁸ The most important way to reduce cognitive side effects is to use electricity on only one side of the brain (unilateral) rather than both sides of the brain (bilateral).⁵⁹ At Manisa and Bakirköy, the more dangerous form of bilateral ECT is used. In addition, large numbers of closely spaced treatments may contribute to cognitive deficits. At Bakirköy, the chief of the ECT unit said that ECT is occasionally administered intensively – up to five times a week for five or six weeks.

^c Neuroleptic malignant syndrome is a dangerous medical condition created as a side-effect of neuroleptic medications used to treat major mental disorders.

C. No standards of care

Psychiatrists at Marmara University Hospital state that the ongoing misuse of ECT is emblematic of a larger problem that endangers patients throughout the country's mental health system: the lack of enforceable standards of care.

We know ECT may be used as a punishment. This is possible because you do not have standards of treatment. Medical standards would protect against abuse.

– Professor of Psychiatry, Marmara University

At Manisa, the assistant director explained that the lack of standards goes far beyond the use of ECT. “There are no standards for any treatment,” this psychiatrist explained. A psychiatrist at Dokuz Eylül University Hospital in Izmir reports that in May 2005, the Turkish Psychiatric Association (TPA) adopted standards for the first time, guiding treatment for people with schizophrenia, bipolar disorder, and anxiety disorders. The standards adopted by the TPA include descriptions of the psychotherapy and psychosocial supports needed for individuals with these diagnoses. The psychiatrist pointed out, however, that it would be “impossible” to implement these standards at major psychiatric facilities such as Bakirköy because of the lack of staff available to any individual patient.

D. Custodial care without rehabilitation

The segregation of a person from society in a closed institution for a long or short period of time is enormously disruptive to a person's life in the community. For a young person, it may disrupt his or her education, professional development, and establishment of normal social ties. For a working person, it may mean the loss of a job and the economic opportunity to care for oneself or one's family. For a mother, father, husband or wife, placement in an institution may take a person away from family members they love and who depend on them. Research has shown that the dependency created by long-term institutionalization is particularly dangerous, leading to a decline in social and psychological functioning. Thus, it has been a trend in mental health policy for the last thirty years to move away from custodial institutionalization wherever possible. The vast majority of people with psychiatric disabilities can live in their own homes, and many can keep jobs when they are provided with mental health care and social support in the community.

Due to the enormous deprivation of liberty entailed in placement in an institution, the European Convention requires independent legal oversight in any case where a person is detained. Many people detained in institutions may not be aware of their choices or may be so distressed by their emotional condition that they cannot stand up for their rights. Thus, independent oversight of psychiatric commitment is required by international law, whether or not a person actively protests.⁶⁰ In Turkey, there are no legal protections against improper detention in a psychiatric facility. Section IV of this report describes the inadequate protections against detention under Turkish law.

In addition to legal protections in the commitment process, European human rights standards require that any placement in a psychiatric facility be limited to circumstances where “placement includes a therapeutic purpose.”⁶¹ Care within an inpatient facility rather than the community can only be justified when “no less restrictive means of providing appropriate care are available.”⁶² If a person must be treated in an inpatient setting, he or she “should receive treatment and care provided by adequately qualified staff and based on an appropriate individually prescribed treatment plan.”⁶³ The United Nations has adopted similar human rights principles. The UN standards state that the “treatment of every patient shall be directed towards preserving and enhancing personal autonomy.”⁶⁴ The UN Special Rapporteur on the Right to Health, Paul Hunt, has recently observed that:

Decisions to isolate or segregate persons with mental disabilities, including through unnecessary institutionalization, are inherently discriminatory and contrary to the right of community integration enshrined in international standards. Segregation and isolation in itself can also entrench stigma surrounding mental disability.⁶⁵

At every state psychiatric facility visited by MDRI – Bakirköy, Erenköy, and Manisa – we observed violations of these basic human rights standards. The situation is most serious for thousands of so-called “chronic” patients who are detained for life. We also observed that many short-term acute patients are treated unnecessarily in an inpatient setting. Treatment for both groups is inadequate and frequently undermines a person’s ability to develop the psychological support and skills needed to live independently and return to the community as soon as possible. In some circumstances, particularly at Manisa hospital, we observed degrading and dangerous conditions of living.

The lack of community alternatives also leads to the inappropriate and unnecessary institutionalization of people capable of living and receiving treatment in the community. At Manisa hospital, the assistant director reported that of 500 patients at the facility, only 50 would need to be detained as in-patients if community-based services were available. At Bakirköy, more than 1,000 people remain in the institution for life. According to psychiatrists at Bakirköy, these people are generally not violent or in need of acute care. The assistant director at Manisa says that for most people, the institution serves as a “hotel” where they stay because they have no place else to go. For these individuals, the institution provides no care that could not otherwise be provided in the community (if community-based supports were available). Yet, unlike a hotel, these people cannot leave. Having been detained so long, the assistant director of Manisa says, “most of them have lost all contact” with the outside world.

It is beyond the scope of this report to assess all the human rights concerns of inpatients in Turkish psychiatric facilities. At Manisa, we were prohibited from visiting residential wards. From four visits to Bakirköy and one visit to Erenköy, however, one major observation stands out: the near total inactivity of patients. At both facilities,

people sat in beds or chairs or wandered the grounds of the facility with little to occupy them. It is widely accepted in the field of psychiatry that isolation from society combined with inactivity in an institution contributes to a decline in a person's social and psychological functioning. A person who lives entirely dependent on an institution becomes psychologically dependent or "institutionalized."

While our access was most limited at Manisa, our concerns at this facility were the greatest of the psychiatric facilities we visited. People wandering the grounds were generally in filthy clothing, and their hands and feet were so dirty it appeared as if they had not washed in days. Many people were missing teeth and obviously had not received dental care. A former patient said that most patients had lice in their hair and bed sheets. People at Manisa for short-term acute care are mixed together with people who have been detained for a lifetime. They are also kept on the same ward as individuals with criminal records or those who are awaiting trial for violent crimes. On occasion, children are detained on these same wards. While there are 150 women among the 500 people detained at this facility, we only saw three women outdoors during our July 2005 visit, whereas many men were freely roaming the grounds. According to the assistant director, at least 80 women are kept on a locked ward and are not allowed outside "because they cannot protect themselves from being raped." MDRI is concerned that violence among patients or by staff goes unreported since there is no system for tracking incident reports in Manisa.

MDRI is also concerned about the denial of necessary medical treatment in psychiatric institutions (a serious problem we found in Turkey's rehabilitation centers). We were not able to conduct a thorough investigation of this matter, but we did observe one striking case at Manisa. We observed a man at Manisa with cotton balls stuffed permanently in the remnants of his mouth and eye socket, which had been torn apart from a bullet wound. He is unable to eat except through a tube left hanging from his nose. He had attempted suicide and was told that he could not have an operation for his condition until he is released from the psychiatric facility in nine months.

At Bakirköy and at Manisa, staff psychiatrists complained about the pressures on them due to shortages of staff. MDRI is not in a position to evaluate the actual number of psychiatrists available to see patients, since we were unable to obtain precise staff to patient ratios. At Bakirköy, our team observed numerous professionals on every ward we visited. During our visits, however, we observed staff gathered at nursing stations talking amongst themselves while patients received little attention. The limited amount of time that any professional staff spends with patients is obviously a problem. The assistant Director of Manisa, as well as a psychiatrist at Bakirköy, explained that there are adequate numbers of psychiatrists, but other care givers (such as social workers or nurses) are in short supply. Despite apparently large numbers of psychiatrists on staff at Bakirköy, authorities report that psychiatrists can see patients for no more than 10 minutes at a time. Whatever the reasons for the short staff time available to patients, the result is that the public mental health system provides almost no psychosocial rehabilitation or care other than medications. Authorities at Manisa report that they only have 25% of the nurses and direct care-givers they would need for such care.

II. Abuses in Rehabilitation Centers & Orphanages

MDRI examined conditions at three so-called “rehabilitation centers” for children and adults with disabilities under the authority of SHCEK, serving a total of approximately 900 people. We visited one rehabilitation center outside of Ankara (Saray), one in Istanbul (Zeytinburnu), and one in a remote area two hours from Ankara (Ayas).⁶⁶ We also visited the Kecioren orphanage for 310 children in Ankara, of whom 30 are diagnosed with mental disabilities. According to documents provided to MDRI by SHCEK authorities, there are some 18,000 children and adults in rehabilitation centers out of a total of 30,000 people in residential institutions. Our findings lead us to believe that there may be many more children and adults with disabilities in institutions than officials would indicate.^d To the extent that the four institutions visited by MDRI are representative of all SHCEK facilities, we conclude that everyone detained in a SHCEK institution is at risk of serious human rights violations. For most people with mental disabilities, placement in a SHCEK facility is a life sentence that will leave them segregated from society for the rest of their lives.

My daughter is 11 years old and has a disability. I have tried to get her into six different schools, but I always get rejected. I have never worked so I can't get the 300 million [Turkish Lire] social security I need to pay. And they say she is a difficult child. She has no toilet training and is hyperactive. But I have to think of my child's future. Now I am a single mother and I need to work to take care of us. There should be all-day schools but now I have no options left. I don't want to send her to Saray. A neighbor of mine told me that some children had died there because they were beaten. She told me to give her to Saray only when you know you are going to die.

– Mother of a child with a disability

I love my daughter, but I hope she dies before I do. I do not know what will happen to her after I die and can't take care of her any longer. I do not want her ever to have to live in the institution.

– Mother who is also director of a private school for children with mental disabilities

^d It is difficult to establish exactly how many people with mental disabilities are detained in SHCEK institutions because information provided to the public and MDRI investigators has varied widely and at times has been conflicting. The actual number of institutionalized people in SHCEK institutions may be higher than numbers cited by SHCEK, as each facility MDRI visited housed many more people than the “legal census” established by SHCEK. MDRI also received conflicting information from SHCEK authorities about the number of people with mental disabilities among the total institutional population. Certain facilities are designated for people with mental disabilities, while others are not. Despite this, two of four SHCEK facilities visited by MDRI teams that were not designated for mental disabilities did indeed house people with mental disabilities.

A. Inhuman and degrading conditions of detention

The Council of Europe has established that “[f]acilities designed for the placement of persons with mental disorder should provide each such person...with an environment and living conditions as close as possible to those of persons of similar age, gender and culture in the community.”⁶⁷ The European Committee for the Prevention of Torture (CPT) has issued standards regarding “conditions and treatment” and specifies, “inadequacies in these areas can rapidly lead to situations falling within the scope of the term ‘inhuman and degrading treatment.’ The aim should be to offer material conditions which are conducive to the treatment and welfare of patients.”⁶⁸

Conditions in the SHCEK rehabilitation centers visited do not meet this standard. MDRI observed degrading physical conditions, a total lack of privacy, overcrowding, the use of physical restraints, lack of appropriate care and habilitation,^e the denial of medical care, and the lack of protection against physical and sexual abuse in all SHCEK rehabilitation centers. Together, these conditions amount to inhuman and degrading treatment prohibited by the European Convention for the Prevention of Torture and Inhuman and Degrading Treatment or Punishment (the ECPT) and article 3 of the European Convention on Human Rights (ECHR). In some cases, violence in the institution, unhygienic conditions, and lack of treatment are dangerous and life-threatening. Failure to protect children and adults from dangerous conditions violates their right to life under article 2 of the ECHR.

Over prolonged periods, the inactivity and degrading conditions of living in institutions will have a major physical and psychological impact on most individuals, leading to lethargy and depression, loss of self-esteem, and a tendency not to maintain basic living or self-care skills that a person may have upon entry.⁶⁹ Long-term institutionalization in degrading conditions contributes to a person’s disability. All three SHCEK rehabilitation centers observed by MDRI were degrading and long-term detention in such a facility violates the right to the “highest attainable standard of physical and mental health.”⁷⁰ Children are particularly vulnerable to the dangers of being raised in a congregate setting.⁷¹ Conditions we observed violate the Convention on the Rights of the Child (CRC), which guarantees that “a mentally or physically disabled child 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.”⁷²

The following is an overview of observations in four institutions:

1. Saray Rehabilitation Center, Ankara

Saray is the largest state run residential rehabilitation center, officially designated for children with developmental or intellectual disabilities in Turkey. Located on the access road to the airport, on the outskirts of the city, it warehouses 750 children and adults with a variety of disabilities. With an official capacity of 408 residents at Saray,

^e Habilitation is the term used by professionals to describe assistance needed by people with intellectual disabilities to preserve and enhance their basic living skills.

there are over 3000 children on the waiting list for admission into this already overcrowded institution. Although billed as a “rehabilitation” facility for children, it is essentially an orphanage where most people are detained indefinitely. As of September 2003, the director reported that there had been only one adoption and one foster care placement from Saray since 1988. Yet there is approximately one new admission per day.^f

The population at Saray consists mainly of children and young adults between the ages of 8 and 21 years, although babies and older adults also reside there. The majority of residents are labeled as “moderately or severely retarded” and many have physical disabilities such as cerebral palsy or muscular dystrophy, and some have neurological conditions such as epilepsy.

The Saray institution consists of buildings spread out over a dusty campus separated by concrete courtyards, grassy fields, and dirt paths. Children and adults with limited or no apparent disability roam the grounds aimlessly. People are roughly separated among buildings by age, sex, and levels of disabilities. Within these buildings, people are detained in large dormitories made up of rows of beds or cribs. In most areas, there is no decoration or any place a person could keep personal possessions of any kind. Most people remain in the facility for a lifetime.

While there are some new, brightly painted buildings on the Saray campus, living conditions for residents with more severe disabilities are far worse than conditions for people with less severe disabilities. During our February 2004 visit, we observed children tied down to their beds in a barren room. When we returned in July 2004, boards had been nailed up over the windows of this room. While we could not see in, we could smell the overpowering odor of urine and feces from outside the windows.

Unable to see in through the boarded windows, I walked ahead of our guide so that I could visit the children met on my previous trip. I was able to glance into the room, where I observed a naked boy tied to a large cage-like crib. As I looked in, he tried to stand up and then he smashed his face into the metal bars. Staff wheeled out a large basket of bed sheets with an overpowering smell of excrement. The door was slammed and we were not permitted to enter.

– MDRI investigator

In one ward, children and teenagers, unable to walk or feed themselves were crammed two to a crib and left to a life of near total inactivity. Without any physical therapy and confined to cribs, MDRI observed children whose arms, legs and spines had atrophied and had become twisted and contorted. Many of these children suffered from skin and eye ailments.

^fThe large number of admissions without corresponding outplacements would suggest a very high death rate in the facility. Authorities at Saray were not willing to provide information on the number of deaths at the facility.

I observed one child who had vomited all over himself and his bed sheets left for more than half an hour covered with flies and without any help [see photo #7]. Unable to sit up or use his hands, he continued to spit up and then swallow his vomit.

– MDRI investigator

There were no toys in any of the cribs or any stimuli (such as music or television) in the rooms. According to the director interviewed in September 2003, 400 of the 750 people confined to Saray “don’t do anything and are in bed all of the time.” Treating children in this way exacerbates any existing disability and can cause more serious and life threatening health problems.

In a room on the ground floor, two attendants sat with about twenty boys who appeared to be between 8 to 14 years old. Most seemed ambulatory, though many lay or sat unresponsively on the floor, which was cold cement (February). The only items in the rooms were a few dirty, foam mattresses. The attendants ignored the boys, allowing them to punch, scratch and bite each other.

– MDRI investigator

While considerable resources are being dedicated to new buildings at Saray, living conditions in new buildings are not significantly better than in the older ones. In one new building housing adults with developmental disabilities, we observed rooms filled with ten to twenty people sitting on chairs, laying on the floors, or wandering from room to room doing nothing. These individuals lack any form of privacy or control over their daily routine. They live in total inactivity most of the day.

2. Ayas Rehabilitation Center

On a mountainous road approximately two hours drive outside of Ankara is the Ayas Rehabilitation Center. A state-run, residential facility, it is home for 74 children and young adults diagnosed with “severe developmental disabilities and spastics,” according to the center’s director (staff apparently use the term “spastic” to refer collectively to a broad range of neuro-muscular or motor disabilities such as cerebral palsy and muscular dystrophy). Children range in age from 7 years to those 18 and over. Ayas’ director explained, “the older ones are the spastics and the younger ones tend to be the ones with the developmental disabilities – and 35 or so have epilepsy.” The two-story building is surrounded by a small yard and wire fence. There are no toys or playthings either outside or inside the facility. The front door is locked and there are no elevators or ramps.

As at Saray, people live in large congregate settings with no privacy, no decoration and no place to put personal possessions. On the first floor, MDRI found a large day room where 20 to 30 children and young adults are kept all day. The room is a square, empty box. There were no benches or tables, toys, games, television or music. Residents were lying or sitting on the floor, looking out the window, or walking around in circles. Several were rocking and chewing or biting their hands. Staff reported that no

rehabilitation programs for self-abuse are available (indeed, they appeared to be unaware about what such treatment might entail).

On the second floor of the facility were dormitory style bedrooms. MDRI found one room with eight bedridden “spastic” young adults. Non-professional caregivers known as “mothers” came in to feed them and never raised their heads or sat them up. They were fed lying flat in their beds. Staff reported that these young people are never able to go outside due to the inaccessibility of the stairs and the lack of wheelchairs. Residents have no personal items or decorations of any kind. Although there was a television in the room, it was turned off.

In the basement of the building was the kitchen and dining area. According to the director, 50 residents are capable of feeding themselves, while the other 24 are fed by staff. There are no programs to assist people in learning to feed themselves.

In one room, we observed a young man sitting in a puddle of urine. No one came to clean or help him. Two staff were on duty at the time but there was no evidence of any habilitation or physical therapy being given. The director stated he would like benches for the day room and a play area for the children, and, if possible, to put a sound system throughout the center. “There isn’t much we can do with them,” he said, “We can’t teach these kids anything, so music is all we can give them.”

In another room, MDRI investigators found a 32 year old blind man alone in bed. Staff explained that he is kept away from others because he “harms others” and stays in bed all of the time, except for ten minutes a day, when staff allow him to take a brief walk. Staff stated that he was given tests in Izmir when he was 12 years old and that he has a “zero IQ.” However, while investigators were in the room he spoke Turkish and asked for a glass of water.

3. Zeytinburnu Rehabilitation Center, Istanbul

From the street, I looked through the fence to the playground, filled with the smiling faces of primary school children taking a break from their studies. Laughing, giggling, day dreaming, sharing a sweet with a friend, catching a ball – enjoying childhood, as they should. Across the alley is the center for children with disabilities. I peered through the barbed wire, hoping to hear laughter, but there was none.

– MDRI investigator

Tucked in the alley, just behind a large and well-appointed primary school, is the Zeytinburnu Rehabilitation Center. The rundown and overcrowded building is home to 72 children with developmental and physical disabilities, although most are labeled with some degree of mental retardation. Built for 50 children between the ages of 3 and 18, many residents remain at the center well into their twenties, until placement in an adult facility can be found. According to authorities at Zeytinburnu, their residents all face the prospect of a life in one institution or another.

There are two types of staff attending to the children, untrained female staff known as “mothers,” as well as trained professionals. During the day shift, there are six care mothers and three professional staff. Evening and overnight staffing drops to four care mothers and one professional. These numbers are woefully inadequate to care for the needs of 72 children with disabilities. As one staff person commented, “We need at least 20 more care mothers.” There are 16 children who are referred to as “difficult cases,” who are confined to beds and who are not toilet trained. They require more, specialized assistance, which they often do not receive. Staff admitted to “locking children into rooms for their own safety” because there was no staff to watch over them. Self-abuse and violence among residents is also a major problem at the center, exacerbated by low staffing and an inadequate budget. “If we had more staff, it would greatly reduce behavioral problems,” stated one staff member.

Overall physical conditions at Zeytinburnu are cleaner and treatment practices are better than at Saray or Ayas. Children are divided into small rooms. Due to a lack of staff, however, authorities reported that they had to lock some children in their rooms without direct supervision during much of the day (staff on the ward may look in on them through glass windows in the door). Day living areas are mostly barren. In the absence of adequate furniture, many residents spend the day lying on the floor. Overcrowding has forced children to sleep on the floor and two to a bed. There are only two toilets for every 14 children and little space for children to play. Only recently, a “warm water” system was installed, along with a donation of desperately needed paint and carpeting – both gifts to the center from businesses and private citizens. Staff told MDRI investigators that they expect a “severe food shortage” over the next few months.

