# Human Rights & Mental Health: Hungary

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## **Mental Disability Rights International**

a project of the
Center for Human Rights & Humanitarian Law
Washington College of Law, American University
and the
Bazelon Center for Mental Health Law

Washington, D.C. March 1997

This report includes the full text of the United Nations
Principles for the Protection of Persons with Mental Illness
and the
Declaration on the Rights of Mentally Retarded Persons

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## **Mental Disability Rights International**

Mental Disability Rights International (MDRI) is an advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. MDRI documents human rights abuses, supports the development of mental disability advocacy abroad, assists advocates seeking legal and service system reforms, and promotes international oversight of the rights of people with mental disabilities in the United States and abroad. Drawing on the skills and experience of attorneys, mental health professionals, system users and their families, MDRI is forging a new alliance to challenge the discrimination and abuse of people with mental disabilities worldwide. MDRI is a joint project of the Bazelon Center for Mental Health Law and the Center for Human Rights & Humanitarian Law, Washington College of Law, American University.

MDRI has assisted mental disability rights advocates in Uruguay, Argentina, Mexico, Ukraine, Hungary, the Czech Republic, Romania, and Slovenia. MDRI=s first report, *Human Rights & Mental Health: Uruguay*, was released in 1995.

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#### **Forward**

In this publication the reader will find a sincere, objective, and sobering report on the conditions of a large group of people with chronic mental disabilities. More generally, the report provides an overview of the current state of mental health care in Hungary. The report is based on a fact-finding mission conducted by Mental Disability Rights International (MDRI), a non-governmental advocacy organization based in Washington, DC. The mission included experts in human rights and mental health professionals who visited Hungarian mental health facilities and nursing homes (or Asocial care homes@) for the mentally disabled.

As documented in this report, the social care homes are Adead ends@ for people with mental disabilities. There are almost no opportunities for people placed in social care homes to return to a normal life, even though many of them have the ability to reach a degree of competence and sanity which would enable them to live and function in the community.

From my experience, I would say that social care homes are more or less unique to Hungary. Other countries of the former Communist block have not created so many institutions of this particular kind, custodial institutions with limited psychiatric care.

Social care homes were once regarded as progressive developments. People with chronic mental disabilities, rejected by their environment, families, and communities, were given some chance to survive. Paternalistic and hospital-orientated, Hungarian psychiatrists have felt that social care homes are preferable to alternatives we have heard about in Western countries. We were told that people with chronic mental disabilities in the West were simply Adumped@ on to the streets as institutions were closed, forcing many of them to live on the streets, homeless. As described in this report, the reality in Hungary and the West is much more complex.

In Hungary, individuals who have advocated closing psychiatric hospitals and integrating patients into the community were branded as being under the evil influence of Aanti-psychiatry. Anti-psychiatry, to this way of thinking, can encompass any criticism of traditional attitudes and practices of psychiatry. The author of these lines has been labeled as anti-psychiatric many times for claiming that psychiatry needs reform. My major claim: that psychiatric treatment must aim not only at the disappearance of symptoms but also at the restoration of the ability to fully participate in community life. I have also pointed out that social care homes helped the former political regime maintain an image of a perfect society - a society where patients could not be seen in the streets and would not disturb the public.

Without social care homes in past years, many of their inmates would undoubtedly have died earlier through physical neglect or suicide. Communities were - and in many respects still are - rigid, closed, and rejecting, especially in rural areas. Until recently, there were no voluntary assistance organizations, no civil rights or civil protection programs, and no self-help or mutual aid groups. As a result, communities were unable or unwilling to absorb and shelter people with mental illness who were not always able to conform to the static rules of community life. There was no tolerance of diversity, no pluralism. This milieu was not supportive for people with mental disabilities, and there was little to counteract their isolation and alienation.

Despite challenges throughout society, some psychiatrists working in social care homes have, over the years, tried to pinpoint the dysfunctional characteristics of these institutions. A number of

psychiatrists have criticized the inadequate legal protections for the rights of people in institutions, including the superficial and mechanical application of guardianship laws. For years, individuals who tried to bring about change received little support.

After the political transition of 1989, changes have been slow with regard to both community development and mental health system reform. As the MDRI report describes, the country has adopted progressive new mental health legislation, but implementation is limited and has not reached much of the mentally disabled population. The protections of the new civil commitment law are only beginning to reach people in facilities for acute and chronic mental health care. On the whole, Hungarian psychiatrists are used to the *status quo* with regard to life and work in the mental health care system. They have become comfortable with ideologies that rationalize life in a social care home; placement in an institution is widely considered to be better than living at home and continuing the odyssey of the revolving door, going in and out of psychiatric care.

This report draws our attention back to the cold facts. We must be aware that comprehensive changes and radical reforms are needed urgently and quickly. Hungarian experts cannot avoid facing this fact. Mr. Rosenthal and members of the fact-finding mission give voice to the reality that living conditions in social care homes are often inhumane and degrading; conditions are sometimes poor in other places of treatment and care, as well.

Some reformers have claimed that the reintegration of people into the community is less expensive than keeping people in large institutions. Unfortunately, as this report points out, this may not be correct. Most follow-up studies of deinstitutionalization and subsequent community placement have shown that costs are higher. In Hungary, I believe that proper community integration of people with mental disabilities would be very difficult and expensive, except in some urban areas (just like in some northern cities of Italy). Nevertheless, this effort should begin as soon as possible if Hungary wants to become a member in the larger European network of countries. The cost of reform should be accepted as part of the price of enforcing human rights.

We should thank Mr. Rosenthal and Mental Disability Rights International for this investigation and report, whose observations and recommendations should be taken seriously. We must face the tremendous need for reform of psychiatry, with respect to human rights and quality control for mental health care and therapy. This report raises issues that are serious and timely. This report will be a catalyst for change and will help bring about the development of mental health and human rights reform in Hungary.