B. Physical restraints and seclusion

The use of physical restraints and seclusion are some of the greatest limitations on individual liberty to which any person may be subjected. Particularly when used for prolonged periods without regular oversight, restraints and seclusion can be dangerous and can cause great suffering. The European Court of Human Rights has specifically stated that article 5(1) of the ECHR requires any use of restraints to be limited to circumstances prescribed by law.⁷³ In general, the Council of Europe recognizes that “persons with mental disorder should have the right to be cared for in the least restrictive environment and with the least restrictive or intrusive treatment available, taking into account their health needs and the need to protect the safety of others.”⁷⁴ Thus, “[s]eclusion or restraint should only be used...to prevent imminent harm to the person concerned or others...” It must only be used “under medical supervision” and should be “regularly monitored.” The “reasons for, and duration of, such measures should be recorded in the person’s medical records...”⁷⁵ The United Nations has established similar standards, making it clear that restraints or seclusion “shall not be prolonged beyond the period which is strictly necessary” to protect against “imminent harm.”⁷⁶

None of the institutions we visited has a written policy to protect against abuse or guide health professionals or staff on the use of physical restraints. There are no time

limits on the use of restraints or any requirement that use be monitored or documented in a patient record. At Ayas, the Director expressed his own confusion as to whether the use of restraints might ever violate the human rights of his patients. He said that international charities had donated “restraint pajamas” (similar to a straightjacket that can be tied around the back) and he asked MDRI visitors whether we knew if it was “legal” to use them under international law. In the absence of official Turkish guidelines, the Director of Ayas explained that he uses restraints for both children and adults.

At Saray, the abuse of physical restraints is particularly serious. MDRI teams observed children restrained or tied into cribs or beds. Some children appeared to be permanently restrained. In one unit, we saw a pale and emaciated girl, who appeared to be about ten years old, lying in a crib. The girls’ arms and legs were tied in four point restraints. A staff person explained that she was restrained to keep her from eating her diaper.

Personnel get cut in half on the weekends. On some of the units, children are restrained. If you let them go, they go after the quiet children. They are just bored and frustrated. So they are restrained all the time. [The children] are between seven and fifteen years old.

– Saray staff

I was in what they called the “hyperactive ward” and this girl who looked at least ten or eleven years old, she had outgrown the crib, was tied down at the waist to the bed. Her arms and legs were tied down and she had something wrapped around her head and plastic bottles over her hands.

– Report from Saray visitor

In addition to being tied to beds, MDRI teams observed children at Saray left permanently with plastic bottles taped over their hands. One liter plastic bottles had been cut in half and were used to prevent children from having any use of their hands. The thick duct tape left the skin on their arms and wrists exposed and raw. According to staff, bottles are left permanently on these children’s hands to prevent children from self-abusing or self-stimulating. Experts in the field of disability agree that hitting, scratching or biting oneself is often a reaction to mind numbing boredom and lack of age appropriate stimulation (**see photos and expert analysis, appendix 1**). Preventing children from ever being able to touch themselves causes further developmental and cognitive delays. Children raised without learning to use their hands never gain control of the nerve pathways to their hands and may never be able to develop motor control – even if the bottles are eventually taken off.

One room housed about 26 children, who looked to be about five to ten years of age, although some were teenagers. All of the children were confined to cribs. Four cribs held two children each. One ten-year-old had bottles taped over her hands. Other children were unattended as they tried to eat rags and blankets.

– MDRI investigator at Saray

In a unit at Saray that housed 30 girls without any physical disabilities, MDRI found a tiny cell or seclusion room, with only a small window covered in bars. There was a mattress on the floor with no bedclothes. The cell had no toilet and the stench of urine was overpowering.

C. Lack of habilitation, active treatment, physical therapy or education

The degrading conditions of confinement at SHCEK facilities make it inherently difficult to promote the habilitation or rehabilitation of people with mental disabilities. Every SHCEK rehabilitation center visited by MDRI teams was lacking in programs to help people with developmental disabilities preserve or enhance their daily living skills (known as “habilitation”). These centers also lacked rehabilitation programs, occupational therapy or vocational training to assist individuals with psychiatric disabilities develop the skills they would need to be independent or return to the community. The lack of such programs violates UN and European standards. The UN Convention on the Rights of the Child provides that children with disabilities have a right 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...”⁷⁷ The Council of Europe recognizes the right for adults to receive care from “qualified staff” according to “an appropriate individually prescribed treatment plan.” This includes a right to vocational rehabilitation to promote their integration into the community.⁷⁸

Medication is the only form of treatment available to most residents of SHCEK rehabilitation centers. According to the director of Ayas, all residents are on some form of medication, either for epilepsy or sedation. He said the doctors of neurology or psychiatry arrange medications because the doctor at the institution “has no specialty.” While medication may help manage psychiatric or neurological symptoms, this treatment alone does not help with an individual’s habilitation. Indeed, high levels of sedating medications may make it more difficult for a person to take care of himself.

During our visits at Saray and Ayas, there was almost no engagement of staff with any residents. For the most part, staff watched over people who stood, sat or slept with no form of meaningful activity. Institutions report that there are considerable numbers of professional staff working at rehabilitation centers. Yet direct care at both Saray and Ayas is provided by cleaning staff hired from private janitorial agencies. The director of Ayas reported to MDRI investigators that staff include a doctor, nurse, director, three assistant directors, a psychologist, three social workers, a physical therapist and two child educators. However, the direct care workers, especially in the evening shifts, are cleaning staff hired from TLT Gurup. According to the director, “the professional staff get in-service training in Ankara and then they come back and teach the [janitorial] workers.”

The lack of physical therapy is particularly dangerous for children with cerebral palsy and other children confined to their beds. MDRI teams observed children whose

arms, legs and spines have become twisted and atrophied from a lack of movement and physical therapy (see photos and expert analysis, appendix 1).

Perhaps the most dangerous problem caused by the lack of active treatment is the high rate of self-abuse at the institution. Much of the self-abuse may be attributed to the lack of human contact or any form of stimulation for residents. Nor are there any programs to help children who are self-abusive. When we asked the staff and the director at Saray as to whether these programs are available, they were uniformly unaware of what such programs might be. Physical restraints appear to be the only way staff think they can respond to children who are self-abusive.

At Saray and Zeytinburnu, there are some occupational therapy programs. While these programs have value in keeping people engaged in some form of activity, they are not designed to assist in developing skills that might help enhance independence or opportunities for work outside the institution. Also, these programs are available only to a small number of children. Children with more severe disabilities are not offered the opportunity to participate in these programs. In July 2004, the Director of Saray reported to MDRI that the World Bank had funded a sewing program. However, he stated that it would be “dangerous” for Saray residents to do the sewing themselves, so they are engaged only in helping the staff do the sewing.

The one major exception to the lack of vocational assistance is a café in central Ankara where a dozen or so residents are able to work. This very impressive program permits people from Saray to engage in real work in an integrated environment in the city. It demonstrates that people with mental disabilities can work and can be socially integrated. Only a small proportion of residents of Saray participate in this program, however. Despite the capability of people with mental disabilities to live in the community, the individuals working at the café must return to Saray at night, where they remain living in a segregated environment on the outskirts of the city.

D. Denial of food and medical care

Whenever a person is detained in an institution, authorities are under an affirmative obligation to provide food and basic health care. These are essential to protecting the right to health of all people detained in institutions. Adequate food and health care are also fundamental requirements of international law protecting the right to life, as well as the right to protection against inhuman and degrading treatment. The International Covenant on Civil and Political Rights (ICCPR) establishes that “[a]ll persons deprived of their liberty shall be treated with humanity and respect for the inherent dignity of the human person.”⁷⁹ The UN Human Rights Committee has clarified that this protection “imposes on States parties a positive obligation towards persons who are particularly vulnerable because of their status as persons deprived of their liberty and complements for them the ban on torture or other cruel, inhuman or degrading treatment or punishment....”⁸⁰

MDRI investigators observed many bedridden children and young adults at Saray who appeared emaciated – with little more than skin covering their bones (see photo 4). MDRI investigators observed staff feeding many of those with the most severe disabilities by propping bottles into their mouths filled with pureed food or liquid and with large holes cut out of the nipples. Children were fed lying down and received no assistance from staff.

Many of the children could not feed themselves. Some were struggling to hold onto or reach the bottles and much of the contents spilled out onto beds or wasn't eaten. A little girl, who looked to be about 2 years old, was crying and squirming in her crib. A full bottle of formula was lying in the corner of her crib, just out of reach. I watched for over an hour, and no one came to feed her. She would have had nothing if I hadn't eventually helped her.

Over the course of a number of feedings, I watched as staff came quickly into the room, dropped off bottles, and then picked up the bottles as they left the room. If a child could not pick up the bottle to eat or drink, she starved.

– MDRI investigator

MDRI investigators observed many children who were emaciated. We were told by staff that children who appeared to be 3 or 4 years old were, in fact, 7 or 8 years old. In addition to our observations of children who were extremely thin, we observed children with mobility disabilities such as cerebral palsy and muscular dystrophy, who had difficulty swallowing and who had auto-regurgitation disorders. We observed that these children were fed while lying down, which creates a serious risk of aspiration and choking.

MDRI investigators learned that some of the older children with less severe disabilities began to feed children who were unable to feed themselves, especially on weekends when staffing fell below already inadequate levels. According to a former resident of Saray who helped with the feeding, both the children and the teenagers thrived as a result of the interaction. Despite this, authorities at Saray ended the program by transferring the teenagers out to an elderly care home.

MDRI investigators received numerous reports from direct care staff of life threatening denial of medical care to the children living at Saray, especially to those with the most severe disabilities. Several staff members told MDRI that when children become ill, they are rarely if ever seen by a doctor and many die. If they do receive any medical attention, it is often substandard.

Nurses come to the units and stand in the doorway. They ask workers if there are any sick children, they just yell in. The workers always say no even if the children are very ill. When children get sick, they are no longer bathed and are not allowed to be taken out of bed. They are tied into their beds at times. If children are not taken care of, they do die. One is dying now.

– Saray staff

No medication is given for teeth extraction. I once saw a child lying down on a linoleum floor, a boy about 8 or 9 years old. There was blood all over the floor. The nurse had pliers in her hand and she was straddling the boy and pulled his head back and pulled another tooth out. Standing next to them was the assistant director of the institution. I was crying and nothing struck me more in the gut than that. The nurse looked at me and said, "They don't feel pain."

– Saray staff

Adding to the problem of children's frail state of health, staff reported many times there was no hot water for baths, so children are bathed once every five to ten days in cold water or not at all. In the winter, staff reported that the heat is frequently broken or not adequate and the sleeping areas "cold."

One boy had a swollen wrist. No one took him to the doctor for a long time. When the doctor finally checked on him he said [the boy's] wrist was swollen due to bad circulation because of the cold weather.

– Saray staff

E. Physical abuse and sexual violence

Both the ECHR and the ICCPR require institutions to protect all residents against harm, including physical abuse or sexual violence.⁸¹ These protections are particularly important at SHCEK facilities, because they are used by authorities to house children who have been victims of sexual violence. Yet these children do not receive trauma counseling or any special assistance to help them recover from the abuse. Indeed, further human rights violations and sexual abuse at Saray may exacerbate disabilities that stem from this trauma.

A young girl, 23 years old, was transferred from another institution about two years ago. They said she was mentally ill. I was told that she kept running away and getting raped and pregnant. When they brought her to Saray, they locked her in a room. She was kicking and shouting to be let out. So a worker threw her against the walls – from one wall to another. They tied her legs spread apart in the bed and they kept hitting her. And the assistant director said she deserves this, she keeps running away and getting raped. She is still at Saray. I am told by other staff that they think that she is pregnant now.

I know several girls have been raped. The older boys take the mentally disabled girls somewhere on the grounds. And the bedridden children are raped. I know bedridden children. I know their bodies. I bathe them. I can tell when they are raped. It happens mostly at night or on the weekends.

Some of the spastic boys are very bright. But the workers would put them on cold floors and spray them with water. Sometimes burning hot – sometimes freezing cold. The workers joked about one boy's penis – if he had an erection.

All the boys were humiliated and they play with them sexually. And they never really clean them.

One of the worst things for me was this seven year old boy.... I love this boy and I was there and watched when his mother dropped him off. I wanted to see him not in pain. When he was new, he was under observation in the clinic. Then he was transferred to the boy's house and he was raped. He was living with 11 and 12 year old kids but he was raped by a twenty year old. One of the other boys told me about the rape. I told the hospital director. The boy who was raped was beaten and locked in his room.

– Saray staff

With the older kids it's a real problem. There is no privacy. They are all naked together during bath time. Boys and girls in the same sleeping quarters. Two boys, ages twelve and fifteen, were found having sex in a bathroom.

– Saray staff

F. Concerns about care in orphanages

Authorities at SHCEK officially designated certain facilities as “rehabilitation centers” and others as “orphanages.” MDRI is concerned about the rights of children in either kind of facility, and our research indicates that there is considerable overlap between institutions labeled as one or the other. In practice, there are children with and without disabilities in SHCEK rehabilitation centers who have no contact with their parents and these facilities are functioning as orphanages. By the same token, our visit to the Kecioren orphanage in Ankara indicates that some orphanages house children with disabilities. Whether or not a child is identified as disabled, it is dangerous to raise children in a congregate setting and may lead to avoidable developmental disabilities.⁸² As the Council of Europe has stated in its 2005 recommendations on children’s rights, “[t]he family is the natural environment for the growth and well-being of the child....” If a child is placed in an institution, “a small family-style living unit should be provided.”⁸³

At Kecioren, all children are raised in a congregate setting without a family-like environment. While all children at Kecioren are living in conditions that may create disability, children with disabilities are particularly at risk. Our visit to Kecioren suggests that children officially designated as “disabled” receive much the same lack of treatment and habilitation experienced by children at official rehabilitation centers.

According to authorities at Kecioren, they are not legally allowed to admit children with disabilities, but they do so because rehabilitation centers are already overcrowded. In July 2004, authorities at Kecioren reported that 30 of the 310 children at the orphanage are identified as children with disabilities. Many of these children are placed in the orphanage as infants. Most of these children are diagnosed with cerebral palsy or mental retardation.

Authorities admit that a larger number of children at the orphanage may have intellectual or psychiatric disabilities. Any child raised in a congregate setting is at risk of acquiring a mental disability, and this risk is particularly high for children placed in a facility under the age of four. The Kecioren orphanage is used for the placement of children who have been physically or sexually abused in their own homes. We interviewed staff at Kecioren who are aware that these children are at high risk for having psychiatric problems. We observed volunteers who visited the disability ward to conduct “play sessions,” but we were not able to identify programs at Kecioren to assist children to deal with the traumatic effects of abuse. Medications appear to be the only form of treatment. Authorities report that many children at Kecioren receive psychotropic medications for “behavior problems.” Staff on the unit serving infants and children with disabilities said that one of the biggest problems at the institution is a lack of medical and psychiatric care. They reported that there is only one physician available for all 300 children at the facility.

Overall physical conditions for most children at Kecioren are much better than at any of the rehabilitation centers we visited. Yet, as at rehabilitation centers, conditions are much worse for children with disabilities. The ward for infants and children with disabilities was brightly decorated but smelled badly of excrement. Children with cerebral palsy are kept in cribs in a section for children 0-2 years of age, even though some of them are older. In one room with twelve cribs, we observed seven children who remain in bed all day. Many of these children were rocking back and forth, commonly a sign of children who have received little attention or stimulation. While staff were actively playing with the children who were able to leave their beds, we observed no staff contact with the children left in cribs.

The staffing on the ward makes it impossible to provide individual care or habilitation to children with disabilities. On a ward for 31 infants and children with disabilities, there were only three staff on duty. Staff said that it was impossible to provide individual attention and care for this number of children. They explained that the usual staff for this ward is seven, but that the number was reduced throughout the summer and during the night. When asked about the biggest challenges they faced, they reported, “We need more staff and mothers [care-givers].” They also reported that they needed the services of at least one full time pediatrician on the unit. Instead, they said, a physician stopped by once a day, but explained that “he’s not a pediatrician and he doesn’t stay long.”

We observed a number of children with arms, legs, and spines twisted dangerously backwards. Staff on the ward report that there is physical therapy available for these children but could not tell us more concretely how much, other than “perhaps a couple hours a week.” Staff said that more care was once available when there was a physical therapist on staff at the institution. At present, no professional physical therapist is available, so children must be sent outside the facility for care at great expense. Instead, they say they try to organize outside volunteers to play with the children.

We visited the “F Block,” a ward with children between 9 and 10 years old. Staff reported that a number of children had mental disabilities on this ward and are kept on psychotropic medications, including Ritalin and Resperidol (a powerful neuroleptic intended for use with major mental illness). We visited at 12:30 P.M. and found most children in bed for what we were told was a daily two-hour nap. Boys said that they were frequently kept at naptime for four hours, from noon to 4 P.M., as punishment. For this age group, more appropriate after-lunch activities should be available. Extended rest periods following lunch are not required for children this age and may further debilitate them.

If the situation at Kecioren is representative of institutions designated as “orphanages” by SHECK, then the problem of institutionalized children with disabilities is more widespread than official statistics would indicate.

G. Findings from a Parliamentary Commission on Human Rights

During the course of MDRI’s investigation, we received numerous independent reports about abuses at the Saray Rehabilitation Center. In addition to the reports by staff and parents of children with intellectual disabilities interviewed by MDRI as part of this investigation, there has been independent corroboration of our findings (and, in some cases, far more serious abuses reported) by the press and the Human Rights Commission of the Turkish Parliamentary Commission. They did not prepare an official report but the findings were reported in Turkish newspapers. As reported in *Milliyet* in January 2005, the investigative committee of the Parliamentary Commission “came across scenes that could compete with Nazi concentration camps.”⁸⁴ As reported in *Sabah*, both medical and dental care is inadequate at the facility.⁸⁵ Based on the investigation, the Parliamentary Commission concluded that people with mental retardation were subject to conditions of “psychological torture.”⁸⁶ The Commission reportedly found that “girls were locked up in rooms, tied up to their beds from their waists....”⁸⁷ Seclusion and restraint were used as a form of punishment:

Three girls aged 12-13 were found locked in a very small cold barren room on this cold winter day and they were naked. The reason for locking them up was that they had tried to escape from the institution. The institution director told the parliamentarians that the girls were there for a few hours, but it was discovered that they had been there for the last 12 hours. One of the girls had diabetes. In addition, the committee found out that the bathrooms and toilets were in very bad condition as opposed to the nice rooms of the social workers. Thirty to 40 people were staying in wards with a capacity of 15.⁸⁸

III. In the Community: No alternatives to institutions

Throughout the world, there is a growing consensus that the overwhelming majority of people with mental disabilities – including both people with psychiatric and intellectual disabilities – can live in the community with appropriate services and support systems.⁸⁹ UN Special Rapporteur on the Right to Health, Paul Hunt, has observed that:

As a result of increased knowledge about mental disabilities and new models of community-based services and support systems, many people with mental disabilities, once relegated to living in closed institutions, have demonstrated that they can live full and meaningful lives in the community. People once thought incapable of making decisions for themselves have shattered stereotypes by showing that they are capable of living independently if provided with appropriate legal protections and supportive services. Moreover, many people once thought permanently or inherently limited by a diagnosis of major mental illness have demonstrated that full recovery is possible.⁹⁰

Twenty years ago, the World Health Organization found in Europe “a remarkable degree of common ground” regarding the importance of shifting away from reliance on large psychiatric institutions and promoting community-based services that permit the maximum possible integration into the community.⁹¹ In a study of 30 European countries published in 1985, the WHO found that:

During the last 30 years, psychiatric practice has undergone profound changes, and in consequence so too has the organization of services for the care and treatment of the mentally ill. New mental health programs, policies and legislation have been developed in many countries and continue to be developed in others.... Institutional psychiatry has given way to community psychiatry. ...⁹²

Over the last three decades, the shift toward community mental health has come to be recognized not just as good mental health practice – but as a basic human right under international law. As early as 1971, the United Nations adopted the Declaration on the Rights of Mentally Retarded Persons to promote the integration of people with intellectual disabilities “as far as possible in normal life.”⁹³ In 1991, the United Nations General Assembly stated that “[e]very person with a mental illness shall have the right to live and work, as far as possible, in the community.”⁹⁴ The Montreal Declaration on Intellectual Disability, adopted in 2004, states that “[f]or persons with intellectual disabilities, as for other persons, the exercise of the right to health requires full social integration....”⁹⁵ For people capable of living in the community, the UN has established that segregated inpatient service systems “inherently discriminate” against people with mental disabilities.⁹⁶ To avoid such discrimination, “[s]tates should take steps to ensure a

full package of community-based mental health care and support services conducive to health, dignity, and inclusion.”^g

The structure of Turkey’s mental health and social service system for people with psychiatric and intellectual disabilities is out-of-step with changes that have taken place in Europe over the last thirty years. The lack of alternatives to institutional care constitutes a form of discrimination against people with mental disabilities, which is impermissible under international human rights law.⁹⁷

Large numbers of people detained or receiving treatment in rehabilitation centers, orphanages, and psychiatric facilities are improperly and unnecessarily detained because of a lack of community-based services. The great majority of people with mental disabilities in Turkey live in the community with family members – yet they receive little assistance from the mental health or social service system. Without adequate community supports or community-based treatment, family members often become impoverished and socially marginalized by the responsibility of taking care of a disabled relative. While there is some income support for people with mental disabilities (either psychiatric or intellectual disabilities), Turkey’s state disability pension is well below what any person would need to live in the community.