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### **Conclusions and Recommendations**

This report is a product of a fact-finding investigation conducted by Mental Disability Rights International (MDRI), a non-governmental advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities.<sup>1</sup> investigation was conducted during a series of site visits in 1995 and 1996 by a team of experts in disability law and psychiatry. The MDRI team spent several weeks visiting social care homes, psychiatric institutions, psychiatric wards of general hospitals, outpatient clinics, and one community-based rehabilitation program. The team interviewed psychiatrists, nurses, and other medical professionals in practice and in academia, governmental officials at the Ministry of Health and Social Welfare, judges, judicial experts, practicing attorneys, human rights advocates, and the National Human Rights Ombudswoman. We also interviewed users and former users of the mental health system (referred to in this report as Aconsumers@), their families, friends, and representatives of consumer advocacy and family organizations.

We are aware of the limitations inherent in describing a complex system of services, laws, financing and advocacy in a relatively short period of time in an unfamiliar context. Through repeated cross-checking of our observations, however, and with the assistance of many people in Hungary who spoke candidly and gave generously of their time, we believe that we have been able to develop an accurate picture of Hungary=s mental health system. We recognize that there are a number of important programs and initiatives that are not included in this report.<sup>2</sup> We also recognize that important changes are taking place within the system within recent months that may not be reflected in this report.

This report is intended to add to the spirited discussion now taking place in Hungary about mental health system reform and the human rights of people with mental disabilities. We believe that one of the contributions we can make comes from our perspective as independent outsiders, as well as our experience examining the mental health systems of other parts of Central and Eastern Europe, Latin America, and the United States. The experiences of the co-authors of this report

<sup>&</sup>lt;sup>1</sup> This report refers to people with Amental disabilities,@ a broad term that includes people with mental illness, people with mental retardation, and people with other developmental disabilities. The mental health system of Hungary is primarily designated to serve people with mental illness, but many people with mental retardation are also detained in psychiatric institutions.

<sup>&</sup>lt;sup>2</sup> We encourage people to contact MDRI with any additional information that would help us accurately portray the human rights situation of people in Hungary=s mental health system.

include extensive involvement in mental health treatment, mental health system planning and reform, and human rights advocacy in the United States and other countries. We hope that this report will add to the already extensive knowledge of people in Hungary. Drawing on the experiences of the United States and other countries, Hungarians can build upon the achievements of other countries in bringing about successful mental health system reform and can avoid mistakes that have been made in the United States and other countries. We present this report in the spirit of collaboration and dialogue.

This report identifies Hungary=s obligations to enforce the rights of people with mental disabilities under the *International Covenant on Civil and Political Rights* (the ICCPR), *the European Convention on Human Rights* (the ECHR), and the *International Covenant on Economic, Social, and Cultural Rights* (the ICESCR). This report relies primarily on the *Principles for the Protection of Persons with Mental Illness* (the MI Principles), adopted by the United Nations General Assembly in 1991, as a body of internationally recognized minimum standards for the treatment of people with mental disabilities.<sup>3</sup>

#### **Overview of Hungary=s Mental Health System**

Hungary=s mental health system includes approximately 10,000 inpatient beds, divided between psychiatric institutions and psychiatric wards of general hospitals. An extensive network of out-patient clinics exist, and approximately one-third of psychiatrists in Hungary are employed in these clinics. Outside the officially recognized mental health system, people with mental disabilities are placed in long-term institutions (social care homes), usually for a lifetime. There are 7,000 people living in social care homes designated for people with mental illness. In addition, there is an extensive system of social care homes designated for elders and for people with mental retardation. Children with mental disabilities are also excluded from schools and placed in institutions, leading to a lifetime of institutionalization.

<sup>&</sup>lt;sup>3</sup> This report refers to people with Amental disabilities,@ a broad term that includes people with mental illness and people with mental retardation. The mental health system in Hungary is primarily designated to serve people with mental illness, but many people with mental retardation are also detained in psychiatric institutions.

<sup>&</sup>lt;sup>4</sup> There is no careful distinction made between people with mental illness and mental retardation in the social care homes. An estimated 14,000 people with mental retardation are institutionalized in Hungary, many of whom are placed in institutions designated for people with mental illness. MDRI has not been able to ascertain the number of people with mental illness placed in social care homes designated for elders or people with mental retardation.

Hungary=s system of outpatient clinics, while extensive, provides a limited array of services and support. A large proportion of outpatient resources is devoted to providing psychotherapy for a few individuals, while the majority of people in outpatient treatment have limited contact with psychiatrists or other mental health professionals. For most people receiving outpatient services, treatment is limited to the provision of psychotropic medications. Aside from a few innovative rehabilitation programs, the services and support needed to maintain stability in the community for people with mental disabilities do not exist. Case management, supportive vocational programs, supported residential programs, and crisis intervention (crisis resolution teams that can help stabilize people in their homes, respite beds, crisis hostels, etc.) are not available to the vast majority of people with mental disabilities. In the absence of these services, thousands of people with mental disabilities are forced to seek or receive treatment in hospitals and other non-medical institutions for short or long periods of time. In most cases of chronic mental illness, people are forced to choose from a narrow and limited range of medication-oriented outpatient services or long term, custodial care in institutions or social care homes. Institutionalization of this kind cuts off people from their families and friends and leads to an unnecessary breakdown in ties with the community. Despite caring and dedicated efforts of staff, long-term institutionalization creates social isolation and contributes to increased dependency and mental disability.

In some locations, conditions within social care homes, psychiatric institutions, and psychiatric wards of general hospitals are inhuman and degrading. Basic rights of people in these institutions to make large or small decisions about treatment or daily routine are not recognized. Closed from public view in institutions without human rights oversight or advocacy available to them, people are vulnerable to the most serious human rights violations prohibited by international law. Major restrictions on individual liberty are routinely delegated to the administrative discretion of ward staff without due process of law. In some areas, the MDRI team observed people placed in cages for unlimited time periods without supervision.

Over the last year, the human rights of people with mental disabilities have come to national attention. On July 17, 1996, the Human Rights Ombudswoman, Katalin Gönczöl, issued a report documenting serious human rights abuses in social care homes. The Gönczöl report found that these abuses violate the Hungarian Constitution and called for immediate action to improve the conditions in these settings. In the view of the MDRI investigators, the human rights issues at stake are not limited to the degrading internal conditions in social care homes. Even if these conditions are improved, the use of such institutions to segregate people from society deprives them of adequate treatment and opportunity for rehabilitation. As currently structured and operated, the mental health system of Hungary deprives people with mental disabilities of the right to work and live in the community and to participate as full members of society.

The lack of community-based service and support systems critically limits the rights of people with mental disabilities throughout society, not just in social care homes. Hungary has a network of psychiatric wards in general hospitals, for example, that are generally located near the community. Without a network of community-based services and support systems, however, it is difficult to integrate people from these wards into the community. Discharge options are limited, and psychiatrists are forced to discharge people back into society with only a fraction of the kinds of support they need to remain stable, much less flourish as human beings. Under these conditions, many people become a burden on their families. Inside or outside institutions, often awaiting

placement in social care homes, people spend their lives vegetating. Most people never obtain assistance to learn the vocational or survival skills needed to lead an independent life. Many people decompensate repeatedly and are forced to return over and over to hospitals. This is not only a waste of their human potential, it is a wasteful and inefficient use of hospital beds and mental health system resources. The absence of comprehensive community services traps Hungary in a cycle in which the vast majority of mental health resources are allocated to institutional care, leaving few resources to promote or sustain community living.

#### Human rights enforcement: recommendations and warnings

Proposals currently under consideration to reform mental health legislation and up-date Hungary=s system of health care finance and insurance reimbursement create enormous opportunities for improvements in the human rights of people with mental disabilities. A failure to recognize the rights of people with mental disabilities and plan for their integration into society, however, could lead to a further entrenchment of the current system of segregation and inadequate community support.

Hungary has recently adopted new legislation governing civil commitment to psychiatric institutions and general hospital psychiatric units. The Ministry of Health and Social Welfare is also conducting an extensive review of current law and is drafting new legislation regulating health care practices. These legal initiatives represent an important step toward the recognition of the rights of people with mental disabilities, but they do not address the fundamental structural problems of the mental health system, i.e. the segregation of people with mental disabilities and the need to create community-based alternatives to psychiatric institutionalization.

Many of the current reform efforts are intended to remedy the inhuman and degrading conditions in social care homes identified in the Gönczöl report. Without a reduction in the census of social care homes, however, it will be difficult for Hungary to free up financial resources to improve conditions within institutions. Without the creation of an improved system of health care financing and insurance reimbursement that recognizes and prioritizes community-mental health service and supports, people with mental disabilities will not have true alternatives to institutionalization. Without planning for the creation of a comprehensive system of community services, resources now directed to general hospital psychiatric units and outpatient services will continue to provide isolated pockets of treatment that do not provide the full support people need to avoid unnecessary institutionalization.

The history of mental health system reform in the United States and other countries demonstrates that there are dangers associated with legal reform not accompanied by a national commitment to plan and finance community services. Full enforcement of commitment laws without the establishment of community-based alternatives to institutions could lead to irresponsible discharge of people from hospitals and social care homes without adequate services and protection in the community. In practice, failure to develop community- based services is usually accompanied by a failure to enforce civil commitment and other human rights laws. The recognition of patients= rights without the creation of real choices for people with mental disabilities may be changes in form rather than substance. Without meaningful choices, many of the new legal rights now under consideration may be a dead letter from the moment they are enacted.

The rights of people with mental disabilities, including legally enforceable minimum standards of treatment, should be established both in institutions and in the community as part of a comprehensive system of support and care. Human rights oversight and advocacy systems must be established to ensure that these rights are enforced throughout the mental health system. As part of this system of support and advocacy, the government should recognize and finance consumercontrolled support and advocacy programs. The process of reforming the mental health system must be fully informed by a recognition of rights of people with mental disabilities and must include full public participation. In addition to the participation of existing civic and professional organizations, people with mental disabilities and their representatives must be included in the process of conceptualizing and planning mental health system reform and human rights enforcement.

#### A. **Social Care Homes**

Approximately 7,000 adults of all ages live in long-term institutions, known as Asocial care homes,@ designated for people with mental illness. The Social Care Act regulating social care homes does not require the provision of rehabilitation. Thus, social care homes are not officially recognized as part of the Amental health system. @<sup>5</sup> Additional institutions exist for children and people with other mental or physical disabilities. An estimated 14,000 people live in similar longterm institutions designated for people with mental retardation.