While many mental health professionals we interviewed support the creation of improved community-based services in theory, there is a widespread impression among psychiatrists at state psychiatric institutions that Turkey has a shortage of inpatient beds. Instead of investing in the creation of community services, the Ministry of Health is directing resources to increasing inpatient services. In Izmir, for example, a university hospital has just been rebuilt, a new psychiatric ward of a general hospital is being created, and the nearby Manisa state psychiatric hospital is being expanded from 400 to 600 beds. New in-patient beds for short-term acute care stays at a general or university hospital are an improvement over long-term placements in a large psychiatric facility such as Manisa. Without a broader plan to create follow-up care for these inpatient services, however, these new services will not be as effective in helping people live and receive treatment in the community. There appears to be a similar direction in services

^g UN Special Rapporteur on the Right to Health, Paul Hunt, describes the “full package” of community-based mental health services as “including medication, psychotherapy, ambulatory services, hospital care for acute admissions, residential facilities, rehabilitation for persons with psychiatric disabilities, programmes to maximize the independence and skills of persons with intellectual disabilities, supported housing and employment, income support, inclusive and appropriate education for children with intellectual disabilities, and respite care for families looking after a person with a mental disability 24 hours a day. In this way, unnecessary institutionalization can be avoided.” Paul Hunt, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Commission on Human Rights, 61st session, Item 10, E/CN.4/2005/51, para. 43 (Feb. 11 2005) [hereinafter Hunt Report]. “Persons with intellectual disabilities often require specialized support services which are tailored to their individual needs. This might include habilitation, speech pathology, occupational therapy, physiotherapy, and behavioral therapy. . . . Support is also essential for the families of persons with severe intellectual disabilities, given the acute demands that care and support can place on them. For some individuals with intellectual disabilities and their families, a good environment may include access to a small, open community house with a stable staff and specialized support services.” *Id.* para. 81.

under the authority of SHCEK. In 2003, SHCEK authorities reported that seven new residential rehabilitation centers were being created. At Saray, new buildings are being constructed. Despite these investments in new residential facilities, the vast majority of people with mental disabilities living in the community do not receive the basic supports that they need.

A. Lack of services for people with psychiatric disabilities

In 2004, there were 784 staff psychiatrists working for local and national public mental health services, of whom 359 work in large public psychiatric hospitals (one psychiatrist per 100,000 people in the population as a whole – half that ratio outside of big cities).⁹⁸ There are “few psychiatric social workers and psychiatric nurses” in Turkey.⁹⁹ While the mainstay of Turkey’s public health care system is a network of 5,800 primary health care centers in the country, Turkish psychiatrists who studied the field concluded that there are “no functional basic mental health services available at the primary health care level.”¹⁰⁰

There are a few model community-based programs, some of which were set up in the Marmara region with international funding and support following the earthquake. Despite efforts by mental health professionals involved in these programs to replicate them at the national level, there has been a lack of political support for their national replication.¹⁰¹ As a result, Turkey’s mental health system is almost entirely centered around large regional psychiatric institutions. For people who do not live near a major psychiatric institution, many travel 1,000 miles from Eastern Turkey to obtain care at one of the major facilities in Istanbul.¹⁰² Turkish mental health professionals have described the lack of a “coherent system of mental health services” which leaves a “void” of services for people with psychiatric disabilities.¹⁰³

Despite the lack of publicly funded community-based services for people with mental disabilities, the use of anti-depressants and other psychiatric medications are reported to be common among the population as a whole. One study conducted in 1998 showed that 5% of the general population takes some form of psychiatric medication.¹⁰⁴ For people with mental disabilities who cannot afford medications – or people who require a broader array of support and care – available support is limited. Apart from some excellent programs at university hospitals serving a small number of people, the psychiatric system provides no outpatient care of any kind other than psychotropic medications or ECT.

According to official policies, psychotropic medications are available to people with psychiatric disabilities in the community. In practice, psychiatrists and patients report that medications can be difficult or impossible to obtain for people with psychiatric disabilities who cannot afford to pay for them. In Istanbul, people reported to MDRI that they have to travel all the way to Bakirköy Hospital and then wait on line all day for their medications. Over the last year, lines became so long that some people reported to MDRI that they had given up trying. According to the assistant director of Manisa:

In theory, it is possible to get medications in the community...[but] the government is trying to save money. It is made so difficult for patients that they just can't get it. It is very bureaucratic. Also, they may require a small contribution by the patient. Even though it is small, patients who are poor can't afford it.

A psychiatrist may only write a prescription for 10 days, so people must go to a psychiatrist on a regular basis. Physicians can write prescriptions, but social security will not pay for medications unless the prescription comes from a psychiatrist. In parts of Turkey, there are no psychiatrists. At Manisa, there are only two psychiatrists working in outpatient services and they often must see 200 patients a day.

The lack of community-based services means that people who live far from urban areas with inpatient facilities must travel great distances to receive care. Many family members may commit a relative into the hospital because of the difficulties of travel. For those who stay in the community, there is almost no continuity of care. After their release from the hospital, follow-up is nearly impossible. At Manisa Hospital, which provides services for an area spanning nearly a quarter of Turkey's landmass, the assistant director reports that patients from far away rarely receive any form of follow-up care. "We send letters to the local health centers describing needed medications," he stated, "But we've never had a case where we heard back from the centers."

The lack of community care leaves thousands of individuals with mental disabilities abandoned with no support. Psychiatrists at Manisa reported that in western Turkey many people with mental disabilities never get out of their homes. The assistant director of Manisa said he knows of cases where people with psychiatric disabilities are locked inside their homes for years.

B. Lack of services for people with intellectual disabilities

For people with mental disabilities who cannot work, disability pensions are too small to enable a person to live in the community. Families seeking to take care of a disabled relative often become impoverished. When families cannot cope with the cost of caring for a relative in the community, many family members are faced with a heart-breaking lack of choices, often resulting in the institutionalization of many people who could live in the community with appropriate supports. At Saray, there is a 3,000 person waiting list for admission. At Zeytinburnu in Istanbul, there is a 2,000 person waiting list.

Staff at one SHCEK institution pointed out that most placements could be prevented – and thousands of children could remain with their families – if only inexpensive child care services were provided for children with mental disabilities. In one case, staff introduced us to a child placed in the institution because his mother had to get treatment for cancer. His parents could not afford the cost of transportation to visit the boy at the facility. Staff said the boy cried for a month when he was left at the institution.

MDRI interviewed one mother of a child with an intellectual disability who said that she would rather see her daughter die than be submitted to care in abusive facilities such as Saray. This mother works with an impressive civic association that operates a private school for children with intellectual disabilities. As long as this mother is alive, her daughter is safe. Hundreds of such private associations exist throughout Turkey. They are made up of dedicated parents providing dignified care and education to their relatives. Yet such groups receive no government support and their services are available only to a select group of people.

Families who have an employed member who pays into the social security system may obtain some basic services in the community, including access to special schools. The special schools visited by MDRI provided little more than respite care, permitting family members to go to work during the day. Meaningful vocational training or appropriate education is almost entirely lacking for people with intellectual disabilities.

People who come from economically disadvantaged families are not so lucky. MDRI interviewed a single mother who had a child with an intellectual disability. Without social security benefits, the daughter could get no services or education. Authorities informed the mother that she should place her daughter at Saray. Having heard about the abusive conditions at Saray, and unwilling to give up her daughter to an institution, this woman chose to keep her daughter at home, living with her in desperate poverty.

IV. Lack of Legal Protections & Oversight

People with mental disabilities can be particularly vulnerable to abuse and violations of their human rights.¹⁰⁵ Accordingly, many countries, including every member of the European Union, have enacted mental health legislation or provisions in general health laws to protect people with mental disabilities from arbitrary detention and from abuse and torture during confinement. International human rights law creates a number of important rights that all countries are obliged to include in their mental health laws.¹⁰⁶

Turkey has no enforceable mental health law or any law governing the treatment of people with mental disabilities in its general health laws. Individuals facing confinement in Turkish mental institutions have no protection against arbitrary detention, and once committed, they have no right to periodic review of their commitments or to appeal the commitment order to a court or independent authority. Individuals in Turkish mental institutions do not have a right to participate in treatment decisions as they are denied the right to provided informed consent or to refuse treatment.

Without a legally enforceable right to due process or independent review, everyone detained involuntarily in Turkey's psychiatric facilities is detained in violation of the European Convention on Human Rights (ECHR). Having ratified the ECHR, Turkey is under an immediate obligation to create these protections.

A. Arbitrary detention

One of the most important among the broad array of rights that should be protected in any mental health law is the protection against arbitrary or improper detention in an institution.¹⁰⁷ The European Court of Human Rights has ruled that every detention in a psychiatric facility be reviewed by an independent judicial authority.¹⁰⁸ The procedures for implementing this right have been recently set forth by the Council of Europe in Recommendation (2004)10.¹⁰⁹ These standards specify that involuntary treatment may only be ordered for “therapeutic purposes”¹¹⁰ and where “the person’s condition represents a significant risk of serious harm to his or her health or to other persons.”¹¹¹ People subject to psychiatric detention have a right “to be heard in person or through a personal advocate” at the hearing.¹¹² The standards provide, “Where the person cannot act for him or herself, the person should have the right to a lawyer and, according to national law, to free legal aid.”¹¹³ Individuals also have the right to appeal a commitment decision and to review of the lawfulness of such commitment at “reasonable intervals.”¹¹⁴

In Turkey, there is no legal prohibition against arbitrary detention in psychiatric facilities. The Ministry of Health has adopted a Patients’ Rights Directive #23420, which applies to all health facilities and provides some guidance to doctors who oversee the commitment process.¹¹⁵ But the Directive addresses only general issues regarding consent and treatment and does not provide legally enforceable standards for civil commitment or any procedures by which an individual may challenge or appeal an involuntary commitment order.¹¹⁶ The Directive does not provide the right to counsel, the right to present evidence, to cross-examine witnesses, or to appeal to a higher court as required by international law.¹¹⁷ According to the former vice president of the Turkish Psychiatric Association, the Directive is applied inconsistently throughout Turkey.

Authorities at Bakirköy maintain that the Directive does not have the force of law and does not restrict the decisions of the institutions. In April 2005, authorities at Bakirköy told MDRI that they believe a new mental health law is urgently needed. In part, this is to protect the institution’s authorities. The Patients’ Rights Directive permits the institutional authorities to defer to the judgment of family members – but it does not specify which family members to listen to or when. The authorities are put in a particularly difficult position during marital or other family disputes where individuals may be trying to “get rid of” a family member.

B. No right to informed consent or to refuse treatment

International law also recognizes the right of every person receiving care in a mental health facility to “informed consent.”¹¹⁸ The right to informed consent includes the right to “understandable information in a form and language understood by the patient,” including information about his or her diagnosis, “purpose, method, likely duration and expected benefit of proposed treatment” as well as “[p]ossible pain or

discomfort, risks and side-effects of the proposed treatment.”¹¹⁹ The right to informed consent also entails a right to refuse treatment if a person so desires.¹²⁰

The right to informed consent and the right to refuse treatment may be restricted, but only under limited circumstances specified in international standards.¹²¹ As recently described by the UN Special Rapporteur on the Right to Health, Paul Hunt, strict protections are needed to protect the right to informed consent for people with mental disabilities:

In the Special Rapporteur’s experience, decisions to administer treatment without consent are often driven by inappropriate considerations. For example, they sometimes occur in the context of ignorance or stigma surrounding mental disabilities, and expediency or indifference on the part of staff. This is inherently incompatible with the right to health, the prohibition of discrimination on the ground of disability, and other provisions in the [UN’s MI Principles]. In these circumstances, it is especially important that the procedural safeguards protecting the right to informed consent are both watertight and strictly applied.¹²²

The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment has stated that “patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of persons to a psychiatric establishment on an involuntary basis should not be construed as authorizing treatment without their consent.”¹²³

Under European Standards, “[t]he decision to subject a person to involuntary treatment should be given by a court or another competent body.”¹²⁴ Involuntary treatment may only be ordered when “the person’s condition represents a significant risk of serious harm to his or her health or to other persons” and “no less intrusive means of providing appropriate care is available.”¹²⁵ Even when involuntary treatment is ordered, “the opinion of the person concerned” must be “taken into consideration.”¹²⁶ Involuntary treatment may be ordered in emergency circumstances “for a short period of time,” but a court must review such care if treatment is to be continued “beyond the emergency situation.”¹²⁷

For a person involuntarily detained in a psychiatric facility, Council of Europe Recommendation (2004)10 does permit a physician to order involuntary treatment.^{128 h} However, this provision only applies to people who are lawfully detained¹²⁹ – a process which entails review by a court at a hearing in which a person is represented by counsel (see discussion above). Whether it is part of an initial commitment, or whether a specific hearing is held for the purpose of reviewing competence to consent, the international law

^h This provision of Recommendation (2004)10 appears to be inconsistent with statements by the European Committee for Prevention of Torture, as cited above, which states that involuntary detention should not be the basis for involuntary treatment. Council of Europe, Committee of Ministers, Recommendation (2004)10, art. 20 at [http://www.coe.int/T/E/Legal_Affairs/Legal_cooperation/Bioethics/News/Rec\(2004\)10%20e.pdf](http://www.coe.int/T/E/Legal_Affairs/Legal_cooperation/Bioethics/News/Rec(2004)10%20e.pdf).

is clear: some kind of review by a court or other independent body is required before involuntary psychiatric treatment can be ordered.

Turkish law provides no such rights. Instead of the patient's consent, Patients' Rights Directive #23420 provides family members the right to provide consent. This transfer of rights or deferral to family members is a clear violation of international law. Under the MI Principles, "[a]ny decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue shall be entitled to be represented by counsel."¹³⁰

Perceptions about the role of individuals in relation to their families vary widely among different cultures, and effective approaches to medical care and informed consent must be sensitive to these differences.¹³¹ Thus, models have been developed in some societies that actively involve family members in helping a person to make informed decisions.¹³² While family members can be tremendously valuable resources, conflicts of interest between family members and individuals receiving treatment are often inevitable. This is why international human rights law ultimately provides rights to make decisions about treatment to individuals subject to that treatment and not to families.¹³³

Individuals seeking medical treatment in Turkey have a limited right to informed consent and a limited right to refuse treatment pursuant to Directive #23420. Under the directive, physicians are required to consult with a patient and obtain his or her consent to treatment – if the psychiatrist considers that person to be mentally competent to make decisions, and only if there is no medical emergency which might require immediate treatment. The Directive requires patients to consent to treatment in “health facilities,” but not if the person is “mentally ill.” There is no requirement that patients sign forms indicating their consent to treatment or to provide them an opportunity to refuse or seek alternative forms of treatment. If a psychiatrist comes to the conclusion that a person is not mentally competent to make treatment decisions, no consent is required under the current Directive.¹³⁴

There is no generally accepted practice of informing people about the risks and side effects of treatment in psychiatric institutions or for providing them an opportunity to refuse or seek alternative forms of treatment. When we interviewed patients, MDRI investigators were told that psychiatrists frequently do not ask for any form of consent to treatment. We interviewed numerous patients in every state psychiatric facility who had never been informed about risks or side-effects of treatment or any alternative choices for treatment that might have been available.

Many hospital authorities reported that they do respect a patient's right to informed consent. In most cases, psychiatrists were under the impression that obtaining consent from family members was adequate. Some hospitals informed us that they had consent forms for patients to sign. If a person signs these consent forms, they agree to accept any treatment that the institution may deem appropriate. In theory, a person may

refuse to sign this consent form. In practice, however, hospital authorities informed us that they would not allow a patient to remain in the facility without signing the form. Thus, in order to receive any form of care in the institution, most patients have to sign away their rights. University hospitals generally are much more attentive to obtaining signed forms consenting to treatment. But at Dokuz Eylül University Hospital, patients must sign a general consent form for all treatment before being admitted. This form does not mention psychotropic medications or ECT. As of July 2005, Dokuz Eylül had no consent form for ECT. Where consent forms are used, as at Bakirköy, family members are permitted to consent to any form of treatment to be provided by the institution.

At Manisa and Erenköy, staff report that they intentionally mislead patients to obtain their cooperation to perform ECT. Deferral to the opinion of family members without due process is a violation of the rights of people receiving treatment. International human rights law protects individuals with mental disabilities and does not permit family members to consent on their behalf without some formal hearing at which due process protections are provided. In the absence of any such protections, all coercive treatment – including ECT – is administered in violation of international human rights law.

Directive #23420 contains a limited right to refuse treatment, but includes no mechanism for its implementation. A patient theoretically has a right to refuse treatment so long as his or her choices are “medically viable.” But because a psychiatrist would decide whether a choice is “viable,” any actual independent ability to refuse treatment the patient might have is seriously undermined, if not eliminated.

At Dokuz Eylül, staff report that as a matter of hospital policy they will recognize the right of patients to refuse medications or ECT. However, if a person is too “disordered” to understand this decision, the psychiatrist can administer medications over the objection of the individual. There are no written guidelines for when a person can and cannot object to medication, and there is no requirement that the authorities document this determination in the patient’s record. When a patient refuses medication, he or she is usually asked to leave the facility. As one psychiatric resident explained, “there is no purpose in the patient being here” if he or she is not receiving medication.

At Manisa there is not a policy of respecting the views of patients or family members. The assistant director told MDRI investigators:

Ninety-nine percent of patients object to their treatment. So we can’t take them seriously. Family members may be no more reliable. Mental illness is genetic, so family members may also be mentally ill. We may try to do what they ask but it is not always convenient.

C. Lack of oversight and transparency

Effective mechanisms for monitoring, oversight, and rights enforcement are needed in any country. Both the MI Principles and Council of Europe Recommendation

(2004)¹⁰ require countries to establish independent human rights monitoring mechanisms. The Council of Europe specifies that monitoring is required to ensure compliance with both (1) legal standards and (2) professional standards.¹³⁵ The Council of Europe requires that oversight and monitoring should be conducted by a body that is “organizationally independent from the authorities or bodies monitored.”¹³⁶ Such monitoring should entail regular “visits and inspections of mental health facilities, if necessary without prior notice.”¹³⁷ The Council also states that systematic and reliable statistical data on mental health practices and information on the implementation of the mental health law should be made available to the public.¹³⁸

People detained in institutions under the authority of the Ministry of Health or SHCEK are denied a broad range of other rights guaranteed by international human rights law. There are no laws to protect people detained in institutions against improper seclusion or restraint, or improper or coercive treatment. Bakirköy Hospital has recently established a patients’ rights committee, but this body is not independent of the facility. Members of this committee are retired staff from the institution. Committee members explained that they are under no obligation to represent the views of patients who present complaints. Nor are they under any obligation to document the kinds of complaints that they receive or to report to the public in any way about their work.

The recent efforts of the Parliamentary Human Rights Commission to bring attention to abuses in Saray are a welcome development. Yet such efforts are not systematic, and many other institutions in Turkey have not received similar attention. There is no other form of independent human rights monitoring or oversight to protect against abuses in institutions.

In the absence of established oversight mechanisms, non-governmental organizations can play a particularly important part in monitoring rights in institutions. Open discussion and assessment of need and opportunities for reform becomes impossible when the public is not allowed to obtain information about the operation of service systems. While many government officials and institutional authorities were open with MDRI investigators, there were circumstances in which we were unable to obtain basic information about the operation of service systems under both SHCEK and the Ministry of Health. This was a particular problem at Saray and Manisa Psychiatric Hospital. While we were permitted extensive access to Saray on our early visits, access was limited severely from 2004 onwards after Turkish newspaper accounts of abuse were published. At both Saray and Manisa, authorities informed MDRI investigators that they needed permission from authorities in Ankara to allow us to visit the facility. At Saray on our last visit in 2004, the director informed us that he was not at liberty to provide information about any aspect of the treatment or care provided at the institution.

Recommendations

International human rights law creates obligations on the government of Turkey to protect the rights of all children and adults detained in psychiatric institutions, rehabilitation centers, and orphanages. International law also recognizes the rights of all people with mental disabilities to live, work, and receive treatment in the community. It is the obligation of the government of Turkey to reform its mental health and social service systems to provide the community-based services necessary to permit full social integration of people with mental disabilities. It is up to the government of Turkey to determine which government agencies implement these rights. As mental health and social services are currently split between the Ministry of Health and the Directorate for Social Services (SHCEK), the following recommendations apply to both agencies. We encourage the government of Turkey to create a mechanism for collaboration between these agencies, since there is extensive overlap in the population of people who receive services from the two government agencies.

Immediate action should be taken to end the most egregious abuses and human rights violations taking place in institutions. These include:

A. Ending the abuse of ECT

- A-1 Unmodified ECT should be banned in all circumstances; in the future, this practice should be criminalized.
- A-2 ECT should be used *only* with the informed consent of the patient and with the right to refuse the treatment.
- A-3 The use of ECT should be halted where there is no clinically proven justification in accordance with internationally accepted professional standards.

B. Protecting against inhuman and degrading conditions in institutions

- B-1 Stop the improper use of physical restraints, such as tying children to beds or cribs or taping bottles over their hands; professional attention and behavior programs should be provided to assist all children who are self-abusive.
- B-2 All children and adults shall be ensured adequate food and water; where necessary, additional staff must be provided to assist people who, because of their disability, are unable to feed themselves.
- B-3 Provide all necessary medical and dental care needed to protect the health and safety of institutionalized persons.
- B-4 Provide habilitation and rehabilitation services and low-cost interventions to provide freedom of movement, stimulation, human contact and rehabilitation; all people detained in institutions – but particularly children – should be provided

with regular activities and opportunities to leave the institution and participate in recreation, sports, cultural life, and other forms of stimulation in the community. Recruiting outside volunteers and non-governmental organizations to assist in these activities can be particularly valuable.