- 1. **Isolation from the community** - Social care homes are located in remote parts of Hungary, often on Hungary=s borders, isolated from major population centers. Once a person is placed in a social care home, he or she is considered to be beyond rehabilitation. Thus, there is little or no effort at active treatment, rehabilitation, or reintegration into the community. The vast majority of people placed in social care homes remain there for life.
- X MDRI finds that the system of social care homes unnecessarily isolates and segregates people with mental illness from normal life. Individuals placed in social care homes are denied the right to live, work, and receive treatment in the community. Isolation and failure to make efforts to return people to the community violate the right Ato be treated near his or her home or the home of his or her relatives and friends and ... the right to return to the community as soon as possible. @ MI Principles, principle 7(2). People in social care homes are deprived of the right to treatment Adirected towards preserving and enhancing personal autonomy.@ Principle 9(1). Detention without any meaningful effort at rehabilitation violates article 10 of the ICCPR (A[a]ll persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person. (2)

<sup>&</sup>lt;sup>5</sup> The Hungarian mental health system consists of in-patient and out-patient psychiatric facilities administered by the National Psychiatric Institute, under the authority of the Ministry of Health and Social Welfare. Approximately 10,000 people receive treatment in these in-patient facilities, and many more receive out-patient treatment (this system of services is described further in part B of this chapter, and in more detail in chapter II of the report).

- 2. Arbitrary placement in social care homes There is no legal process for placement in a social care home. There is a law in Hungary governing civil commitment to psychiatric institutions, but this law is not applied to placement in facilities designated as social care homes. Most people in social care homes are placed there by family members or other individuals designated as their legal Aguardians. Hungary=s guardianship law does not require independent judicial review of placement in a social care home. Nor does it require review or reconsideration over the course of the individual=s lifetime. Many people interviewed by MDRI investigators had been placed under guardianship as children and have gone for years without any contact with their guardians.
- MDRI finds that Hungary=s practices for placement in social care homes are arbitrary and without appropriate legal process. The failure to provide independent review of commitment to social care homes, with appropriate procedural protections for people subject to commitment violates the *MI Principles* (principles 15, 16, 17, 18). The lack of due process for placement in a social care home, including independent review of commitment, constitutes Aarbitrary detention@ under article 13 of the ICCPR and article 5 of the ECHR.
- 3. Improper detention Officially, people are placed in social care homes because they are considered untreatable or beyond rehabilitation. Despite this, authorities at two social care homes investigated by MDRI estimated that one third to one half of social care home residents could live in the community if they had family to take them in or if other social support networks existed. We believe this estimate is low. Many people in social care homes do not have a major psychiatric diagnosis. Some people are placed in the institution for alcoholism or mental retardation. Others have lost contact with the outside world because they have been in the institution so long they have lost the skills necessary to live in the community. Many people have no experience other than life in an institution, having grown up in an institution since they were children. With appropriate service and support programs, modern social service and psychiatric practice have demonstrated that the majority of these individuals can be reintegrated into the community.
- MDRI finds that the majority of people placed in social care homes do not meet internationally recognized standards for in-patient commitment. People are detained in social care homes in violation of the standards set forth in the *MI Principles* (principle 16, limiting involuntary commitment to people for whom there is a Aserious likelihood of immediate or imminent harm@ or to avoid Aserious deterioration in his or her condition....[for which treatment] can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative.@) Failure to require that people meet internationally recognized substantive standards for commitment constitutes Aarbitrary detention@ under article 13 of the ICCPR and article 5 of the ECHR.
- 4. Inhuman and degrading treatment Placement in social care homes creates isolation and results in the loss of ties with friends and family in the community. In the absence of activities to structure the day and engage peoples= interests, residents of social care homes are left to long hours, days, and years of boredom. Individuals live in dormitory-like rooms and lack privacy or control over their daily lives. In some wards, lights are turned off late in the afternoon and people spend the remainder of the day in the darkness. Clothing is drab, impersonal and often inappropriate. In the worst areas, people have little or no clothing. While some buildings are modern and clean, others are

old, decaying, and unhygienic. In some areas, people are allowed to languish in filth, covered in dirt or their own feces. Oral hygiene is lacking for a large number of social care home residents, who lose their teeth and cannot eat solid food. Patient choice, including the rights of patients to informed consent to treatment, is not recognized under Hungarian law. People in social care homes are subject to the arbitrary use of physical restraints.

- X MDRI finds that conditions in social care homes are inhuman and degrading. Isolation, inactivity, and lack of stimulus leads to the loss of social functioning and a degeneration of mental health. Treatment in social care homes violates numerous provisions of the MI Principles, including the right to be treated Awith humanity and respect for the inherent dignity of the human person, @ principle 1(2); the right to protection against harm, principle 8(2), and the right to an Aenvironment and living conditions ... as close as possible to those of normal life...@ principle 13(2). Conditions in social care homes constitute inhuman and degrading treatment, in violation of article 7 of the ICCPR and article 3 of the ECHR. Placement in a social care home promotes further mental deterioration, violating the right to the highest attainable standard of mental health under article 12 of the ICESCR.
- 5. **Improper physical restraints and use of cages -** Some people are placed in cages as a form of physical restraint and permanent detention. Cages are constructed of a metal frame supporting a cloth or wire mesh over a bed. People can sit up or roll over in the cage, but they cannot stand up. Some individuals are placed in cages for weeks or months for behavioral control. Other individuals are kept permanently in cages because of lack of staff to supervise them. With such limited movement, people in cages are subject to dangerous, and potentially life threatening pressure ulcers (bed sores). Unable to leave the cage to go to the toilet, people are often covered in their own feces.
- X Use of cages constitutes inhuman and degrading treatment, and creates life threatening dangers. Detention in cages violates the strict standards for the use of physical restraints and protection from harm, established under the MI Principles, principle 11(11). Such detention constitutes inhuman and degrading treatment under article 7 of the ICCPR and article 3 of the ECHR. Placement in cages is dangerous and can be life threatening, in violation of article 6 of the ICCPR and article 2 of the ECHR.