B-5 Enforceable laws protecting a broad array of rights in institutions, such as protections against improper seclusion and restraint, should be established in accordance with international human rights standards; until such time as the Turkish parliament establishes such a law, both the Ministry of Health and SHCEK should adopt and abide by written human rights policies. These policies should be widely disseminated to staff and patients in institutions.

B-6 All staff working within institutions should be provided with human rights training; non-governmental organizations (NGO's), including representatives of people with mental disabilities and former patients and family members, should be involved as trainers.

C. Improper and arbitrary detention in institutions

C-1 Cease plans to construct any more residential or long-term facilities for people with mental disabilities.

C-2 Family supports and supported foster care programs should be established to help children remain in their families or live with substitute families; such programs must include oversight and monitoring to ensure safety and quality of care in the community; it should be possible to create such programs within six months; after this time, no new admissions of children shall be permitted in orphanages or rehabilitation centers.

C-3 An enforceable mental health law consistent with international human rights standards should be adopted; this law should protect against arbitrary detention and should provide a right to a hearing in all cases of involuntary treatment. Individuals should have a right to counsel at these hearings. Until such time as the Turkish parliament adopts this law, the Ministry of Health and SHCEK should adopt and adhere to written policies that protect these rights.

D. Oversight and enforcement

D-1 All institutions should be opened up to public oversight in accordance with the requirements of Council of Europe Rec. (2004)10; an independent human rights monitoring agency should be created to:

- a. conduct on-site inspections day or night with no advance notice;
- b. inspect patient records;
- c. take photographic and video evidence;
- d. publish their findings;

- e. include people with disabilities and former users of Mental Health or SHCEK services in their work;
 - f. report to an independent board that includes respected members of the community, including representatives of non-governmental organizations, including groups made up of people with mental disabilities.
- D-2 Human rights committees should be created at each institution that include current and former patients, as well as members of the community. These committees should have full access to all parts of institutions and should meet outside the institutions in a place where they can be assured privacy and independence. Human rights committees should be provided with funding independent of the institutions.

Service System Reform

In order for Turkey to shift from a institutional-based system to a community-based system of care and to protect the human rights of people with mental disabilities, the government should appoint a high level, national planning commission, with broad participation of professionals, provider organizations, families, activists, and people with disabilities who use services (as required by the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities) along with government representatives, to develop a master plan within the next six months regarding the adoption of a national policy on the provision of services to people with mental disabilities in the least restrictive environment. While the service needs of people with psychiatric and intellectual disabilities are very different, these populations overlap in many institutions. Thus, the national planning commission should include representatives of all relevant ministries. The plan should include:

- A. A comprehensive system of services and support systems for people with mental disabilities. Any complete community-based mental health service system should include community inpatient and outpatient treatment, treatment and case-management teams, supported housing, supported employment, twenty-four hour crisis services, respite care, clubhouses run by current or former users of mental health services, as well as user, family, and legal oversight and advocacy.¹³⁹ Accessible and affordable transportation must be available to ensure that people with mental or physical disabilities can make use of services. A system of income supplements (disability pensions) for individuals unable to support themselves is also essential. Such programs should be integrated into mainstream educational and primary health care systems and adapted to work in conjunction with community structures.¹⁴⁰
- B. All new community-based services should be based on the most progressive and integrated models proven to be effective around the world. Programs should maximize independence and choice.

- C. As recently recommended by the World Health Organization in its 2005 Helsinki Declaration, it should be a priority to create mental health systems build on a “recovery” model.¹⁴¹ A recovery model program is one that assumes that people can live independent lives in the community. The goal of the recovery model is not simply alleviation of symptoms but assistance in achieving full participation and inclusion in the life of the community;¹⁴²
- D. Development of programs for family support and child care to prevent the break-up of families and prevent the placement of children in institutions; family support programs should include financial support (disability pensions), as well as medical and mental health care in the community, and respite care for family members;
- E. A plan to phase down and eliminate long-term custodial care institutions for people with mental disabilities once community-based services have been established. Turkey can draw on the experience of other countries that the closure of such large state institutions is possible, while avoiding problems of “patient dumping” homelessness, and abandonment of people with mental disabilities in the community;¹⁴³
- F. A schedule of planned discharges and the phase down and closure of SHCEK residential institutions;
- G. Creation and expansion of family support and substitute family programs for children with mental disabilities who lack family support;
- H. Integrated and appropriate education in mainstream schools for all children with mental or physical disabilities;
- I. Legal protections to protect all people receiving mental health care. This includes the right to independent and periodic reviews of all involuntary commitment orders, the right to an individualized treatment plan and all other internationally recognized mental disability rights instruments;
- J. Coordination with independent human rights oversight bodies (as established above);
- K. As part of a system of independent human rights oversight, provisions should be made for reporting violent incidents, as well as every death in institutions to a human rights oversight body. The oversight body should have the power to investigate the causes and circumstances surrounding a death;
- L. A broad-based anti-discrimination law to protect the rights of people with mental disabilities to live full lives in the community;

- M. A national campaign to implement a program of public education to combat stigma and discrimination against people with disabilities;
- N. A plan for national implementation and financing;
- O. A time-line for implementation with discrete objectives, identifiable progress indicators, and a system of public feedback and reporting on progress.

ENDNOTES

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- ² *Id.* art. 10(xii).
- ³ *Id.* art. 10(v).
- ⁴ European Convention for the Protection of Human Rights and Fundamental Freedoms, Sept. 3, 1953, 213 U.N.T.S. 222 (ratified by Turkey Nov. 9, 1997).
- ⁵ European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, E.T.S. 126, (entered into force Feb. 1, 1989, ratified by Turkey Jan. 11, 1988).
- ⁶ International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966) 999 U.N.T.S. 172, 296 (1974) (entered into force Mar. 23, 1976, ratified by Turkey Sept. 23, 2003) [hereinafter ICCPR].
- ⁷ International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No.16, at 49 U.N. Doc. A/6316, 993 U.N.T.S. 3 (1966) (entered into force Jan. 3, 1976, ratified by Turkey Sept. 23, 2003) [hereinafter ICESCR].
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- ¹⁰ Winterwerp v. Netherlands, 2 Eur. Ct. H.R. 387, 60 (1979).
- ¹¹ *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 46/119, 46 U.N. GAOR, Supp. No. 49, Annex 188-192, U.N. Doc. A/46/49 (1991) [hereinafter MI Principles].
- ¹² See Rosenthal & Sundram, *supra* note 9, at 512-527 (reviewing international human rights protections against torture, inhuman, or degrading treatment).
- ¹³ World Health Organization, WHO RESOURCE BOOK ON MENTAL HEALTH, HUMAN RIGHTS, AND LEGISLATION 11 (2005) [hereinafter RESOURCE BOOK ON MENTAL HEALTH]. Protections against inhuman and degrading treatment are so fundamental that they cannot be limited or “derogated” even under conditions of national emergency.
- ¹⁴ General Comment No. 5 (1994) on Persons with Disabilities, Report on the Tenth and Eleventh Sessions, U.N. ESCOR 1995, Supp. No.2 [according to U.N. Doc. E/1995/22/Corr.1 E/C.12/1994/20/Corr.1], at 112, para. 15, U.N. Doc. E/1005/22-E/C.12/1994/20 (1995) [hereinafter General Comment#5].
- ¹⁵ Standard Rules on the Equalization of Opportunities for Persons with Disabilities, G.A. Res. 48/96, U.N. GAOR, 48th Sess., Supp. No. 48, Annex at 202-11, U.N. Doc. A/Res/48/49 (1993); see Rosenthal & Sundram, *supra* note 9, at 510 (describing the right to community integration under international law); see also Eric Rosenthal & Arlene Kanter, *The Right to Community Integration for People with Disabilities under United States and International Law in DISABILITY RIGHTS LAW & POLICY: INTERNATIONAL AND NATIONAL PERSPECTIVES* (Mary Lou Breslin & Silvia Yee, eds., 2002).
- ¹⁶ CRC, *supra* note 8, art. 23(3).
- ¹⁷ Report of the Committee on Petitions on the Rights of the Mentally Handicapped, A3-0231/92, Rapporteur: B. Schmidbauer, June 29, 1992. For a discussion of EU standards and policies on the rights of people with mental disabilities, see Elizabeth Shaver Duquette, *The Human Rights of the Mentally Handicapped: Can European Union Law Help?* 21 NY L. SCHOOL J. INT’L & COMP. L. 573 (2002).
- ¹⁸ European Parliament Resolution on the Rights of Disabled People, Dec. 13, 1996, A4-0391/96.
- ¹⁹ This includes a ward for forensic psychiatry, a neurology ward, a children’s ward, as well as general psychiatric wards for acute and long-term chronic patients. According to authorities at Bakirköy in April 2005, there are 1800 patients in general psychiatric wards.
- ²⁰ Bulent Coskun, *Psychiatry in Turkey*, in INTERNATIONAL PSYCHIATRY 13 (2004) [hereinafter Coskun].

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- 22 American Psychiatric Association, *THE PRACTICE OF ELECTROCONVULSIVE THERAPY: RECOMMENDATIONS FOR TREATMENT, TRAINING, AND PRIVILEGING 59* (2001) [hereinafter American Psychiatric Association].
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- 26 *Id.* at 69.
- 27 *Id.* at 71.
- 28 National Institute for Clinical Excellence, *GUIDANCE ON THE USE OF ELECTROCONVULSIVE THERAPY 12* (Apr. 2003) [hereinafter National Institute for Clinical Excellence].
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- 31 American Psychiatric Association, *supra* note 22.
- 32 *Id.* at 8-12.
- 33 National Institute for Clinical Excellence, *supra* note 28, at 5.
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- 42 P Slawson, *Psychiatric Malpractice and ECT: A Review of National Loss Experience*, 5 *CONVULSIVE THERAPY* 126-30 (1989).
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- 48 *Id.*
- 49 *RESOURCE BOOK ON MENTAL HEALTH*, *supra* note 13, at 64.
- 50 Council of Europe, Committee of Ministers, *"White Paper" on the Protection of the Human Rights and Dignity of People Suffering From Mental Disorder, Especially Those Placed as Involuntary Patients in a Psychiatric Establishment*, Jan. 3, 2000, DIR/JUR (2000)2, para. 10.
- 51 Government of Turkey, *FOLLOW-UP REPORT OF THE TURKISH GOVERNMENT IN RESPONSE TO THE REPORT OF THE EUROPEAN COMMITTEE FOR THE PREVENTION OF TORTURE AND INHUMAN OR DEGRADING*

TREATMENT OR PUNISHMENT (CPT) ON ITS VISIT TO TURKEY FROM 5 TO 17 OCTOBER 1997 18 (Dec. 16, 1999).

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54 European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, REPORT TO THE TURKISH GOVERNMENT ON THE VISIT TO TURKEY CARRIED OUT BY THE EUROPEAN COMMITTEE FOR THE PREVENTION OF TORTURE AND INHUMAN AND DEGRADING TREATMENT OR PUNISHMENT (CPT) FROM 5 TO 17 OCTOBER 1993 (Feb. 23, 1999), para. 182, *at* <http://www.cpt.coe.int/documents/tur/1999-02-inf-eng.htm#II.C.3>.

55 *Id.*

56 Among the diagnoses for which ECT is not considered effective are personality disorders, dementia and amnesic disorders, and substance abuse related disorders. *See* Fink, *supra* note 29, at appendix 2.

57 National Institute for Clinical Excellence, *supra* note 28, at 5.

58 American Psychiatric Association, *supra* note 22, at 67.

59 *Id.*

60 HL v. UK (2004).

61 Council of Europe, Recommendation (2004)10, art. 16(1)(iii) *at*

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62 *Id.* art 16(1)(iv).

63 *Id.* art 12(1).

64 MI Principles, *supra* note 11, principle 9(4).

65 Paul Hunt, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Commission on Human Rights, 61st sess., Item 10, E/CN.4/2005/51, para. 54 (Feb. 11, 2005) [hereinafter Hunt Report].

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73 *Varbanov v. Bulgaria*, App. No. 31365/96, Eur. Ct. H.R. 455, paras. 43-53 (Oct. 5, 2000).

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76 MI Principles, *supra* note 11, principle 11(11).

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84 *Concentration Camp for Mentally Retarded*, MILLIYET, Jan. 24, 2005.

85 *Retarded Girls Kept Locked in Empty Rooms*, SABAH, Jan. 24, 2005.

86 *Id.*

87 *Id.*

88 *Id.*

89 WHO, World Health Report 89-91 (2001).

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91 WHO, *Public Health in Europe*, MENTAL HEALTH SERVICES IN EUROPE: 10 YEARS ON 75 (1985).

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98 Kerim Munir et al., *A Window of Opportunity for the Transformation of National Mental Health Policy in Turkey Following Two Major Earthquakes*, 12 (4) HARVARD REVIEW OF PSYCHIATRY 238, 239 (2004).

99 Coskun, *supra* note 20, at 14.

100 *Id.*

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102 Munir, *supra* note 98 at 240. One patient at Erenkoy Hospital in Turkey told MDRI that he traveled 1,000 miles once a year to receive psychiatric services. Given the difficulties of this long distance travel, he would stay 30 days at the facility each year.

103 *Id.* at 246, 245.

104 Coskun, *supra* note 20, at 14.

105 See RESOURCE BOOK ON MENTAL HEALTH, *supra* note 13, at 1.

106 See WHO, *supra* note 9, at 1; See also Rosenthal & Sundram, *supra* note 9, at 469.

107 RESOURCE BOOK ON MENTAL HEALTH, *supra* note 13, at 19.

108 *Winterwerp v. Netherlands*, 2 Eur. Ct. H.R. 387, at 60 (1979). The UN's MI Principles also provide such rights. See MI Principles, *supra* note 11, principle 17.

109 Rec. (2004)10, *supra* note 61, arts. 17-20.

110 *Id.* art. 17(1)(iii).

111 *Id.* art. 18(ii).

112 *Id.* art. 25(1)(ii).

113 *Id.* art. 25(3).

114 *Id.* art. 25(1).

115 Directive 23420 became effective on August 1, 1998, when it was published in the Official Gazette. Available on the WHO International Digest of Health Legislation website at <http://www3.who.int/idhlrls/results.cfm?language=english&type=ByVolume&intDigestVolume=50&strTopicCode=XIA#Turk>.

116 *Id.* The Directive includes a number of potentially important rights, such as a right to refuse treatment, but it creates no mechanism for its implementation. The patient has a right to refuse treatment so long as his or her choices are "medically viable." Presumably, a mental health care worker would decide whether a choice is viable, effectively undercutting any actual independent ability to refuse treatment the patient might have.

117 MI Principles, *supra* note 11, principle 11.

118 *Id.* Limitations of the right to informed consent in the MI Principles are discussed in Rosenthal & Sundram, *supra* note 9, at 501.

119 *Id.* principle 11(2).

120 *Id.* principle 11(4).

121 *Id.* principle 11.

122 Hunt Report, *supra* note 65, at paras. 90-91. Paul Hunt has called for stricter protections of the right to

informed consent for people with mental disabilities under international law.

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¹²⁴ Rec. (2004)10, *supra* note 57, art. 20(2).

¹²⁵ *Id.* art. 18(ii-iii).

¹²⁶ *Id.* art. 18(iv).

¹²⁷ *Id.* art. 21(2-3).

¹²⁸ *Id.* art. 20(2)(ii).

¹²⁹ *Id.*

¹³⁰ *Id.* principle 1(6). In order to ensure independence, the “counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest” *Id.*

¹³¹ Leslie J. Blackhall et al., *Ethnicity and Attitudes Toward Patient Autonomy*, 274 JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 820 (1995).

¹³² Larry O. Gostin, *Informed Consent, Cultural Sensitivity and Respect for Persons*, 274 JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 844 (1995).

¹³³ See Rosenthal & Sundram, *supra* note 9, at 501.

¹³⁴ Directive 2340, at Regulation on the Rights of the Patients (Official Gazette: 01.08.1998, No. 23420).

¹³⁵ Council of Europe Rec. (2004)10, art. 36(1).

¹³⁶ *Id.* art. 36(2)(ii).

¹³⁷ *Id.* art. 37(1).

¹³⁸ *Id.* art. 38.

¹³⁹ See WHO, TREATMENT OF MENTAL DISORDERS: A REVIEW OF EFFECTIVENESS 304-321 (Norman Sartorius et al. eds., 1993) [WHO Review of Effectiveness] (describing international experiences with the implementation of such programs); see also Loren Mosher & Lorenzo Burti, *Community Mental Health: A Practical Guide* (1989) (a guide to the development of community-based mental health services drawing from experiences in the United States and Italy); Robert Desjarlais et al., *WORLD MENTAL HEALTH* 38 (1995).

¹⁴⁰ *Id.* at 269.

¹⁴¹ *European Ministerial Conference*, *supra* note 1, at “Priorities” art. 7(iii).

¹⁴² Laurie Ahern & Daniel Fisher, eds., *PERSONAL ASSISTANCE IN COMMUNITY EXISTENCE (PACE)* (1999).

¹⁴³ See Robert Okin, *Testing the Limits of Deinstitutionalization*, 46 *Psychiatric Services* 569 (1995) (describing the transition to a completely community-based mental health system in western Massachusetts).

Appendix 1 Photos



1. Bedridden child, unable to move on his own, in crib at Saray Rehabilitation Center



2. Without physical therapy, this child's disability will continue to worsen and become permanent
– Saray Rehabilitation Center



3. Plastic liter bottles are permanently duct taped over the hands of young, bedridden children who, due to mind-numbing boredom, scratch or bite themselves
– Saray Rehabilitation Center



4. Emaciated, bedridden child biting one hand and plastic liter bottle taped to the other hand
– Saray Rehabilitation Center



5. Children and young adults spend their days in total inactivity – Saray Rehabilitation Center



6. Children with relatively minor disabilities will grow up segregated from society – Saray Rehabilitation Center



7. Bedridden child left unattended after vomiting on himself – Saray Rehabilitation Center



8. Patients languish on the grounds of Bakirköy Psychiatric Institution



9. Without any mental health laws to protect them, many psychiatric patients have no hope of ever getting out of institutions



10. Staff demonstrate how they hold down terrified patients to receive electro-convulsive or “shock” treatment **without** the use of any anesthesia, a violation of the European Convention for the Prevention of Torture – Bakirköy Psychiatric Institution

Appendix 2 Children of Saray: Analysis of photos

By

KAREN GREEN MCGOWAN, RN, CDDN

Qualifications & background:

I have been a Registered Nurse for 42 years and I have worked in the field of developmental disabilities for most of that time. My specialty is working with and training families, direct care and clinical professionals how to meet the needs of persons with complex physical, intellectual and medical disabilities. I have worked as an expert witness in class action court cases, mostly for the United States Department of Justice and public interest advocacy organizations in the United States.

I entered the field when children with disabilities were routinely admitted shortly after birth to state institutions. I worked as a nurse on the Diagnostic and Evaluation Team, the gatekeeper for the institution where I spent my first 7 years. Because in those days, we commonly told parents to go away and let their children “adjust,” almost 25% of these youngsters died by the end of the first three months of placement.

Observations of Saray Photographs

We used to believe that deformity and lack of responsiveness was inevitable, so that those who work with the children at Saray are likely to believe that these misshapen bodies are the result of the brain damage and not the neglect and mistreatment. In the pictures from the Saray facility, the little boy with his head twisted back on his spine has a disability that appears to be athetoid cerebral palsy (**see photo 2**). What is ironic is that these children and adults are often intellectually normal or gifted, because the damage is in the part of the brain that controls movement and not the cerebral cortex. The posture you see him in is not intentional on his part. This abnormal reflex posture is called extensor spasticity (sometimes opisthotonus) and prevents normal movement without extensive help by his caretakers. This will result in permanent deformity very soon if this child does not receive proper physical management.

The child with hands in mouth and flexion contractures of both arms (**see photo 4**) is in danger of dislocating one or both hips (if indeed this has not already happened) because he is lying with his legs windswept to the left, which puts incredible pressure on shallow hip sockets to hold the ball at the top of the femur in place. Hands in mouth is often a self-stimulatory behavior, but can also be a way to increase the flow of saliva for swallowing, particularly if the person receives medications that dry up secretions (such as behavioral or anticonvulsant drugs).

The youngster with the foot sticking out from the bedrails (**see photo 1**) is stuck in the side-lying position with his head extended, and probably cannot move out of this position on his own. If this posture is allowed to continue over long periods of time,

gravity will squash the chest and restrict his breathing capacity. In addition, with his head pushed back, part of every swallow (whether it is his own secretions or liquids from a cup or bottle) will go directly into his airway.

The little boy with the arm restraints (looking like plastic bottles are taped to his arms) (**photo 3**) is trying to provide for his own stimulation. In addition, “hands-in-mouth” behavior is correlated with inflammation of the lower esophagus about 30% of the time. This will eventually lead to bleeding in the GI tract and is associated with an intense level of pain. We think the behavior is intended to produce saliva to swallow, which decreases the pH of the acid backing into the esophagus.