#### **Recommendations:**

- A-1 Inhuman and degrading treatment practices should be terminated at once.
- The use of cages should be prohibited as a means of detention, physical restraint, or ward A-2 management.
- The national legislature of Hungary should adopt a body of enforceable patients rights that A-3 will apply to all people in Hungary=s mental health and social care system. Consistent with internationally recognized human rights standards, this legislation should recognize the right of individuals to live in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the individual=s health needs and the need to protect the safety of others. Every individual should have the right to live, work, and be treated and cared for in the community to the extent his or her condition permits. Until such time as this

- new legislation is adopted, the Ministry of Health and Social Welfare and local governments should issue guidelines for the respect of patients rights.
- A-4 All people in institutions should be notified of their rights under Hungarian and international law in a form and language which they understand.
- A-5 All new admissions to social care homes for people with mental illness or mental retardation should be stopped immediately.
- A-6 A comprehensive review of placements in all social care homes should be conducted. People who no longer require guardianship should have the recognition of their legal capacity restored.
- A-7 Immediate efforts should be made to provide alternative accommodations and support for every social care home resident capable of living in the community. Individuals who meet internationally recognized standards for in-patient commitment should be transferred to facilities as close as possible to the community from which they originated
- A-8 The government of Hungary should develop a plan to phase down the system of social care homes.

### **B.** Institutional and Community Care

The officially designated mental health system of Hungary provides services for 10,000 people as in-patients and many more people as out-patients. The National Psychiatric Institute (known by its Hungarian acronym as OPNI) in Budapest is responsible for regulating all aspects of treatment and quality of care throughout the mental health system. The majority of in-patient care takes place in psychiatric wards of general hospitals. The OPNI administers the largest psychiatric institution, also known as OPNI or Lipót. Lipót has 800 to 1,000 in-patient beds, and it serves 70,000 out-patients in the community. An additional 30,000 receive out-patient psychiatric treatment through clinics administered by local hospitals. The majority of patients are reported to remain in the institution from three weeks to three months, but some people remain in the institution much longer. Individuals deemed Achronic patients@ or individuals who cannot take care of themselves and who lack a family to support them may remain in the institution for years. Every year, approximately ten percent of all patients at Lipót are designated for transfer to social care homes.

1. Unnecessarily restrictive environment - The great majority of Hungary=s mental health system resources are directed toward in-patient care, at the expense of providing adequate outpatient and community-based treatment. The existence of psychiatric wards of general hospitals creates potential for inpatient care close to the community. In practice, however, people in such wards are often isolated from the community. In some cases, psychiatric wards of general hospitals are used for long-term care. Even when treatment is short-term, general hospital psychiatric wards are often not effectively integrated into community-based service or health care systems. This is due to the limited availability of community services and to the lack of coordination with existing services.

In some cases, the national insurance and pension systems promote unnecessary in-patient treatment by providing benefits to individuals in in-patient care who could function in the community if they received necessary support. As a result of limited community-based services, many people are forced to seek treatment in an in-patient setting even though they are capable of

living, working, and receiving treatment from out-patient services in the community. This is true for people diagnosed with major mental illnesses and for people diagnosed as neurotic.

According to the Director of the National Psychiatric Institute, approximately 25 percent of people receiving treatment as in-patients are diagnosed as Aneurotic@ and do not have any major psychiatric diagnosis. In one institution visited by MDRI, the Director estimated that only 30 percent of in-patients have major psychiatric diagnoses. Some Hungarian psychiatrists estimate that 90 to 100 percent of individuals without a major psychiatric diagnosis could live and receive treatment in the community. The practice of unnecessary in-patient treatment for people with major mental illness and neuroses creates social dislocation, stigma, and often the loss of work or other social ties. In many cases, this breakdown in ties to the community leads to long-term in-patient care and segregation from the community.

- X MDRI finds that the structure of services in Hungary forces many people to seek inpatient treatment when they are capable of living, working, and receiving treatment in the community. These services often lead to unnecessary, long-term segregation of people with mental illness in institutional settings. Unnecessary in-patient treatment and the failure to provide community based alternatives violate the Aright to be treated in the least restrictive environment ... appropriate to the patient=s health needs....@ under the MI *Principles*, principle 9(1). The practice of unnecessary in-patient treatment violates the right under article 12 of the ICESCR to the Ahighest attainable standard of physical and mental health@ of which people with mental disabilities are capable.
- 2. Inhuman and degrading conditions - Conditions in Hungary=s psychiatric institutions vary widely. In some areas, impressive efforts have been made in recent years to improve conditions. Even in some of the clean, modern buildings, however, people lack privacy, living conditions are impersonal, and inactivity is the rule. Long-term patients may spend years awaiting placement in a social care home without active rehabilitation programs or other activities. There is no recognition of the rights of patients to make basic choices about their lives or to provide informed consent to treatment, as required by the MI Principles. In other areas, conditions are worse, particularly in locked wards and wards for chronic patients. In some wards of this kind, people receive less staff attention and their conditions degenerate. Physical and oral hygiene is lacking, clothing is inappropriate, and some people are not allowed outdoors for weeks or months. Some residential areas are large and dormitory-like with ten to twenty beds in a room. In a small number of cases, people are restrained (tied to chairs or belted to beds) or placed in cages because of the lack of staff to provide them with adequate supervision. As in social care homes, described above, people in cages are unable to leave to go to the toilet, and they are at risk of bed sores from lack of movement.
- X Some in-patient psychiatric facilities subject patients to inhuman and degrading treatment. The failure to provide a clean, safe, and socially appropriate environment, creates unnecessary suffering and undermines opportunities for rehabilitation and reintegration into the community. The lack of an environment conducive to rehabilitation violates the MI Principles, principle 13, and the right to Atreatment ... directed towards preserving and enhancing personal autonomy, @ principle 9(4). The failure to inform people of their rights, and to enforce those rights, violates principles 11, 12 and 23. The use of

physical restraints at the discretion of ward staff, without time limitations or adequate safeguards, violates principle 11(11), and the failure to protect against harm violates principle 8(2). These conditions cause needless degradation and suffering, in violation of article 7 of the ICCPR and article 3 of the ECHR.

- 3. Inadequate community services and support Out-patient treatment for many people consists almost exclusively of psychotropic medication. While a small number of people receive individual or group psychotherapy, other services such as psychosocial rehabilitation, vocational support, and supported living programs are lacking. Due to the large case load of psychiatrists in out-patient practice, many people are not able to see a psychiatrist more than once a month, and some psychotropic medications cannot always be used as needed (such as lithium).
- MDRI finds that the lack of community-based services and support leads to unnecessary institutionalization and inappropriate care in the community. The use of psychotropic medications without adequate monitoring can lead to unnecessary and debilitating side effects and life-threatening danger. The lack of community based services and supports leads to a violation of the right to Ahealth and social care as is appropriate to his or her health needs,@ including the protection from harm against inappropriate medications. MI Principles, principle 8.

#### **Recommendations:**

- B-1 Immediate steps should be taken to create a comprehensive community-based service and support system to permit people to live, work, and receive care in the community to the extent possible. Community-based services should include: supported housing, supported employment, crisis services, case management, respite care, consumer-controlled supportive clubhouses, consumer and family advocacy, and legal advocacy.
- B-2 The national plan for mental health service reform should identify the cost of reform and should allocate resources necessary to protect fundamental human rights. An additional infusion of funds will be necessary during the transition to a community-based system. Effective national planning will be necessary to permit a quick (two to five years) and efficient reform of the service system.
- B-3 Community based service and support systems and integrated educational programs for people with mental retardation should be established.
- B-4 The insurance and pension systems should be revised to end incentives for in-patient treatment at the expense of out-patient treatment. These programs should provide the funding necessary to permit people to live and work in the community to the extent possible.
- B-5 Standards for in-patient and out-patient services should be established, consistent with internationally accepted practice standards and human rights. These should include individual habilitation or rehabilitation plans for adults and individualized educational plans for children.
- B-6 Continuing education programs should be established for all staff.
- B-7 Legislation should be adopted to ban discrimination against people with mental disabilities, including discrimination in education, employment, housing, public services and public accommodations.

#### C. **Civil Commitment and Guardianship**

Hungary has recently amended its laws governing civil commitment to psychiatric facilities to harmonize them with international human rights law, as well as standards recently established by the Council of Europe. Hungary=s new legislation limits involuntary detention to people who are diagnosed as mentally ill and constitute an Aimmediate and serious danger@ to themselves or others. The commitment standard established by Hungary=s new law is consistent with international human rights law. However, the commitment law is severely limited by its failure to provide the procedural protections required by international law.

- **Inadequate right to counsel -** In practice, many people with mental disabilities cannot take advantage of the new commitment law-s protection because they do not have adequate access to counsel. The commitment law does not have a clearly defined right to counsel, as required by international human rights standards. The legal representative of the person subject to commitment is referred to as a Acasual guardian,@ leaving judges and official legal representatives with the impression that the position is actually that of a guardian. A guardian, unlike a true legal advocate, represents what he or she thinks is best for the client, not necessarily what the client wants. The legislation also fails to provide the client a right to be heard, to cross examine witnesses, or to obtain an independent psychiatric evaluation.
- X MDRI finds that Hungary=s civil commitment law lacks necessary procedural protections, including the right to counsel. The lack of adequate right to counsel violates the MI Principles, Principle 18.
- 2. Lack of resources for effective review - When the new commitment law was enacted, no new resources were provided to the judicial system to handle the enormous new caseload. As a result, hearings are forced to take place on psychiatric wards, often without adequate protection of privacy. Judges and legal representatives have such a large case load that each review usually lasts about ten minutes. Legal representatives usually do not meet their clients or hear about the facts of the case until the moment of the hearing. Civil commitment hearings are so cursory as to be nearly meaningless. In an environment in which decisions about every aspect of care and treatment is left to the discretion of psychiatrists, judges are hesitant to override the recommendation of a psychiatrist based upon the judges= limited exposure to the facts of the case.
- X MDRI finds that, due to a lack of resources for civil commitment cases, judicial review is cursory and close to meaningless. Psychiatric commitment is effectively left to the discretion of psychiatrists. Independent review of psychiatric commitment is guaranteed by the MI Principles, principle 16, the ICCPR, article 9, and the ECHR, article 5. The MI Principles and international conventions protecting arbitrary detention require that states make the minimal investments necessary to ensure adequate, independent review of psychiatric commitments.
- 3. Failure to protect people committed to social care homes - Hungary=s civil commitment law does not apply to the people who need its protections the most - people who are placed in social care homes. In most cases, people are placed in social care homes by family members or other

Alegal guardians@ without any judicial review. Since most people are placed under guardianship, the detention in a social care home is treated as a Avoluntary@ process. A Aguardianship authority@ may be required to approve a social care home placement, but this is a purely administrative review process with no established standards or procedural protections.