The young men sitting along the wall have nothing to do and no stimulation available in this sterile environment (**see photo 5**). All of these young men could be engaged in meaningful activities. With supportive services, they could also hold jobs in the community. I can see no one in this picture who is not capable of doing some form of functional and productive activity.

The little boy lying on his back with the yellow blanket tucked under his chin looks starved for attention and lacking in any form of human interaction or stimulation (**see photo 7**). This alone could be the cause of the extent of his intellectual disability.

Historically, most individuals with these types of disabilities were perceived as sub-human organisms or objects of pity, and there seemed little reason to do more. I have not seen conditions like those in the photographs in US facilities since 1965. Any facility here receiving funding would be closed down if these conditions were discovered.

Infants born with neuro-developmental obstacle to movement need help to move in the ways that nature intended. There is nothing wrong with the trunk or limbs of these infants at birth. The damage is in the brain and the body changes shape due to lack of appropriate movement signals. The body changes shape across a lifetime to accommodate the manner in which it is used. Form always follows function. This body reshaping happens with greatest intensity in the first 18 months of life, but most of us over 40 know that our bodies do not look the same as they did when we were 20. After the age of 30, gravity causes all of our body parts to begin an avalanche to the floor.

In infants with motor damage to the brain, this same force acts on body parts exposed to the vertical plane. When infants and children are left to lie in one position for long periods of time (usually on their backs) chests flatten out or hips dislocate from the lack of weight bearing on shallow joints that normal infants develop by stomping across the floor. Because all children will try to move regardless of the level of brain damage, children with neuro-motor patterns use their bodies in ways that change its shape in bizarre forms, rather than the normal changes that infants and children experience when they move in more typical ways.

When any person is allowed to simply lie without stimulation, multiple factors come into play. First, gravity causes the body to assume the shape of the predominate

position. Secondly, lack of stimulation is not acceptable to young children, so they will either self-stimulate, if that is within their movement repertoire. Or, they will withdraw and develop a condition known as *marasmus*:

“The effects of bleak caretaking environments were studied by Rene Spitz and William Goldfarb in 1945. Spitz was a consulting doctor at a foundling home whose infants wasted away and died from a condition called marasmus. He discovered, that despite hygienic surroundings and a nourishing diet, the babies received minimal stimulation from the social and physical environment. Spitz showed that mothering is essential to healthy psychological development and to life itself. Similarly, Dr. Goldfarb’s comparative studies of children cared for in institutions and those removed to foster homes showed abnormal development in the institutionalized children in the areas of intelligence, motor coordination, behavior, and language.” (3)

Basic human needs are the same for those with and without disabilities. We all need someone in our life who is passionate about our welfare and who probably isn’t paid to care about us. We need access to people and places that stimulate learning. We need a decent home and help with things we can’t do on our own. We need to be perceived as valuable human beings with access to family, friends and a chance to make mistakes and learn from them. All children, regardless of their level of disability, should be raised in families. Within the United States, there are states that have closed down all institutions for people with intellectual disabilities. Allowing children to live in congregate care settings with multiple caretakers is less and less common in much of the world.

We have long recognized that placing any child in a setting with little human interaction is equivalent to an emotional and physical death sentence.

“The effect of sensory deprivation in animals was the subject of numerous clinical studies in the 1940-50s. Ralph Thompson and Ashley Montagu both determined that touch had the utmost importance in predicting the later behavior of animals, especially humans. When deprived of the comfort of this stimulation, they noted abnormal behavior patterns. The famous Harlow’s monkeys experiments in 1969 indicated that maternal touch and comfort was essential for normal development. In the 1970s, Jean Ayres, a psychologist trained in Occupational Therapy, identified Sensory Integrative Dysfunction (SID), a neurological disorder that results in inefficient organization of sensory input received by the nervous system. Children who are deprived of touch, movement, sound and other normal sensory input may exhibit SID. Some of the characteristics described include:

- Overly sensitive to touch, movement, sights or sound
- Under-reactive to sensory stimulation (such as pain) or seek out intense sensory experiences (e.g. body whirling)
- Activity level that is unusually high or low
- Coordination problems

- Delays in speech, language, motor skills, or academic achievement
- Poor organization of behavior
- Poor self concept.”(3)

From my experience, the difference in children with the same level of severe disabilities raised in congregate care settings, and those who have stayed with their families is simply stunning. In numerous right to treatment court cases in the US, the use of clinical “twins” to demonstrate to the court the dramatic, clinically superior and cost-beneficial effects of home-like settings was used very effectively. If one were to compare two youngsters with Down’s Syndrome, one raised at home and one raised in a sterile congregate care setting, we may see a difference of as many as 50 IQ points and an individual who is capable of semi-independent living versus one who is nearly totally dependent and lacking in any level of daily living skills. In my 40 year career in developmental disabilities, I have personally experienced this incredible difference.

There have been many citations in my literature search about conditions in Eastern European orphanages:

“In many Eastern European orphanages, there was no consistent, responsive care giving provided to children with special needs. Children had multiple care givers, who through understaffing, ignorance or disinterest, tended to the children’s needs with as little contact as possible. Rooms were often bare of stimulating mobiles, toys, or music. In some institutions, children were physically, psychologically or sexually abused, malnourished, neglected, or exposed to life-threatening environmental conditions.”(3)

In the early 70s as part of discovery in a court case, I spent eight hours observing in a large children’s facility in central Texas. I counted the number of minutes of human interaction received by eight children in a single cubicle of the facility which served more than 60 youngsters under the age of twelve. Including two meals and a sponge-bath, no child in this group received more than ten minutes of individual attention over the eight hour period. I was gratified to have been part of the process of closing that facility down.

In yet another Texas facility, part of the Gary W. court case in 1975, a nurse in charge of a 150-bed facility told our group, consisting of lawyers from the State Attorney General’s Office and the US Department of Justice: “You know, these children are better off dead, and we try to help them whenever we can.” That facility is also no longer in operation, but the attitude is one which may be operational in the facilities in question here. If a child with a disability is seen as sub-human or evil, the person providing care can see their role as keepers rather than as providers of treatment or education.

In a discussion on the consequences of institutionalization for young children from a meeting in Copenhagen, Denmark in March of 2004, Dr. Rebecca Johnson of the University of Birmingham, United Kingdom, stated:

“The literature reviewed supports the following conclusions:

- Severe deprivation can result in cognitive, social, behavioral and emotional delay. However, some children may recover to within ‘normal’ range with appropriate quality of care, but there is still an impact.
- Quality of institution is vital; even ‘good’ institutional care can result in social, behavioral and emotional difficulties.
- Return to biological family not necessarily better.
- Optimal infant brain development needs the support of a sensitive caregiver.
- Room for optimism-evidence that positive change can occur when the child is removed from the deprived institutional environment.”(8)

In the United States, there is increasing evidence and support for the notion that the only appropriate place for children is in families. For children with extensive disabilities, this may be in specialized foster care, with adequate support and subsidy to assure that the child receives adequate attention for very special needs. The state of Michigan has a policy that says that no child will be in other than a home environment. Macombe-Oakland Regional Center has been a leader in finding and retaining foster families that have been remarkably stable for long periods of time for even children with highly technical medical needs, such as respiratory equipment and ventilators.

More importantly, although we are far from perfect, there is increasing legislative support for family assistance to allow children to remain in their own homes, with both personal attendants and medical support if necessary.

Recommendations – Children with Intellectual Disabilities

1. There should be no child considered incapable of responding to a well-planned program of service.
2. The institutional model of care should be abolished and replaced with a family-centered approach.
3. Everything should be done to keep a child with a disability in his/her natural home, if that home has the capacity to be nurturing given sufficient support.
4. When the natural home is not an option, specialized foster care should be the next option of choice.
5. Children should have an option for a permanent family through subsidized adoption if their natural families are incapable of assuming the responsibility over a reasonable period of time.

6. Children with neuro-developmental disabilities, such as cerebral palsy, should have assistance from developmental therapists (e.g. physical, occupational and speech therapists) to assure the following:
 - Y That the child's needs for physical and nutritional management (movement, positioning and handling, eating and communication) are assessed, programmed and taught to the family and educational program.
 - Y That each child who is not able to move on his/her own has a range of positioning options that alter weight-bearing surfaces and facilitate active movement.
 - Y That each child has support to move around and explore his/her environment and interact with non-disabled peers.
 - Y That each child is promptly reassessed when lack of progress or significant progress occurs.
 - Y Lack of progress should be placed on the circumstance and not on the child.
7. Children with behavioral issues should be presumed to be communicating in a language not readily understood by others and provided with some means for more acceptable communication.
8. Medical antecedents to behavior or lack of such should be explored before resulting to psychiatric or behavioral medication.
9. For children who must remain in congregate care until other options are developed, caretaker ratios should be reduced to no less than 1 caretaker for each 4 children during waking hours, and every effort made to assure that the fewest number of caretakers interact with each child.
10. Children should be held and talked to for at least two hours each day regardless of the perceived level of disability.

Conclusion

I approach the task of analyzing conditions of children in Turkey with the humility of an American who has observed very serious human rights abuses in my own country. At the same time, I have also seen tremendous progress. This gives me great optimism, even as I observe very disturbing photographs from Turkey. The most serious abuses experienced in the United States have been largely eradicated -- and there is no reason to believe the Turkish experience will be much different. The United States is a rich country, but the mistreatment of people with developmental disabilities is ultimately not caused by a shortage of financial or technical resources. It is caused by the lack of recognition for the basic humanity of individuals with developmental disabilities. People with developmental disabilities have now demonstrated that, no matter how serious their disabilities, they are capable of living and enjoying life in the community. Even with limited resources, we now know how to remove the barriers and provide the supports people with developmental disabilities need to thrive as members of our society.

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(3) The Parents Network for Post-institutionalized Children, 1995: *The Long Term Effects of Institutionalization on the "Behavior of Children from Eastern Europe and the Former Soviet Union: Research, Diagnoses, and Therapy Options"* by Teri Doolittle, PA-C, MHP, p. 6.

(4) Ibid, p. 7.

(5) Braddock, David and Susan L. Parish "An Institutional History of Disability" in Braddock, D (Ed.) **DISABILITY AT THE DAWN OF THE 21ST CENTURY AND THE STATE OF THE STATES**. American Association on Mental Retardation, 2002, p. 38.

(6) Lakin, Braddock and Smith, p. 235.

(7) Parent's Network, p. 9.

(8) Paper presented at a Conference held by the World Health Organization in Copenhagen, Denmark in March, 2004 called "Mapping the number and characteristics of children under 3 in institutions across Europe at risk of harm, 2.1.1 Consequences of institutionalization for young children: A review." Dr. Rebecca Johnson, University of Birmingham, United Kingdom.

Appendix 3 The Case for a Turkish Mental Health Law¹

Introduction

Human rights in Turkey are under international scrutiny as the country begins the process of accession into the European Union (EU). As part of its pre-accession strategy, Turkey has passed a series of constitutional and legal reforms that demonstrate Turkey's commitment to human rights and the democratic rule of law. Despite these valuable reforms, Turkish law does not adequately protect the human rights of people with mental disabilities.

Current Turkish Mental Health Law

At present, Turkey has no enforceable mental health law.² Unlike every other country in the EU, Turkey has no law that protects people with mental disabilities against arbitrary or improper detention in psychiatric facilities. Nor is there any Turkish law that recognizes the right of people with mental disabilities to procedural protections in the commitment process, the right to treatment in the least restrictive setting, or to participate in their treatment by providing informed consent or refusing treatment.

¹This analysis was drafted by Professor Arlene Kanter of Syracuse University College of Law, with the assistance of law student Nevhiz Calik. MDRI Executive Director Eric Rosenthal reviewed and edited this analysis.

²In 2001, the Turkish Parliament amended its Civil and Penal Codes to authorize the involuntary confinement of people who are considered "abandoned or homeless" in order to protect them from harm. Section Six, article 432 and 437 of the Turkish Civil Code provides as follows:

Persons who have mental illness, mental infirmity, habitual drunkenness or substance addiction and thus harm their own family and surroundings can, by order of a court, be placed in a health center for their protection. In making this determination, the court has to consider the amount of harm that the person committed under influence.

Hukukcu (Lawyer) Website, Turk Medeni Kanunu (Turkish Civil Code).

<http://hukukcu.com/bilimsel/index.htm> and The Office of the Prime Minister, Directorate Genral Press and Info Wesite: <http://www.byegm.gov.tr/on-sayfa/new-civil-code.htm>. (This website is in English). This provision of the Civil Code was enacted to expand the scope of the government's authority to treat people against their will, but it is not considered a mental health law. It does not provide any process by which a person may be committed or any standard for determining who may be committed. Further, the Code provides in article 433 that the same court that commits a person also has the power to decide to free the person from the institution. Yet no standards for release are contained in the code.

Following the passage of article 432, courts began sending abandoned and homeless people to psychiatric hospitals. According to Dr. Mustafa Sercan of the Turkish Psychiatric Association, hospitals had no beds for these people nor the capacity to admit them. Accordingly, the hospitals requested the courts to stop sending people who did not necessarily need treatment to mental hospitals. Apparently the Turkish courts supported the hospital's position as at least one court has held that mental hospitals are not "care houses" despite article 432's mandate. According to Dr. Serjan, Vice President of the Turkish Psychiatric Association (TPA), the TPA has specifically criticized this provision of the Civil Code because it does not conform to international standards regarding involuntary commitment of people who are labeled mentally ill. In practice, he says, the provision is not used.

Currently, Turkey is a member of the Council of Europe, and it has applied for admission to the European Union. The Council of Europe has recognized the rights of people with mental illness to procedural safeguards in the commitment process. All countries in the EU also have enacted either separate mental health laws or laws governing the detention of people with mental illness in their general health laws.³ By failing to enact legislation to protect the rights of people with mental disabilities, particularly those in Turkish institutions, Turkey jeopardizes its standing among European nations and risks the opportunity to be granted ascension to the European Union.

In lieu of an enforceable mental health law, Turkey does have a Directive, which was issued by the Ministry of Health. This Directive provides some guidance to doctors who oversee the process of involuntary detention.⁴ In theory, the Directive also recognizes a right to informed consent. However, the Directive does not have the force of law, nor is it applied consistently.

Psychiatric authorities at Bakirkoy report that the Directive is not applied consistently. Without the protection of an enforceable law, men, women, and children who are confined in Turkey's institutions do not have the benefit of any legal processes when they are forcibly treated or detained in psychiatric institutions. Without enforceable laws governing their continued confinement, and without adequate alternatives to hospitalization, individuals involuntarily confined in Turkish mental hospitals may be allowed to languish there for years without legal oversight or independent review of their continued confinement.

Further, patients in psychiatric institutions in Turkey have no enforceable right to informed consent about treatment. Psychiatric facilities in Turkey routinely require patients to consent to all treatment upon admission. Yet once a patient signs a blanket consent to treatment, he or she may not withdraw consent except under very narrow and ill-defined circumstances.⁵ In the absence of community-based alternatives, any patient seeking treatment has no practical choice, therefore, but to sign himself or herself into an

³ Most members of the EU regulate compulsory admission of mentally ill people in mental health laws. Only Greece, Italy and Spain are exceptions. The reason these countries do not have special mental health laws is to avoid the stigmatizing effect of separate rules and regulations for people with mental illness from those in effect in the general health laws. *See* Compulsory Admission and Involuntary Treatment of Mentally Ill Patients: Legislation and Practice in EU Member States, Final Report (May 15, 2002).

⁴ Directive 23420. The Directive became effective August 1, 1998 when it was published in the Official Gazette. The Directive is on the Ministry of Health website at http://www.saglik.gov.tr/sb/codes/hasta_haklari/hasta/haklari_yonetmeli.htm. The Ministry also has an English website at <http://www.saglik.gov.tr/eng/>.

⁵ The Directive permits consent to be withdrawn if the treatment is "dangerous" to the person's life and only if it is medically viable to desist from treatment from the point of view of the treating psychiatrist. The law does not define what constitutes a "danger" nor what procedures must be followed in deciding the dangerousness of the patient's condition. Further, under the Directive, if the patient is a minor, with no parent or guardian, or if the child's parents or guardian cannot be reached, or if the patient cannot understand the treatment decision, the Directive allows involuntary treatment without any consent. The Directive provides no procedure for determining whether the patient "understands" the decision. It states specifically that there is no need to wait for consent under these circumstances.

institution – and thereby forego any opportunity to make further decisions about treatment. Moreover, with regard to civil commitment in particular, the Directive provides no specific standard for involuntary treatment, nor does it establish a process for determining who may be committed to a psychiatric facility.

A body of case law has developed within Europe and internationally to protect certain rights of individuals within the mental health system. In most EU countries, these rights are included in separate mental health laws which authorize involuntary commitment only in certain limited circumstances, and only after a full array of procedural protections are provided.⁶

In particular, the European Court of Human Rights has recognized a broad range of human rights protections for people with mental disabilities under the European Convention on Human Rights (ECHR), including protections against improper detention.

The European Court of Human Rights has itself identified three conditions that must be met in order for the detention of a person with mental illness to be lawful within Article 5(1)(e) of the European Convention on Human Rights. The conditions justifying compulsory confinement require first that the person must have a mental disorder that is established before a competent authority on the basis of objective medical expertise;⁷ second that the mental disorder must be of a kind or degree warranting compulsory confinement, usually as a result of dangerousness to the person or others;⁸ and third that the validity of the continued confinement depends on the persistence of the disorder.⁹ The European Court of Human Rights has made no distinction between persons with mental illness who have committed criminal offenses and those who have not, therefore the same heightened level of legal protection must be applied to all people labeled as mentally ill, regardless of the reason for their confinement.

Further, in order to comply with international human rights standards, individuals facing involuntary commitment have the right to a hearing, to an independent review of the commitment order, to counsel, and to present evidence.¹⁰ And although the mental health laws of the members of the European Union differ with respect to the standards for commitment, they all guarantee the right to appeal a decision of involuntary detention to

⁶ In *Herczegfalvy v. Austria*, the European Court of Human Rights held that detention is justified under article 5(1)(e) of the Convention only when an individual who is mentally ill is also dangerous. Merely querulous behavior resulting from mental disturbance cannot in itself justify detention under article 5(1)(e). Although this court also deferred to medical judgment regarding treatment decisions, the court emphasized that “the position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with.” 15 EHRR 437, para. 82 (1992).

⁷ *Ashingdane v. United Kingdom*, 7 EHRR 528, para. 37 (1985). See also *Van Der Leer v. The Netherlands*, 12 EHRR 567 (1990).

⁸ *Id.* para. 37.

⁹ *Id.* See also *Winterwerp v. The Netherlands*, 2 EHRR 387, para. 39 (1979-80).

¹⁰ *Van der Leer v. The Netherlands*, 12 EHRR 567 (1990). Court held compulsory confinement of individual to a mental hospital without a hearing constituted violation of article 5(1) for failure to comply with procedural requirement of a hearing before confinement may be authorized.

a higher authority.¹¹ Periodic review of the appropriateness of commitment is also provided specifically within the mental health laws of most EU countries and within international human rights instruments. Further, according to the EU, compulsory confinement can be justified only when less restrictive alternatives are not sufficient or available.¹² And under international law as well as EU law, an individual may not be detained in conditions that amount to cruel and unusual punishment.¹³ Finally, once an individual is detained, he or she has the right to family integrity, which includes the right to visitors, and to communicate with people outside of the institution, as well as the right to bodily integrity, safety, and access to health care within the institution.

In the absence of any law governing the involuntary detention or treatment of people with mental disabilities, every person detained in a Turkish psychiatric institution is being arbitrarily detained in violation of the European human rights conventions and international law standards.

Assessment of Turkish Psychiatric Association's Draft Law

The Turkish Psychiatric Association has recently drafted a proposed mental health law that would provide many important new rights. It represents an important step forward in the protection of the rights of people with mental disabilities in Turkey. The proposed law, however, does not comply fully with the requirements of the European Convention on Human Rights (ECHR), Council of Europe guidelines¹⁴ or United Nations standards.¹⁵ Even when the law appears to provide important rights, these rights are undermined by the vagueness of the language in the proposed law. MDRI recommends that the law be redrafted to comply with international human rights standards before it is adopted by the government of Turkey.¹⁶

The Goals of the Proposed Law

¹¹ See *X v. United Kingdom* (1981).

¹² See Council of Europe, Committee of Ministers, “*White Paper*” on the Protection of the Human Rights and Dignity of People Suffering From Mental Disorder, Especially Those Placed as Involuntary Patients in a Psychiatric Establishment, Jan. 3, 2000, DIR/JUR (2000)2, para. 3(d).

¹³ See *Yagiz v. Turkey*, 22 EHRR 573 (1996) (citing *Ireland v. United Kingdom*, Comm. Rep. p. 388); see also *Nasri v. France*, 21 EHRR 458 (1966); *Klass v. Germany* 18 EHRR 305 (1994).

¹⁴ Council of Europe, Committee of Ministers, Recommendation (2004)10 (concerning the protection of the human rights and dignity of persons with mental disorder), at

[http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/News/Rec\(2004\)10%20e.pdf](http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/News/Rec(2004)10%20e.pdf).

[hereinafter Council of Europe Recommendation (2004)10]. See also Final Report of the European Health and Consumer Protection Directorate General Research Project, Compulsory Admission and Involuntary Treatment of Mentally Ill Patients – Legislation and Practice in EU Member States (2002), at http://europa.eu.int/comm/health/ph_projects/2000/promotion/fp_promotion_2000_exs_08_en.pdf.

¹⁵ Principles for the Protection of Persons with Mental Illness (the MI Principles), G.A. Res. 119, U.N. GAOR, 46th Sess., Supp. No.49, Annex 188-92, U.N. Doc. A/46/49 (1991).

¹⁶ MDRI recommends that Turkey review the Checklist on Mental Health Legislation contained in Annex 1 of the recently published WHO Resource Book on Mental Health, Human Rights and Legislation (WHO 2005).

The stated policy goals of the proposed law are consistent with international human rights law.¹⁷ If implemented, these policies would represent an important step forward in the protection of human rights for people with mental disabilities in Turkey. The proposed law identifies four valuable policy goals:

1. To make treatment voluntary instead of involuntary;
2. To overcome the “long-lived presumption in psychiatry (in Turkey) that all psychiatric patients pose [a] danger to themselves and to [the] public...”;
3. To discourage and prohibit the abuse of psychiatry;
4. To “allow psychiatric patients to exercise their rights provided by international standards, the Constitution, the Civil Code and other similar laws regulations to the fullest extent...” while protecting them from danger.

Language of Proposed Law Fails to Implement Stated Policy Goals

Despite the laudable goals of the proposed law, the language of the draft law does not guarantee enforcement of some basic human rights. Indeed, some provisions undermine the promised protections. The draft law has the following limitations:

- 1. Unclear standard of commitment --** The major advance of the proposed law is that it requires review of any involuntary commitment by a court within 24 hours.¹⁸ According to the definition of “compulsory commitment” this practice should be limited to circumstances in which a person is dangerous to self or others.¹⁹ While this language implies that the court must determine whether an individual is dangerous to self or others, the language of the proposed law is not explicit. The current draft states merely that the “[c]ourt shall decide on the continuation of commitment upon the receipt of reports from hospital and opinion of court’s designated expert. Courts may ask for information when needed.”²⁰ The law appears to suggest that the court should defer to the judgment of medical experts. If so, the law does not adequately protect patients’ rights. The law would be significantly strengthened if the language stated explicitly that the court itself must determine whether the individual is dangerous to self or others.²¹
- 2. Lack of clear process for court review --** The proposed law is unclear in a number of places about the process of review by a court. The lack of specificity may entirely undermine the role of the court as an independent reviewer. The draft law:

¹⁷ See Part I, Purpose/Intent of the Proposed Draft Law.

¹⁸ Draft Law Part III, art. 2, para. 5(a).

¹⁹ Draft Law Part II, art. 1, para. 6.

²⁰ Draft Law Part III, art. 2, para. 7(c).

²¹ Currently, an individual in Turkey may be committed under the Turkish Civil Code, which authorizes a court to order an individual detained in a “health center” for “mental illness, mental infirmity, habitual drunkenness or substance addiction.” Article 432 of the Turkish Civil Code. This provision of the Turkish Civil Code does not meet international human rights standards as it fails to require an independent authority to find a person dangerous to himself or others, or in need of services that cannot be provided in less restrictive settings. Further, without a legally enforceable right to due process or independent review, anyone detained involuntarily in Turkey’s psychiatric facilities is detained in violation of the European Convention on Human Rights and international standards. According to the Vice President of the Turkish Psychiatric Association, the implementation of this provision has been suspended since it allowed a court to place people in psychiatric institutions who had no mental health diagnosis.

- does not provide specific deadlines or time frames for review by a court. As a result, the process of review could be extended indefinitely as a patient languishes in a psychiatric institution without legal protections;
- mentions participation by a second psychiatrist, but never requires the court to take this second opinion into consideration;²²
- mentions a process for relatives to apply for transfer of family members from one institution to another. It states that a court in the jurisdiction of the new institution will have authority over such a transfer, but the draft law does not explain how such court will be involved or that it needs to be notified in any way. In the absence of such detail, family members are left with unfettered discretion to control the patient's transfer without review by any court or independent body;
- does not mention whether or not the court plays any role in reviewing a non-protesting or voluntary patient. As a person with a mental disability may not be in a position to express his or her opposition to commitment, the European Court of Human Rights has specified that independent review is necessary in all cases.

3. Emergency commitment includes no guarantee of independent review -- The proposed law improves on the current Turkish procedures for involuntary admission to mental institutions by requiring an expert evaluation of more than one psychiatrist within the first 24 hours.²³ It requires the admitting doctor to prepare a report assessing the necessity of the admission. The proposed law requires a second evaluation by a psychiatrist, however, only “*if one is available.*” By using the language “*if available,*” there is no guarantee that the report by an “independent” expert will be provided.²⁴

4. Failure to define dangerousness -- The proposed law is unclear about the definition of “dangerous” required for psychiatric commitment.²⁵ The draft law defers entirely to the Ministry of Health to adopt regulations that will define this terminology further. The precise definition of dangerousness in a mental health law is critical because it creates the core standard for determining who may or may not be involuntarily detained in a psychiatric facility. The failure to define dangerousness with precision makes it almost impossible to question the judgment of a psychiatrist who may assert that an individual is dangerous, without any substantiation. To the extent that the draft law provides a guideline as to what might be considered “dangerous,” it states that dangerousness may be a threat to “the patient or others’ physical safety or property.” This contravenes the Council of Europe Standard that requires dangerousness to be a “significant risk of serious harm to his or her health or to other persons.”²⁶ The UN

²² *Id.* para. 4(g).

²³ *Id.* para. 4(a).

²⁴ Council of Europe Recommendation (2004)10, article 21 on emergency commitment requires that “involuntary placement or involuntary treatment should only take place for a short period of time on the basis of a medical assessment appropriate to the measure concerned...” In addition, “as far as possible,” authorities should comply with the requirements of article 20(5) and (6) that the doctor “consult with those close to the person concerned” and that “[a]ny representative of the person should be informed and consulted.”

²⁵ Draft Law Part II, art. 1, para. 2.

²⁶ Council of Europe Recommendation (2004)10, art. 17(1)(ii).

Principles are even more stringent, requiring a showing of “a serious likelihood of immediate or imminent harm to that person or other persons.”²⁷ As future dangerousness is particularly hard to predict, the UN’s requirement of “imminence” is particularly helpful in any legislation, requiring a showing of specific and concrete dangers that may be about to befall the individual or others if that person is not subject to involuntary commitment.

5. No right to treatment in the least restrictive environment suitable to an individual’s health condition and the safety of others -- International human rights standards prohibit involuntary detention if treatment can be provided voluntarily or in a less restrictive environment.²⁸ The Council of Europe has recognized that involuntary treatment and involuntary detention should be used *only* as a last resort.²⁹ The proposed law states that its goal is to favor voluntary over involuntary treatment; this statement is an important statement of policy. In the absence of a right to treatment in the least restrictive environment, however, the draft law does not provide any way to implement this stated policy goal. Moreover, the draft law includes no provision guaranteeing the right of people detained in psychiatric institutions to basic health care, regardless of their status as voluntary or involuntary patients. To deny people with mental disabilities the right to health care is discriminatory under Turkish law as well.

6. Right to informed consent and refusal of treatment does not apply to involuntary patients in violation of international standards -- The proposed law establishes a right to refuse treatment for voluntary patients that represents an important advance over current Turkish policy. This significant provision does not apply to involuntary patients, however. Once a person is involuntarily detained in a psychiatric institution, he or she loses all rights to informed consent and the right to refuse treatment. As such, this provision violates international human rights standards. The Council of Europe recommends two separate determinations as to whether a person may be subject to involuntary placement and/or involuntary treatment.³⁰ The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment also has stated that

patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of persons to a psychiatric

²⁷ MI Principle 16(1)(a).

²⁸ Under the United Nations standards, no individual may be involuntarily committed to a psychiatric facility if he or she is not dangerous and capable of living in the community with appropriate treatment. MI Principle 16(1)(b). MI Principle 9 states that “[e]very patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient’s health needs and the need to protect the physical safety of others.” The MI Principles also recognize more broadly that “[e]very person with a mental illness shall have the right to live and work, as far as possible, in the community.” MI Principle 3.

²⁹ Council of Europe Recommendation (2004)10 states that a person may not be involuntarily treated unless there are “no less intrusive means of providing appropriate care available.” Art. 18(iii). The Explanatory Memorandum to Recommendation (2004)10 continues, “[E]very effort should be made to enable the person to accept voluntary placement or voluntary treatment, as appropriate, before implementing involuntary measures.” Art. 16, para. 122.

³⁰ Under Council of Europe Recommendation (2004)10, criteria for involuntary placement is regulated by article 17 and criteria for involuntary treatment is regulated by article 18.

*establishment on an involuntary basis should not be construed as authorizing treatment without their consent. It follows that every competent patient, whether voluntary or involuntary, should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances.*³¹

The proposed law's failure to protect a patient's right to informed consent is compounded by the lack of a requirement that a person be informed about the reasons for the treatment or involuntary detention. As the European Court of Human Rights has held, a person cannot be protected against improper deprivation of his or her liberty rights unless he is promptly and adequately informed about the reasons why he has been deprived of his liberty.³²

7. Family Members are improperly permitted to consent to transfer and treatment on behalf of a relative -- The draft law permits a family member to commit a relative to a psychiatric facility over the objection of the individual. The draft law requires that the Court be "informed" in such a case, but it does not require the Court's review.

In fact, in a number of places, the draft law appears to permit family members to consent to involuntary admission and involuntary treatment on behalf of the individual without any due process of law.³³ The draft law also seems to require that relatives be informed about a right to appeal but does not provide the same right to the individual subject to commitment.³⁴ In general, international human rights law applies to the individual whose rights are at stake and any delegation of rights to other individuals without due process violates the rights of that individual. Both the Council of Europe and UN standards on involuntary commitment specifically provide rights to individuals and not to family members. Even when involuntary commitment or involuntary treatment is ordered by a court, that body must "take into account the opinion of the person concerned."³⁵ Neither the Council of Europe's recommendations nor UN standards would permit informing family members in lieu of the patient about their rights in the commitment process. These international standards are clear and unequivocal: people subject to involuntary detention have a right to be informed of their rights and provided with assistance in understanding them.³⁶ Even when a person's capacity to make

³¹ See REPORT TO THE GOVERNMENT OF IRELAND ON THE VISIT TO IRELAND CARRIED OUT BY THE EUROPEAN COMMITTEE FOR THE PREVENTION OF TORTURE AND INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT (CPT) FROM 20 TO 28 MAY 2002, Publication Number CPT/Inf 36 (2003), at <http://www.cpt.coe.int/documents/irl/2003-36-inf-eng.pdf>.

³² Van der Leer v. Netherlands, judgment of 21 February 1990, application number 000011509/85.

³³ Draft Law Part III, art. 2, para. 4(e).

³⁴ *Id.* para. 4(b).

³⁵ Council of Europe Recommendation (2004)10, art. 20(1)(i) (for involuntary detention); art. 20(2)(i) (for involuntary treatment).

³⁶ Council of Europe Recommendation (2004)10, art. 6: "Persons treated or placed in relation to mental disorder should be individually informed of their rights as patients and have access to a competent person or body, independent of the mental health services, that can, if necessary, assist them to understand and exercise such rights." See also Recommendation (2004)10, art. 22 (Right to Information). The MI

decisions is in question, the right to make decisions applies to “the person whose capacity is at issue” and he or she must be informed of his or her rights.³⁷ Family members may make decisions in place of the person only “after a fair hearing by an independent and impartial tribunal established by domestic law,” and then, only after they have been appointed guardians.³⁸

8. Voluntary patients may be forced to sign away right to consent to treatment -

- The proposed law does not provide for specific consent by voluntary patients nor does it state whether or not a voluntary patient has the right to choose or refuse treatment. In one section, the proposed law reads that “[a] patient who is voluntarily committed has the right to choose or refuse treatment.”³⁹ Yet in another provision, the law seems to require that voluntary patients be admitted “by signing documents that expressly states acceptance of the treatment by the patient.”⁴⁰ As a practical matter, this latter provision of the proposed law seems to undermine the right to refuse treatment by voluntary patients. It also contradicts the stated policy of the draft law that voluntary treatment is preferred over involuntary treatment.

The proposed law also contravenes Council of Europe and UN standards that limit involuntary treatment to people determined by an independent authority to be unable to make treatment decisions for themselves. This proposed provision is particularly dangerous in Turkey, where community-based alternatives to institutional treatment are not available. This proposed provision would make it extremely difficult for a person who needs inpatient care to retain his or her ability to make critical choices about the kind of care he or she receives. Many such individuals will be forced by this proposed provision to receive no care at all or to submit to any care that the institution may choose to provide.

9. Right to review of commitment by a court can be undermined by treating psychiatrist --

The decision to release a patient from involuntary status can be as important as the decision to detain the patient. It may make the difference between a week or a lifetime of detention in a psychiatric institution. The proposed law creates a role for the court to review commitments and determine when involuntary detention is no longer required. The authorization of the court to make such decisions represents an important advance over the current situation (which allows one psychiatrist, acting alone,

Principles have even more detailed requirements that individuals be informed of their rights “in a form and language which the patient understands.” MI Principle 12(1).

³⁷ MI Principles, principle 1(6).

³⁸ *Id.*

³⁹ “Voluntarily admitted patients shall not be subjected to treatment without patient consent or the legal guardian consents to the procedure in a written agreement. A patient who is voluntarily committed has the right to choose or refuse a treatment.” Draft Law Part III, art. 5, para. 3. Since there are no procedural protections for the use of legal guardians, the rights of voluntary patients may be easily undermined by this provision, which allows the guardian to consent on his or her behalf.

⁴⁰ “A person who is willing to be treated voluntarily shall be admitted to the institution by signing a paper stating his willingness to be admitted and to consent to the treatment proposed. A person who exercises the right to voluntary commitment can be discharged from the hospital in accordance with his/her own wishes as long as there is not a dangerous condition due to the psychiatric illness.” Draft Law Part III, art. 2, para. 2.

to authorize the involuntary placement and involuntary treatment as well as the termination of such practices). The most critical factor in authorizing review by a court is that the court is independent of the institution or treating psychiatrist which may be invested in a particular course of medical treatment. Thus, the Council of Europe has emphasized the importance of the role of a court “in order to provide guarantees against possible abusive use of involuntary treatment by doctors...”⁴¹ Further, decisions of the European Court of Human Rights make clear that the European Convention on Human Rights guarantees the “right to appeal against or to have reviewed, decisions concerning involuntary placement or involuntary treatment (or both) at reasonable intervals.”⁴²

Although the involvement of the court is desirable and essentially required by international standards, additional procedural protections are required to guarantee the procedural rights of individuals in the commitment process. First, the right to counsel has been recognized as necessary to protect the rights of individuals facing compulsory detention. The proposed law includes no right to counsel or even access to counsel for people facing involuntary commitment.

Second, the proposed law includes no time limits regarding when the court must review a decision to commit an individual. Without such time limits, an individual may theoretically have the right of court review, but practically may remain in the institution for years without access to a court.

Third, the proposed law appears to create an important role for the court in determining who may require a guardian but it does not do so in practice. The draft law allows the court to appoint the treating psychiatrist as guardian. In so doing, the court abdicates any independent role in overseeing the commitment process. By allowing the court to appoint a treating psychiatrist as legal guardian, the law also creates an inherent conflict of interest. As guardian, the treating psychiatrist becomes solely responsible for deciding the patient’s legal status, without any court oversight. The psychiatrist may change the patient’s status from involuntary to voluntary or, by the same token, the psychiatrist may deny the patient a change to voluntary status. Such continued unfettered deference to psychiatrists contravenes accepted international standards.

10. The proposed law does not protect against improper seclusion, restraint, or other potentially abusive practices -- The draft law allows for seclusion, restraint and other practices without providing safeguards against abuse of such practices. The Council of Europe as well as the United Nations have adopted standards that create a broad array of rights for patients in recognition of common forms of abuse that commonly take place in psychiatric facilities. Foremost among these are protections against improper seclusion or restraint. Both the Council of Europe and the UN limit the use of seclusion and restraint to circumstances when it is necessary to prevent “imminent harm to the person concerned or others.”⁴³ Anyone placed in seclusion or restraints

⁴¹ Council of Europe Recommendation (2004)10, p. 33, para. 153.

⁴² Winterwerp v. the Netherlands, judgment of 24 October 1979, Application number 00006301/73.

⁴³ Council of Europe Recommendation (2004)10, art. 27(1). The UN has an even more restrictive standard, as set out in MI Principle 11(11) (“physical restraint or involuntary seclusion of a patient shall not be

“should be regularly monitored” and “the reasons for, and duration of, such measures should be recorded in the person’s medical records and in a register.”⁴⁴ Further, the use of physical restraints as a tool of administrative convenience or ward management is clearly prohibited by the European Committee on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, which emphasizes that “seclusion and restraint should never be used as a punishment....”⁴⁵

11. Lack of provision for oversight and monitoring -- The proposed law fails to create any mechanism for oversight or monitoring to ensure enforcement of its requirements as required by Council of Europe and UN standards. Such requirements recognize that people with mental disabilities may not have financial resources to hire their own attorney, the mental capacity to articulate or challenge abuses, or the opportunity to obtain access to the courts from within a locked psychiatric facility. The Council of Europe thus specifies that monitoring is required to ensure compliance with both (1) legal standards and (2) professional standards.⁴⁶ To avoid a conflict of interest and ensure that abuses by an institution can be challenged, the Council of Europe requires that oversight and monitoring should be conducted by a body that is “organizationally independent from the authorities or bodies monitored.”⁴⁷ The Council of Europe provides a detailed description of what such monitoring should entail, including regular “visits and inspections of mental health facilities, if necessary without prior notice.”⁴⁸ Systematic and reliable statistical information on mental health practices and information on implementation of the mental health law should be made available to the public.⁴⁹

One of the most innovative and important requirements of the Council of Europe standards is that independent monitoring should be conducted by “mental health professionals, lay persons, and persons with mental disorder and those close to such persons.”⁵⁰ The concept that current or former users of services would be involved in monitoring abuses may be a very new idea in Turkey, yet it is one that has been endorsed by the United Nations General Assembly and is routinely practiced in various countries throughout the world. The UN “Standard Rules on Equalization of Opportunities for Persons with Disabilities” also explicitly recognizes the rights of people with mental and physical disabilities to be involved in monitoring and implementation of human rights that affect them.

12. Other Provisions

The proposed law seems to exempt people in psychiatric institutions from rights which they would otherwise enjoy in Turkish society or in general care hospitals.

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”).

⁴⁴ Council of Europe Recommendation (2004)10, art. 27(3).

⁴⁵ Council of Europe Recommendation (2004)10, p.38, para. 200.

⁴⁶ Council of Europe Recommendation (2004)10, art. 36(1).

⁴⁷ *Id.* art. 36(2)(ii).

⁴⁸ *Id.* art. 37(1).

⁴⁹ *Id.* art. 38.

⁵⁰ *Id.* art. 36(2)(iii).

International law recognizes the right to family integrity, which, in the context of hospitalization, guarantees all individuals the right to visits by their families. Such rights should be specifically provided for within the proposed mental health law.

The proposed law fails to mention the internationally accepted requirement that involuntary detention is to be used only as a last resort when other less restrictive alternatives are not available. Currently, no community mental health system exists in Turkey. The proposed law could promote the development of community integration of people with mental disabilities by preventing inappropriate institutionalization and supporting the development of services in the community.⁵¹

Conclusion

The Turkish Psychiatric Association has drafted a proposed Mental Health Law that represents an important development over current practice in Turkey, which permits the arbitrary and unregulated use of involuntary treatment and detention. The stated policy goal of the draft law is laudable. Its goal is “to make psychiatric treatment a voluntary process instead of an involuntary process in order to protect the rights of patients in accordance with international standards.” The draft law also requires, for the first time, that psychiatric commitments be reviewed by a court. Despite the proposed law’s improvement over current practice, it fails to comply in significant ways with international law. The proposed law does not adequately protect patients’ rights by:

- failing to establish a standard for commitment to be used by a court;
- deferring to the treating psychiatrist to determine the length of confinement;
- failing to provide involuntary patients the right to informed consent and the opportunity to refuse treatment;
- improperly permitting family members to consent to treatment without due process;
- requiring individuals to give up their right to make choices about treatment when seeking voluntary care in an institution;
- ignoring completely the MI Principles and Council of Europe standards requiring that treatment and mental health services be provided in the least restrictive setting possible;
- lacking a broad array of protections that respect patient choice and autonomy and protect against extreme abuses, such as indefinite restraints and seclusion; and
- lacking a requirement of independent monitoring and oversight of rights in institutions.