- Taken together, Hungarian civil commitment and guardianship laws improperly deny the right of people with mental disabilities to protection against arbitrary detention in a social care home. Neither the social care home nor the guardianship authority is required to submit to the substantive standards or procedural protections set forth in the *MI Principles*, principles 15-18. The procedure for detention in a social care home constitutes arbitrary detention under article 9 of the ICCPR and article 5 of the ECHR.
- 4. Lack of judicial review in guardianship proceedings Judicial review of guardianship is limited to a single determination of whether a person can Amanage his or her own affairs. A judge may decide whether a person is put under partial guardianship (under which the ward retains some legal capacity) or plenary (Afulle) guardianship (under which the ward is held to have no legal capacity), but the judge may not specify exactly what powers the guardian has and what legal capacity the ward retains. Once a court determines that a guardian is required, an administrative agency known as a Aguardianship authority appoints a guardian. There is no judicial review of the guardian=s possible conflict of interest with the ward. The judge cannot limit the guardianship over specific duties and cannot review any decision of the guardian. Once a guardian is appointed, there is no further requirement of judicial review for the most important decisions, including the decision to detain a person in an institution. There is no requirement of periodic review of guardianship. MDRI interviewed many people who had been placed under guardianship as children and had not met their guardian in decades. People subject to plenary guardianship have their legal identity taken away from them, subjecting them to an almost complete denial of legal rights in the community.
- MDRI finds that Hungary=s guardianship law unlawfully and improperly limits the scope of judicial review in the guardianship process and delegates a person=s legal rights to a guardian or an administrative guardianship authority. The guardianship process arbitrarily strips people of their legal rights far beyond what may be necessary. Hungary=s guardianship law fails to provide the procedural protections required by the MI Principles, including the right to counsel and the right to periodic review. MI Principles, principle 1(6). The guardianship process denies people with mental disabilities the ability to exercise the same rights as all other people, except to the extent Anecessary to protect@ the rights of that person or others. MI Principles, principle 1(4). Thus, the guardianship law constitutes illegal discrimination under the MI Principles and article 26 of the ICCPR and article 14 of the ECHR.

#### **Recommendations:**

C-1 Hungary=s civil commitment law should be amended to provide due process protections, including a right to participate fully in a hearing, the right to cross examine witnesses, and the clear and unequivocal right to counsel representing the views of the person subject to commitment.

- C-2 Additional resources should be provided to the judicial system to ensure that judges and legal representatives can devote the time and attention needed to each case.
- C-3 The guardianship law should be revised, in accordance with international law, to provide the assurance that people with mental disabilities will retain the same rights as all other people. The guardianship law should explicitly:
  - a. require that any restriction on a person=s legal capacity be made by an independent and impartial decision-maker after a full hearing, at which the person subject to guardianship has the right to effective assistance of counsel;
  - b. provide that the judge, not the administrative agency, shall determine who will serve as guardian and shall review the guardian=s fitness and potential conflict of interests;
  - c. require periodic review of the necessity of continued guardianship at regular intervals established by law, after a full hearing by an appropriate, independent review body;
  - d. require that any restriction on a person=s rights be specified precisely by a court based on findings of fact that an individual lacks the capacity to engage in each specific activity that is limited;
  - e. limit the discretion of a court to restrict a person=s legal capacity to situations in which such a limitation is strictly necessary to protect the rights of the person with a mental disability.

### D. Quality Assurance and Oversight

Apart from basic regulation of physical conditions and staffing, there are no legally enforceable minimum standards or guidelines for the treatment of people with mental disabilities in Hungary=s psychiatric institutions, social care homes, or out-patient programs. Without minimum legal standards, psychiatrists have the discretion to engage in improper, unproven or dangerous treatment practices. No standards exist for the use of physical restraints, and no regulations prohibit the use of cages. No procedures exist for regularly and systematically monitoring living conditions or treatment practices, and no special procedures exist to investigate unusual incidents or allegations of abuse by staff or other patients. The Ministry of Health and Social Welfare has taken the lead in drafting important new legislation regulating mental health care and patients rights. However, there is no official commitment to a policy of social integration for people with mental disabilities and no public, national planning process to end the unnecessary institutionalization of people in psychiatric institutions and social care homes.

MDRI finds a lack of quality assurance and human rights oversight in Hungary=s mental health system. The absence of standards for treatment in institutions creates an environment that permits improper and potentially dangerous treatment practices. The lack of enforceable minimum standards to ensure compliance with the MI Principles and other internationally recognized human rights violates the MI Principles (principles 22 and 23). The failure to provide protections against inhuman and degrading treatment also violates article 2 of the ICCPR, article 1 of the ECHR and article 2 of the ICESCR, requiring States to ensure the enforcement of internationally recognized human rights.

MDRI finds a lack of a national planning to ensure enforcement of the rights of people with mental disabilities and provide for equality, full participation, and reintegration into the community. People with mental disabilities are not included in the planning that takes place. The lack of a national planning process to ensure human rights enforcement and full participation of people with mental disabilities violates the *Rules on Equalization* (rules 3, 4, 15), as does the failure to include people with mental disabilities in the planning that is now taking place. (Rule 14.2). The misallocation of resources leading to improper and unnecessarily restrictive treatment of people with mental disabilities violates article 2 of the ICCPR, article 1 of the ECHR and article 2 of the ICESCR, requiring States to ensure the enforcement of internationally recognized human rights.

#### **Recommendations:**

- D-1 Establish enforceable minimum standards for treatment in in-patient and out-patient services.
- D-2 Create independent patient advocacy programs to assist people in in-patient programs to seek enforcement of their rights
- D-3 Create policies and practices for investigating allegations of abuse or improper treatment in institutions. This should include a public report of complaints and action taken, with protection for complainants and respect for the privacy of individuals involved.
- D-4 Create effective oversight mechanisms to ensure enforcement of treatment standards and internationally recognized human rights.
- D-5 Initiate an inclusive, national planning process to bring about the structural reforms needed to ensure human rights enforcement, equalization of opportunities, and full integration of people with mental disabilities. This process should include:
  - a. participation of people with mental disabilities in any governmental planning body;
  - b. the identification of immediate steps that can be taken to bring Hungary into conformity with international human rights law;
  - c. development of a plan to create community-based service and support systems on a national level;
  - d. development of a plan for financing reform, including a targeted reallocation of funds from psychiatric hospitals to in-patient to out-patient programs, as community services are developed. Additional funds will be needed to finance the extra costs of transition
- D-6 Provide support to independent consumer and family advocacy organizations.
- D-7 Create and fund disability councils to promote the inclusion of people with mental disabilities and their families in the process of identifying human rights concerns and developing reform plans. Disability Councils should be consumer controlled, and they should meet at regularly appointed times during the year to take the testimony of psychiatric system users and former users, family members, service providers, and other concerned citizens. The government should also fund a permanent staff for the Disability Councils to prepare recommendations, subject to approval of a majority of members of the Disability Councils, for government action to respond to the concerns of people with mental disabilities.