In sum, the proposed Turkish Mental Health Law, like the Directive before it, affords nearly unfettered discretion to the medical experts. Mental Disability Rights International recommends that the Ministry of Health revise this draft law to ensure that

⁵¹ See WHO Resource Book on Mental Health, Human Rights and Legislation (WHO 2005), at 6 (discussing several ways in which mental health legislation may promote access to mental health care and community integration).

the new law is consistent with internationally recognized standards of the Council of Europe and the United Nations.

Appendix 4

Letters of Support

OPENING THE CLOSED DOORS

“The history of this type of madness has to be written down: Within the dominant rationalistic culture, before the other form in which people use the cruel language of being unable to be mad takes its own space within the authority of the truth, before it is revived by the lyrism of protest, this moment of conspiracy should be caught.”¹

...
“Our society still excludes insane people.”²
Michel Foucault

We, being human rights activists, were shocked when we read three years ago reports of arbitrary detention and mistreatment of people with mental disabilities in social care and psychiatry institutions like *Dragash Voyvoda* in Bulgaria. The images that reminded us of the concentration camps were horrifying. It is another shocking reality to see that the discrimination that occurs in places far from the eyes of the society in Bulgaria³ also occurs in our country.

The report titled “*Behind Closed Doors*” prepared by MDRI, that describes the problems in psychiatric facilities, orphanages and rehabilitation centres of Turkey from a human rights perspective describes the reality in Turkey. The report includes the results and observations that were accumulated within the two-year investigation. According to the terrifying findings, the inhumane and degrading conditions that people with mental disabilities are exposed to in the institutions far away from public attention are equivalent to torture. This is a very serious claim that needs to be taken seriously.

According to the report, as there is no applicable procedure or law for the independent legal bodies, anyone can be arbitrarily detained in psychiatric institutions, disregarding the international human rights law. This means that you are under serious danger of being exposed to torture and mistreatment. As an example, if you are detained at a psychiatry hospital like Bakirkoy, it is quite possible that you will be given electroshock treatment without anesthesia or muscle relaxants. What is more horrifying is that you might be given this treatment not only for the purpose of treatment, but also as punishment. Another terrifying finding is that electroshock is also applied to children.

¹ Michel Foucault; “Great Detention – Preface to the History of Madness”, pp. 20-21.

² Ibid., p.84.

³ Bulgaria Arbitrary Detention and Ill-treatment of People with Mental Disabilities; AI Index: EUR 15/008; 10 October 2002; www.amnesty.org/library/index/ENGEUR150082002. The reports prepared by Amnesty International, Bulgarian Helsinki Committee and MDRI included investigations between October 2001 and January 2002.

According to the WHO standards, electroshock should never be conducted on children, even with anesthesia.

Another terrifying dimension of the seriousness is that basic needs such as food and water are not sufficiently provided in the rehabilitation centres and orphanages. We also learn from the report that medical care and adequate rehabilitation are lacking in these institutions. Isolation is a widespread method that is applied both on children and adults. The indifference of society regarding the issue makes the situation much more serious.

As in many other places, also in our society, the prejudice against people with mental disabilities is the main reason underlying all these problems. Another important reason is the economic difficulties. Discriminatory treatment due to prejudices breaks off the humane connection between people and results in treating the other like an object. These discriminatory treatments sometimes can also occur at the institutional level and result in suffering that is very difficult or even impossible to repair.⁴

According to the temporary results of Turkey Disability Research, 12.29 % of the whole population, in other words approximately 8.5 million people have disabilities. As the State Minister Guldal Aksit responded to the written inquiry proposal of Bursa Parliamentarian Kemal Demirel, 8,431,937 out of the total population of 68,622,559 have disabilities: 3,783,197 of these people with disabilities are men, whereas 4,648,740 are women. The percentage of men with disabilities is 11.1%, whereas of women is 13.4%. There are also differences in how people with disabilities are scattered within Turkey. The highest number of people with disabilities is located in the north-western Marmara region, whereas the lowest number is located in the south-eastern region. 13.1% of the whole population in the Marmara region has disabilities, whereas this ratio is 9.9% for the south-eastern region. 12.69% of people with disabilities live in urban areas, while 11.67% live in rural areas. 1.25% of people with disabilities have orthopedic disabilities, 0.38% has speech disabilities, 0.60% has visual disabilities, 0.37% has hearing disabilities and 0.48% has mental disabilities. Other types of disabilities are around 9.7%.⁵

We do not have quantitative data on the number of people who are getting (or cannot get) psychiatric treatment. Even the lack of regular data itself can be a good-enough reason to regard the issue as a suspicious one. In addition, as experts also admit, it is difficult for people who have mental disabilities and who are under psychiatric treatment to defend themselves against possible abuses.⁶ When combined with the fact

⁴ Zaman newspaper, Nihat Yıldız, Fikri Kaya, Izmit, 22.03.2002; www.zaman.com.tr/2002/03/22/marmara/butun.htm; Radikal newspaper, 18.09.2004, www.radikal.com.tr/haber.php?haberno=128356.

⁵ CNN TURK, 23.10.2004, 13:08:00 (TSI), www.cnnturk.com.tr/arama/haber_detay.asp?PID=0031&haberID=45440. Also in TURKEY 2003 DISABILITY RESEARCH, State Statistics Institute, http://www.tsd.org.org.tr/istatistik/Engelli_Istatistikleri_02Aralik2003.doc

⁶ Milliyet newspaper, <http://www.milliyet.com/2005/02/25/yasam/yas01.html>.

that the European Human Rights Court has decided many times that Turkey has violated the 3rd article of the European Human Rights Declaration, all these data demonstrate that our suspicions are not irrelevant.

Another dimension of the terrifying reality is that most cases of abuse occur at state institutions and are conducted directly by the state officials. One of the main reasons underlying this is that these abuses occur in remote places far away from public monitoring and behind closed doors. The ones who conduct the inhumane and degrading acts feel more comfortable when they know that no one is aware of what they are doing. When people become aware of the situation, it becomes possible to stop the tyranny or at least to reduce it. The key word in such cases is information because information is the only key to open the closed doors. The success of reliable organizations like MDRI lies in this. They provide us, the public, with sufficient and correct information at the right time so that we can begin to act.

When the above-mentioned perspective is taken, we welcome MDRI's efforts with respect as the Human Rights Agenda Association. The report "*Behind Closed Doors*" does not only describe the human rights violations in psychiatric facilities, orphanages and rehabilitation centres of Turkey, but also provides us with constructive suggestions for solutions. To be able to reach the solutions, it is of vital importance that Turkey signs the *Optional Supplementary Protocol to the UN Convention Against Torture*, that suggests that all places of detention including psychiatric facilities, orphanages and rehabilitation centres are monitored by independent experts through visits and in cooperation with NGOs. This obliges us to establish an independent human rights institution as soon as possible. An independent human rights organization embodying the NGOs in a democratic way can initiate processes like the *Optional Supplementary Protocol to the UN Convention Against Torture*, provide correct evidence for incidents, and the presence of such an organization itself can be preventive. Most importantly, we have to remember that it becomes possible to open the doors only if we can open the doors in our minds.

Hoping that the world will become a place where there are no human rights violations...

Hakan ATAMAN⁷
Human Rights Agenda Association⁷
General Secretary

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When we look at the findings of this study, unfortunately we see that people with mental disabilities experience some inadequacies and abuse in our country. The results and the observations are not in compliance with the sensitive, sharing-oriented and humanistic structure of our society. For this reason, the necessary steps should be taken immediately to change the conditions. We hope that such studies will open the way to improve the services for people with mental disabilities in our country. However, for change and improvement to be accomplished, education specialists, experts, law professionals specializing in this area and the state should work in cooperation. When people with mental disabilities can live in the community with their families, this will prevent them from suffering lack of adequate stimulation and result in an improvement of self-esteem. It is a must that the places providing institutional care are kept under the control of a monitoring body and that the whole system is based upon human rights principles. Another crucial need is that the families of people with mental disabilities are informed about related issues through training programs. Once people with mental disabilities are encouraged to get involved in vocational training, this will decrease the workload of the institutions and also contribute to the social, emotional and physical development of these people.

It is not the choice of people with mental disabilities to live with the difficulties and problems they have. For this reason, it is their natural right to be supported and live in an integrated way with the community, as opposed to being kept outside the community. We believe that there are also some groups and institutions that try their best to provide support and education to the people with mental disabilities in our country and these groups and institutions will initiate change and improvement. We, as The Association for Protecting Trainable Children are trying our best to provide necessary conditions and training on social, emotional and cognitive issues for people with developmental disabilities since the year 1965. We support all innovative efforts for improving the living conditions of people with disabilities with all our sincerity.

Emine Sirin

Board Director, on behalf of the Board of Association for Protecting Trainable Children

SUBJECT: Below is my personal view regarding the report "Behind Closed Doors"

I have been receiving psychiatric treatment for the last 20 years. Throughout this period, I stayed in the hospital for five times. For years, I got treatment using the financial resources of my family. Although I was being treated in state hospitals by paying, nobody told me that I could have social security. Many patients are unaware of their rights to social security. I have been in the board of Friends of Schizophrenia Association for the last six years. Our association functions in accordance with its aims of establishment. We are organizing many activities to increase the life quality of our members. In our conversations with new members or their relatives, it becomes clear again that they are unaware of their social and legal rights, therefore can not defend these rights. This makes the already painful living conditions of patients and their families even more dramatic. Moreover, during the years I have been in the board of our association, we tried to express the needs of people with schizophrenia for rehabilitation opportunities through media and in our conversations with officials, but there has been no change. We are still waiting all day long to get treatment. Our illness, which is already painful, turns into suffering after eight hours of waiting in long lines. Our doctors, who are good professionals are left in a difficult position to cope with the problems in the institutions as the higher official planning is not adequate to solve the problems. However, what we expect from our doctors is to express to the higher authorities and the related ministry that they can not work under such negative conditions. Instead, they prefer statements like "The state does not allocate adequate budget and staff. What can we do?", whenever we raise a criticism. Although the population of our country has been increasing for years, no new facilities or outpatient clinics have been built, especially in Istanbul. The existing ones have inhumane conditions. They are not places that have adequate conditions for a humane living. Sometimes, when I feel bad or hopeless and so want to have some treatment in a facility, I prefer not to because of the possibility that I might be subjected to ECT. Considering that ECT can be practiced in some parts of the world only under certain circumstances and with several permissions, I hope that in the future there will be no ECT at all in our country. I read the report prepared by MDRI. I reached the conclusion that such abuses and wrong practices can exist in all countries of the world but they have to be stopped. I want such abuses to be stopped immediately in our country."

Mesut DEMİRDOĞAN
Friends of Schizophrenia Association
Director

DESPITE EVERYTHING

Being the mother of a child with developmental disability, I am writing on behalf of all people with mental disabilities who do not have chance to express themselves. It can never be known what life will bring and when. Sometimes, something that you want so much slips away from your hands and sometimes you find something in your lap that you never wanted...

I had started to observe some changes in the behavior of my daughter Deniz, who completed her development in a very healthy way till age one and a half. Doctors told me that these changes were due to a severe neurological illness which was damaging the centers for hand movements, walking and speaking. They told me that medical treatment was impossible and her life will be at high risk, that we might lose her anytime and that we should prepare ourselves for this. Later on, together with the additional epilepsy crises, our life had become much harder.

After I went through the first shock I started to think about how I could help her and how I could provide her with a quality life despite everything.

I started by observing Deniz. I tried to understand her interests, preferences, emotions, reactions. In addition there was an invisible wall that she built around herself making it very difficult for me to reach her.

I tried to communicate with her through eye contact, touching and talking. I gave her the following message through my behavior: "You are so important to me!" so I could gain her trust. After long struggles, we could tear down the invisible walls between us. No effort having love remains without a response.

Undoubtedly, education has a very important role in the lives of children with mental disabilities. I told her and repeated the same things for days or even months without getting frustrated. As a result of all these efforts, she could learn some concepts, although limited in how to use her hands, and most importantly how to express herself.

When Deniz became twelve she stopped walking. I taught her to walk again using a method that I discovered through my maternal instincts. It is impossible to describe how a mother feels when she saves her child from becoming dependent on a wheelchair! My own experience taught me that there is nothing that cannot be overcome with love, patience and determination and also that whatever and to what extent his/her disability is, the main nourishment for a child is love...

My efforts have never remained unreturned. Small or big, all the steps we had taken, brought us further and fed our hopes.

Deniz is still a young girl with disability but the fact that she can express herself made our life much easier. In addition to not having lost her, we gained a well-adjusted, participatory, self-confident and happy girl full of love. Can there be any greater happiness for a mother than this?

Despite their disabilities, all people have their own potential. To be able to keep and improve this potential through education and love, what we need is:

1. Appropriate and adequate medical support
2. Appropriate and adequate educational support.

These are crucial for a child with mental disability.

The society does not embrace people with mental disabilities because there are many strict prejudices against these people. For such taboos to be overcome, people with

mental disabilities should be trained vocationally, become productive and have the place they deserve in society. As a society, we should learn to run towards the same end from different lanes. We should also learn that disability is a part of human nature.

Turkey is at a turning point...

Turkey is changing its crust...

Turkey is trying to reach the level that all other civilized countries have reached in terms of social issues.

Turkey is trying to reach the level of contemporary civilizations, without getting detached from its origins on the way that Ataturk has pointed out.

The gains throughout this process should be reflected in all areas of life.

One day,

I dream to live in a society where people are evaluated not in terms of their physical or mental disabilities, but in terms of their characters, their productions and their achievements.

Abide Özkal

Director of Support for Special Children Association

WELCOME TO MACHINE

It has always been too late when you are in a hospital like Manisa. If you are surrounded by the system once, there is no way for being yourself again. You are not asked anything. The only thing you can do is accepting or obeying. It is just like a martial law prison. You are slightly driven to think that you will be staying there forever. What the nurses are saying is "take your medications otherwise you will be here soon again." There are many ways of making you an obedient patient. But all of them include violence. Personally I witnessed many human rights violations. You are just fearing... Fear of being beaten, fear of being the victim of a highly possible fire, etc. The first time, only because I asked nurses if they have still been boxing, I was put in a straight jacket for than an hour or more while nurses were playing silly jokes on me. I asked them so because once while my brother was staying in the same hospital, he had left hospital with black eyes caused by nurses only for not accepting medication, ECT, etc. At another time I witnessed that a very dirty homeless person with schizophrenia was washed on the floor forcibly with a brush, which is usually used for car washing, and with cold water. I also witnessed that some of the patients who were under effect of extra-pyramidal side effects of the conventional anti-psychotics were left without help for hours. That looked like punishment to me. I personally experienced quite similar attitudes when I was suffering from extra-pyramidal side-effects, I was asked to sit on a chair for an hour and to watch other patients. Also, I always felt under threat of HIV and other serious diseases because we were all shaved with the same razor blade by the barber. After a while, when the blade was no longer sharp, we were all bleeding.

I think there is no need to add to the examples. I deeply believe that in the future there will be no need for such institutions just like in many other countries of the world.

I have still been paying my price. Finally, I would like to say that schizophrenia could be another world, but I believe in tomorrows.

Won't you ever call me cute?

Yalcin Eryigit
Izmir Schizophrenia Solidarity Association, Director

Appendix 5

Executive Summary in Turkish

Özet

Kapalı Kapılar Ardında MDRI'nın Türkiye'de iki yıl boyunca yürüttüğü araştırma ve gerçekleştirdiği inceleme gezilerinin sonuçlarını aktarmaktadır; zihinsel engelli ve psikiyatrik rahatsızlıkları olan kişilerin yaşadığı insan hakları ihlallerini ortaya koymaktadır. **Kurumlarda kapalı ve kamuoyunun bilgisinden uzakta tutulan psikiyatrik rahatsızlıkları olan ya da mental retardasyon gibi zihinsel bir engeli olan kişiler işkenceyle eşdeğer tedavi ve bakım uygulamalarına maruz kalmaktadır.** Kurumlarda hapsedilme koşullarının dünyanın pek çok yerinde yaygın bir şekilde insanlık dışı ve aşağılayıcı olduğu görülmektedir. Bu rapor Türkiye'nin Avrupa İşkenceyi Önleme Konvansiyonu (ECPT), Avrupa İnsan Hakları Sözleşmesi (ECHR) ve Birleşmiş Milletler Çocuk Hakları Sözleşmesi (CRC) ve kabul edilmiş başka uluslararası insan hakları ve engelli hakları standartlarını ihlal ettiği durumları ortaya koymaktadır.

Türkiye'de kurumlara yatılı olarak kabul edilen zihinsel engelli ya da psikiyatrik sorunları olan insanların gelişigüzel bir şekilde (yasal düzenleme olmaksızın) kapatılmasını ya da onay vermedikleri tedavilere maruz kalmasını önleyici herhangi bir yasa ya da süreç bulunmamaktadır. Bu insanlara yönelik herhangi bir toplum desteği ya da sistemi de bulunmamaktadır, dolayısıyla desteğe ihtiyacı olan insanların merkezi kurumlardan başka bir seçeneği kalmamaktadır. İnsanlar Bir kez bir kurumun duvarları ardında kapalı kaldıklarında, çeşitli tehlikeli tedavi uygulamalarına tabi olma riskine maruz kalmaya açık hale gelirler. Herhangi bir destek alabilmek için bir kuruma başvuran kişi genellikle kurum tarafından sağlanacak her türlü tedaviyi kabul ettiğine dair genel bir onay vermek zorunda kalır. Bir kurumda alıkonulan kişilerin ise tedaviyi reddetme hakkı ne yazık ki yoktur. Türkiye'de de en kırılgan grupların kurumlarda kapalı tutulma koşulları tehlikeli ve kişinin yaşamını tehdit edecek boyutta olabilmekte.

MDRI'nın tanık olduğu en ciddi insan hakları ihlallerinin bazıları aşağıda özetlenmektedir:

Psikiyatri Kurumları

- **Devlet hastanelerinde elektrokonvulsif terapi ya da şok tedavisi olarak bilinen EKT'nin kas gevşeticileri ya da anestezi kullanılmaksızın, "modifiye edilmemiş / hafifletilmemiş EKT" olarak bilinen formda acımasız ve yaygın bir şekilde uygulanması** – EKT beyine elektrik akımı verilerek uygulanan ve başka tedavilere cevap vermeyen sınırlı durumlarda tedavi edici etkisi olduğu düşünülen bir psikiyatrik tedavi yöntemidir. Ancak, modifiye edilmemiş / hafifletilmemiş formda uygulandığında EKT acı verici, korkutucu ve tehlikeli bir deneyimdir ve Avrupa İşkenceyi Önleme Konvansiyonu'nu ihlal eder özelliklere sahiptir. Dünya Sağlık Örgütü geçtiğimiz yıllarda modifiye edilmemiş EKT'nin yasaklanması yönünde bir çağrı yapmıştır.

Sadece bir kere EKT oldum. İlk ve son seferdi. Seni tutuyorlar, kollarını, bacaklarını, kafanı. Ağzına bir pamuk parçası koyuyorlar. 70-100 volt dediklerini hatırlıyorum. Elektriği ve acıyı hissettim, ölecekmişim gibi geldi.

28 yaşında, Bakırköy'de tedavi görmüş, modifiye edilmemiş EKT'ye maruz kalmış bir kişi

- **EKT'nin bir cezalandırma yöntemi olarak kullanılması** – Dünyanın en büyük psikiyatri kurumlarından biri olan Bakırköy Ruh ve Sinir Hastalıkları Hastanesi EKT Merkezi'nin yöneticisi MDRI araştırmacılarına EKT sırasında anestezi kullanmama sebeplerinden birini şöyle tanımlamıştır: “Majör depresyonlu hastalar cezalandırılmaları gerektiği hissini taşırlar. Bu durumlarda anestezi kullanırsak EKT etkili olmayacaktır çünkü o zaman cezalandırıldıklarını hissedemezler”. Hastaların EKT'yi reddetme hakkı yoktur ve sıkça rastlanan bir diğer uygulama da hastalara yalan söyleyerek EKT yerine röntgen çektirilmeye götürüldüklerinin söylenmesidir. Yaşayacaklarından korkarak EKT odasına gelen hastalara sıklıkla “deli gömleği” giydirilmekte ve hastalar uygulama sırasında hastane personeli tarafından bazen güç kullanılarak sabit tutulmaktadır. Anestezi ya da kas gevşeticisi olmaksızın EKT uygulanması uluslararası olarak kabul edilmiş olan tüm tıbbi standartlara aykırıdır. Görüşülen bazı psikiyatristler de Türkiye’de EKT'nin nasıl ve hangi durumlarda uygulanması gerektiğine dair standartların olmadığını belirtmiştir, dolayısıyla EKT gereğinden fazla ya da bir ceza yöntemi olarak kullanılabilir hale gelmektedir.

“EKT’yi majör depresyonlu hastalara uyguluyoruz. Majör depresyonlu hastalar cezalandırılmaları gerektiği hissini taşırlar. Bu durumlarda anestezi kullanırsak EKT etkili olmayacaktır çünkü o zaman cezalandırıldıklarını hissedemezler”.

*Bakırköy Ruh ve Sinir Hastalıkları
Hastanesi, EKT Birimi Yöneticisi ve
Klinik Şefi*

- **Çocuklara EKT uygulanması** – Dünya Sağlık Örgütü çocuklar üzerinde anestezili dahi olsa EKT uygulanmasını gerekli kılacak hiçbir tıbbi durumun olmayacağını ve uygulamanın her durumda yasaklanması gerektiğini açıklamıştır. Türkiye’de 9 yaşında çocukların bile EKT uygulamasına tabi tutulabildiği belirlenmiştir.
- **EKT'nin gereğinden fazla kullanılması** – Türkiye’nin psikiyatri kurumlarında EKT tıbbi olarak hiçbir meşru gerekçesi olmayan durumlarda bile kullanılmaktadır, dolayısıyla gereğinden fazla başvuru olan bir tedavi yöntemi haline gelmiştir. EKT kurum yetkilileri tarafından yatak sayısının yetersiz olması ve toplum içerisinde tedaviye yönelik daha iyi destek sistemlerinin olmayışı gerekçesiyle gereğinden fazla kullanılmaktadır. EKT'nin gereğinden fazla kullanılması binlerce insanın gereksiz, korkutucu ve tehlikeli bir deneyim yaşamasına sebep oluyor ve Türk hükümetinin Avrupa İşkenceyi Önleme Komitesi’ne karşı olan yükümlülüklerini de yerine getirmemesi ile sonuçlanıyor.

Rehabilitasyon Merkezleri ve Yetimhaneler

Kızımı seviyorum, ama umarım ben ölmeden o ölür. Ben ölünce ona ne olacağını bilmiyorum ve artık ona bakamıyorum. Onun asla bir kurumda yaşamak zorunda olmasını istemiyorum.

*Zihinsel engelli çocuđu olan,
aynı zamanda da zihinsel engelli çocuklara
hizmet veren bir dernek okulunda
yöneticilik yapan bir anne*

- **Açlık ve susuzluk** – MDRI yatađa bağlanmış ve engellerinden dolayı kendilerini besleyebilecek durumda olmayan çocukların yetersiz beslendiđine ve yeterli miktarda yiyebilmeleri için kurum çalışanları tarafından gerekli desteđin sunulmadıđı durumlara tanık olmuştur. Kurum çalışanları da açlıktan ve susuzluktan ölen çocukların olduđunu itiraf etmiştir.

Çocukların çođu kendi kendilerine yemek yiyemiyordu. Bazıları şişeleri tutmak ya da uzanmak için mücadele ediyordu ve şişenin içindekilerin çođu yatađa dökülüyor ya da yenmiyordu. İki yaşlarındaki küçük bir kız ağlıyor ve karyolasında kıvranyordu. Şişe karyolasının köşesinde uzanamayacağı bir yerde duruyordu. Bir saat boyunca ordaydım ve kimse ona yemek vermek için gelmedi. Sonunda ona ben yardım etmeseydim, hiç bir şey yememiş olacaktı.

Beslenme saatlerinde, görevliler hızla odaya giriyor, şişeleri bırakıyor, bir süre sonra gelip şişeleri topluyor ve odadan çıkıyorlardı. Eğer bir çocuk yemek ya da içmek için şişeye ulaşamasaıdı, aç kalırdı.

MDRI araştırmacısı

MDRI araştırmacısı

- **Yetersiz rehabilitasyon ve tıbbi bakım** – Yetimhanelerde ve rehabilitasyon merkezlerinde kalan engelli çocuk ve yetişkinlere yönelik rehabilitasyon ve fizyoterapi imkanları genel olarak oldukça yetersiz. Bu merkezlerde yıllarca hareketsiz kalma durumunun çocuk ve yetişkinlerin engelliliklerini daha da ileri boyutlara varması güçlü bir olasılık. Çocukların kolları, bacakları ve omurgaları hareketsizlikten ve fizyoterapi eksikliğinden bükülüyor ve köreliyor. Kendileriyle yakından ve şefkatle ilgilenen bakıcıların olmayışı ve yeterince uyarana maruz kalmamaları bazı çocukların kendilerine zarar vermeye başlamasına sebep oluyor. Rehabilitasyon merkezlerinde bu durumdaki çocuklara yönelik olarak yatađa bağlamaktan başka herhangi bir yöntem kullanılmıyor. Ziyaret edilen kurumlardan birinde görüőülen personele göre en ciddi boyutlarda fiziksel ya da zihinsel engeli olan çocuklara gerektiğinde tıbbi bakım da uygulanmıyor ve çocuklar ölüme terk ediliyor.

Hemşireler birimlere geliyor ve kapı aralıđında duruyorlar. Çalışanlara hasta çocukların olup olmadığını soruyorlar, sadece içeri sesleniyorlar.

Çalışanlar çocuklar hasta olsa bile yok diyorlar. Çocuklar hastalandığında, banyo yaptırılmıyor ve yataktan çıkarılmıyorlar. Bazen yataklarına bağlanıyorlar. Çocuklar bakılmazlarsa, ölüyorlar. Mesela, şu an biri ölümü bekliyor.

*Saray Bakım ve Rehabilitasyon
Merkezi çalışanı*

- **Çocuk ve yetişkinlere uygulanan fiziksel kısıtlamalar ve izolasyon** – MDRI çocukların karyola ve yataklarına bağlandığı , hatta bazılarının sürekli olarak yatağa bağlı kaldığı durumlara tanık olmuştur. Bacak ve kollarından, yani dört noktadan yatağın ya da karyolanın köşelerine bağlanan çocuklara da rastlanmıştır. Katlanmak zorunda bırakıldıkları sıkıcı ortama bir tepki olarak kendilerini tırmalayan ya da kendilerine vuran çocukların ellerinin sürekli olarak bileklerinden kollarına yapıştırılan pet şişeler içinde tutulduğu gözlemlenmiştir. MDRI araştırmacıları ayrıca tek başına küçücük bir odaya kilitlenmiş küçük bir çocuğa rastlamış, ziyaret edilen bir başka kurumda ise içinde tuvaleti olmayan, idrar kokan küçük bir tecrit odasına rastlanmıştır.

Personel sayısı hafta sonları yarıya iniyor. Bazı birimlerde, çocuklar bağlanıyor. Gitmelerine izin verirsiniz, sessiz ve kendi halindeki çocukları kovalıyorlar. Bu yüzden bütün gün bağlıyoruz. Bu çocuklar 7 ila 15 yaşları arasındalar.

*Saray Bakım ve
Rehabilitasyon Merkezi
çalışanı*

Toplum içerisinde yaygın bakım hizmetlerinin olmayışı

Zihinsel bir engeli ya da psikiyatrik bir rahatsızlığı olan kişiler ve aileleri toplum içerisinde sorunlarıyla baş başa bırakılmakta – Zihinsel engeli ya da psikiyatrik rahatsızlığı olan kişiler için toplum içerisinde yaygın herhangi bir bakım ya da destek sistemi neredeyse yok. Dünya çapında yapılan pek çok çalışmada topluma yayılan programların zihinsel engelli ya da psikiyatrik rahatsızlığı olan kişilerin toplumun bir parçası olarak yaşamalarını, aile üyeleri ve arkadaşlarıyla ilişkilerini yürütebilmelerini, eğitim, iş ve kültürel yaşamın olanaklarından faydalanabilmelerini sağladığı gösterilmiştir. Böyle bir destek sisteminin olmayışı Türkiye’de yaşayan zihinsel engelli ya da psikiyatrik rahatsızlığı olan kişilerin kurumlarda ya da evlerinde kapalı kalarak toplumdan uzak bir yaşam sürmeleriyle sonuçlanmaktadır. Bu durumdaki kişilerin ömür boyu ailelerine ya da kurumlara bağımlı yaşamaktan başka seçenekleri kalmamaktadır. Aile üyeleri ise yeterince destek sağlanmadığında maddi ve manevi olarak bu durumla başa çıkmakta zorlanmaktadır.

Sonuçlar

Uygulanabilir bir ruh sağlığı yasasının olmayışı, Türkiye’de kişilerin tedavi ve rehabilitasyon kurumlarına aslında yasadışı ve gelişigüzel bir şekilde kabul edilmesiyle sonuçlanmaktadır. Kurumların bünyesinde ise Türkiye yurttaşları çeşitli niteliklerde ve ciddi insan hakları ihlallerine maruz bırakılmaktadır. MDRI tarafından tespit edilen en yaygın ve en tehlikeli insan hakları ihlali EKT’nin modifiye edilmemiş, yani anestezisiz ve kas gevşeticileri olmadan uygulanmasıydı. EKT uygulanmayan çocuk ve yetişkinler için bile bir kamu psikiyatri kuruluşunda ya da rehabilitasyon merkezinde alıkonulmak onur kırıcı ve tehlikeli olabilecek bir deneyimdir. Söz konusu kurumlarda aktif ve etkili tedavi ve rehabilitasyon hizmetlerinin olmayışı ise binlerce çocuk ve yetişkini normal yaşama dönme umudundan yoksun bir şekilde toplumun dışında bırakmaktadır. Bu kurumlarda yaşadıkları etkinlik eksikliği ve sosyal izolasyon söz konusu kişilerin gelişimine ve ruh sağlığına ciddi bir tehdit oluşturmaktadır. Kurumlarda bu koşullar altında tutulan kişilerin aslında sağlıklı yaşama hakkı ihlal edilmektedir.

Toplum-temelli ruh sağlığı hizmetlerinin olmayışı yatılı psikiyatri kurumları üzerinde büyük bir baskı yaratmaktadır ve bu durum sağlanabilecek tedavi ve bakımın kalitesini düşürmektedir. Hastanelerdeki yatakların “kronik” uzun süreler hastalara ayrılma zorunluluğunun bir sonucu olarak akut bakıma gereksinim duyan hastalar için varolan kaynaklar azalmaktadır. Türkiye’deki büyük yatılı devlet kurumları çok büyük bir yük altında kalmaktadır. Sonuç olarak, en çok tedaviye ihtiyacı olan, akut psikiyatrik kriz döneminde olan hastalar gereksinim duydukları ilgi ve bakımdan yoksun kalmaktadır. Ziyaret ettiğimiz psikiyatri hastanelerinden ikisinde çalışanlar EKT’nin semptomları en hızlı şekilde ortadan kaldırdığı ve hastanın bir an önce taburcu edilmesini sağladığı için tercih edildiğini belirtti. EKT’nin akut vakaların %20 ila 40’ında uygulanıyor oluşu gerçekten yüksek bir oran. Psikiyatri alanında kabul görmüş uluslararası standartlara göre, EKT’nin etkili olduğu geniş bir belirti grubu olduğu destek görmeyen, hatta aksi iddia edilen bir düşünce. Pek çok hasta MDRI’ya EKT’ye maruz kalmamak için hastaneden ayrılmayı ve bunun için ellerinden geleni yaptıklarını söyledi.

Uzun süreli fiziksel kısıtlanma, modifiye edilmemiş EKT’nin onaysız uygulanması, şiddete karşı korunmasız bırakılma ve genel tıbbi bakıma ulaşamama gibi pek çok ciddi ihlale maruz kalan bu insanlar için, bir kurumda alıkonulmak acı verici, tehlikeli ve yaşamlarını tehdit edecek boyutlara varabilir. Bu tür uygulamalar uluslararası yasalar tarafından yasaklanmış olan insanlık dışı ve onur kırıcı uygulamaların en ciddi boyutta olanlarıdır. Cezalandırılmak için modifiye edilmemiş EKT’ye maruz kalan kişiler aslında işkence tanımı içine giren bir uygulamaya maruz kalmaktadır.

Türkiye’nin kamu ruh sağlığı ve sosyal hizmetler sistemleri zihinsel engeli ya da psikiyatrik rahatsızlığı olan kişileri toplumun dışında tutmakta ve büyük sayıda yurttaşını çeşitli istismarlara açık koşullar altında yaşamaya zorunlu kılmaktadır. Uzun süreli yatılı kurumlara dayalı olan bu sistemler ruh sağlığı alanında kabul edilmiş iyi tedavi ve rehabilitasyon yöntemlerinin yanısıra kabul edilmiş uluslararası insan hakları standartlarına da aykırıdır. Dünya Sağlık Örgütü’nün düzenlediği ve Avrupa hükümetlerinin bir araya geldiği Ocak 2005 tarihli buluşmada, Avrupa Bölgesi’ne dahil ülkelerin sağlık bakanları “ciddi ruh sağlığı sorunları olan kişiler için büyük kurumlar yerine toplum-temelli programları yaygınlaştıracakları” sözünü verdiler. Ayrıca, ayrımcılığı önleyecek ruh sağlığı yasalarını kabul edeceklerini ve “insanlık dışı ve küçük

düşürücü bakım yöntemlerine son verecekleri”ni belirttiler. **Avrupalı hükümetler “ruh sağlığı problemleri olan kişilere bakım ve tedavilerinde ihtiyaç ve kültürel yapıları çerçevesinde, seçme ve katılım hakkı tanıyacaklarının” sözünü de verdiler. Türkiye’deki mevcut ruh sağlığı hizmetleri bu standartları karşılamamaktadır.**

Türkiye’nin Avrupa Birliği’ne üye olma sürecinde, yasa ve uygulamalarını Avrupa standartlarına uygun hale getirmesi ve engelli ve ruh sağlığı sorunları yaşayan yurttaşlarının temel insan haklarını koruması gerekmektedir. Türkiye hükümetinin söz konusu insan haklarını hayata geçirebilmesi için ciddi bir emek sarf etmesi gerekmektedir. Bunun için söz konusu yurttaşlarını kurumların içinde görülen ihlallere karşı koruması ve toplumsal yaşama tam anlamıyla katılabilmeleri ve entegre olabilmeleri için yapıcı ve kapsamlı programlar geliştirmesi gerekmektedir.

Önerilerin Özeti

MDRI, Türkiye hükümetine tehlikeli ve hayati tehlike arz eden koşulları durdurma konusunda hemen harekete geçmesini önermektedir. İşkence, insanlık dışı ve küçük düşürücü muamele tanımına giren uygulamalar derhal durdurulmalıdır. Türkiye hükümeti aşağıdaki konularda harekete geçmelidir:

- Modifiye edilmemiş EKT’nin yasaklanması
- EKT’nin ancak gerekli tıbbi önlemlerin alındığı koşullarda, uluslararası alanda kabul edilmiş sınırlı durumlarda ve hastanın baskı altında kalmadan vereceği aydınlatılmış onam koşuluyla uygulanmasını sağlayacak ilkelerin belirlenmesi
- Bağlama ve tecrit gibi uygulamaların rehabilitasyon yöntemi olarak ve personel yetersizliğini gerekçe göstererek uygulanmasından kaçınılması
- Yeterli miktarda gıda, personel ve tıbbi bakımın kurumlarda kalan herkesin temel sağlık ve güvenlik ihtiyaçlarını karşılayacak oranda sağlanması
- Kurumlarda gerçekleşen fiziksel ve cinsel istismarların durdurulması için gerekli izleme ve denetleme mekanizmalarının hayata geçirilmesi
- Engelli çocukların kurumlar yerine ailevi bir ortamda büyümelerinin sağlanması için aile destek ve koruyucu aile programlarının güçlendirilmesi. Bu programlar yeterince güçlendiğinde kurumlara (rehabilitasyon merkezleri ve yetimhaneler) daha fazla kayıt alınmaması hedef alınmalıdır.
- Uluslararası insan hakları standartlarına uygun ve uygulanabilir bir ruh sağlığı yasasının kabul edilmesi. Söz konusu yasa kişilerin kurumlara yerleştirilmesi sürecinde bağımsız bir değerlendirme talep etme hakkını da içermelidir.

Türkiye hükümeti, zihinsel engelli ve psikiyatrik sorunları olan kişilerin topluma tam anlamıyla entegre olabilmelerini sağlamalıdır. Söz konusu gruba karşı olan insan hakları yükümlülüklerini yerine getirebilmesi, Türkiye hükümetinin toplum-temelli ve kapsamlı bir ruh sağlığı ve sosyal hizmet sistemini hayata geçirmesi anlamına gelmektedir. Söz konusu bireylerin toplum içerisinde yaşayabilmesi, çalışabilmesi, gerek tedavi ve bakıma ulaşabilmesini sağlayacak bu sistemin

hayata geçirilebilmesi için ve acilen bir planlama yapılması için MDRI, ulusal bir komisyonun kurulmasını önermektedir.

Bu raporun sonunda kurumlardaki insan hakları ihlallerinin önüne geçilmesi ve etkili bir toplum-temelli ruh sağlığı ve sosyal hizmet sisteminin hayata geçirilmesi yönünde atılması gereken adımlara ilişkin detaylı bir öneri listesi yer almaktadır.

Türkiye'nin Uluslararası Yasal Zorunlulukları

Türkiye Avrupa İnsan Hakları Sözleşmesi (ECHR), Avrupa İşkenceyi Önleme Konvansiyonu (ECPT), Uluslararası Yurttaş Hakları ve Siyasi Haklar Sözleşmesi (ICCPR), Uluslararası Ekonomik, Sosyal ve Kültürel Haklar Sözleşmesi (ICESCR) ve Çocuk Hakları Sözleşmesi'ni (CRC) imzalamış ülkeler arasındadır.

Türkiye bir an önce tedavi ve rehabilitasyon kurumlarında yasal düzenleme olmaksızın alıkonulmayı engelleyecek yasal düzenlemeleri hayata geçirmek zorundadır. Avrupa İnsan Hakları Mahkemesi'nin belirttiği gibi, yasal düzenlemeden yoksun ve keyfi bir şekilde alıkonulma psikiyatrik kurumlara bu şekilde kabul edilen her kişinin bağımsız yargı organlarına başvurma hakkını doğurmaktadır. Psikiyatri kurumlarına kabul edilen her bireyin ayrıca bu kararlar ile ilgili olarak bir avukat isteme hakkı vardır.

İnsanlık dışı ve aşağılayıcı uygulamaların yanısıra işkence tanımı içerisine giren uygulamalar her koşul altında kesinlikle yasaklanmıştır. Bütçe sıkıntısı söz konusu insan hakları ihlalleri için bir gerekçe olarak kesinlikle kabul edilemez. Dünya Sağlık Örgütü'nün yakın bir dönemde hazırladığı uluslararası insan hakları hukukuna ilişkin özette şöyle belirtilmektedir:

İnsanlık dışı ve onur kırıcı tedavi yöntemleri için mali ya da mesleki kaynakların yetersizliği kesinlikle bir bahane olarak kabul edilemez. Hükümetler temel ihtiyaçlar için yeterli ölçüde kaynak ayırmak ve tedavi hizmetlerinden yararlanan kişileri yetersiz yiyecek ve giyecek, görevli personel tarafından sergilenen uygunsuz tutum ve davranış, temel temizlik ve hijyen için gerekli olanakların olmayışı ve bireyin saygınlığını göz ardı eden ve hafife alan koşullar gibi sebeplerden dolayı yaşanabilecek sıkıntılara karşı korumakla yükümlüdür.

Türkiye'deki ruh sağlığı ve rehabilitasyon hizmet sistemlerinin kişileri toplumdan ayrı tutan yapısı ICESCR tarafından yasaklanan ayrımcılık kapsamına girmektedir. Toplum temelli hizmetlerin olmayışı Birleşmiş Milletler'in "Engelli Kişiler için Olanakların Eşitlenmesine İlişkin Standart Kurallar" olarak tanıdığı toplum içerisinde yaşama, çalışma ve tedavi görme haklarını ve başka uluslararası engelli hakları normlarını ihlal etmektedir.

Türkiye'de zihinsel engelli çocukların yetimhane ve rehabilitasyon merkezlerinde toplumdan uzak tutulması özellikle ciddi bir sorun teşkil etmektedir. Bu raporun 2. Bölümünde daha detaylı olarak anlatılacağı gibi, söz konusu kurumlar gibi kapalı kurumlar özellikle sakıncalı olduğu ortaya çıkmıştır. Dolayısıyla, uluslararası hukuk mercileri son zamanlarda kurumlarda çocuklara yönelik toplu bakım konusunda ciddi bir karşı duruş sergilemektedir. Birleşmiş Milletler Çocuk

Hakları Sözleşmesi'nin 23(1) nolu maddesine göre “zihinsel ya da fiziksel engelli çocuklar saygınlıkları gözetilen, özgüveni teşvik eden ve toplumsal yaşama aktif katılımı kolaylaştıran bütün ve iyi bir yaşam yaşayabilmelidir”.

Avrupa İnsan Hakları Sözleşmesi'nin belirlediği zorunluluklara ek olarak, Avrupa Birliği'ne uyum süreci Türk yasa ve politikalarının ülkenin ruh sağlığı ve sosyal hizmet sistemini AB'nin kabul ettiği politikalar uyarınca değiştirilmesini gerektirecektir. AB Avrupa Parlamentosu Üye Ülkeler'den zihinsel engelli ve psikiyatrik sorunları olan bireylerine eğitim, toplum-temelli hizmetler ve toplum içerisinde yaşama ve çalışma konusunda imkan yaratmaya çağırıştır. Avrupa Parlamentosu ayrıca söz konusu bireylerin bağımsız yaşama ve toplumsal yaşama tam katılım haklarını tanımıştır.