#### E. Recommendations to Advocates and the International Community

To create political support for mental health system reform, advocates in Hungary should:

- Educate the public about the human rights conditions of people with mental disabilities, and E-1 publicize positive models of community integration and effective citizen action.
- E-2 Bring together a broad base of constituents for reform, including system users, family groups, community service providers, mental health professionals, human rights advocates, and other concerned citizens.
- Establish cross disability coalitions of interest groups concerned about the recognition of E-3 rights and the reform of services designated for people with mental illness, mental retardation, and other mental and physical disabilities.
- Establish community-based service programs informed by the best programs from other E-4 countries. Innovative service providers should be sure to document their work so that their programs can serve as models for similar kinds of work throughout Hungary.

The international community should press for the enforcement of international human rights law and should provide support to innovate service and advocacy programs in Hungary:

- International support should be provided for the innovative, nongovernmental service and E-5 advocacy programs now being established advocating for the rights of people with mental disabilities in Hungary.
- E-6 Once Hungary has established the national goal of full community integration and support for people with mental disabilities, loans and development assistance should be provided to the government of Hungary to promote the reform of the service system. Special support will be especially important during the time of transition to a community-based service system. As a condition of such assistance, international funders should require the government of Hungary to agree to provide full funding for community-based services once the transition period is complete.
- The United Nations Special Rapporteur on the Equalization of Opportunities for Persons E-7 with Disabilities should evaluate the conditions of people with mental disabilities in Hungary and should evaluate Hungary=s efforts to create services and programs that will provide people with mental disabilities the full opportunity to live and work in the community. The Special Rapporteur should provide special assistance to Hungary to create service programs in the community and should help raise international financial support for the development of such programs.
- The United Nations Human Rights Committee should review Hungary=s enforcement of the E-8 rights of people with mental disabilities under the ICCPR.
- The United Nations Committee on Economic, Social, and Cultural Rights should review E-9 Hungary=s enforcement of rights of people with mental disabilities under the ICESCR.

## **Preface: Goals and Methods of this Report**

Mental Disability Rights International (MDRI) is a non-governmental advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. MDRI documents human rights abuses, supports the development of mental disability advocacy abroad, assists advocates seeking legal and service system reform, and promotes international oversight of the rights of people with mental disabilities in the United States and abroad.

This report documents human rights conditions in Hungary=s mental health system and recommends steps necessary to bring the system into conformity with internationally recognized human rights standards. This report is not intended to single out Hungary for criticism but to examine the enforcement of international human rights law that applies universally to people with mental disabilities. Indeed, many of the observations and recommendations in the report are relevant to other countries of Central and Eastern Europe where the vast majority of people with mental disabilities remain segregated in closed institutions without adequate opportunity for community integration.

We hope that this report will promote the efforts of the many service providers, consumers, family members, and other human rights advocates in Hungary who have worked so hard to protect the rights and improve opportunities for people with mental disabilities. We also hope that this report will provide guidance to public officials and legislators in Hungary about the actions and legal reforms that the government must take to ensure full enforcement of the rights of people with mental disabilities under international law. This report is also directed to the international community, which can play a much greater role providing oversight of human rights conditions in psychiatric systems and supporting mental health reform.

The identification of human rights violations and deficiencies in the operation of the current mental health system is an essential first step, but reform will not succeed without the participation In that spirit, MDRI has provided detailed of concerned citizens and governments. recommendations to service providers, activists, the Government of Hungary, and the international community.

This report is the product of numerous fact-finding missions to Hungary, conducted primarily in March 1995, November 1995, and March 1996.<sup>6</sup> Members of the MDRI teams interviewed representatives of the Legal Department of the Ministry of Welfare, judges and court-appointed

<sup>&</sup>lt;sup>6</sup> The March 1995 fact-finding team consisted of Eric Rosenthal, Executive Director, MDRI, Elizabeth Bauer, Executive Director of Michigan Protection & Advocacy, Dr. Peter Stastny, Manhattan Psychiatric Institute, and Judith Klein, Director, Central European Mental Disability Advocacy Project. The November 1995 fact-finding team consisted of Eric Rosenthal, Ira Burnim, Legal Director, Bazelon Center for Mental Health Law, and Dr. Robert Okin, Director, Department of Psychiatry, San Francisco General Hospital. Professor Robert Dinerstein, Director of Clinical Programs at the Washington College of Law, American University, and Max Lapertosa, Associate, Mental Disability Rights International participated in part of the November 1995 visit, concentrating primarily on the issue of guardianship. The March 1996 fact-finding team consisted of Eric Rosenthal and Ira Burnim.

medical experts involved in the psychiatric commitment process in Budapest, members of the Guardianship Authority for Budapest, and a professional public guardian who works closely with the Guardianship Authority. MDRI also met with the director of the National Psychiatric Institute and a number of psychiatrists and department directors at the Lipot psychiatric institution in Budapest.

In March 1995, a MDRI team toured one of the psychiatric wards at Nyirö Gyula hospital, three wards at the National Psychiatric Institute (also known as Lipot) in Budapest, and a new psychiatric institution for children on the grounds of Lipot. MDRI also visited the Szentgotthárd social care home. In November 1995, an MDRI team interviewed the directors of two psychiatric departments at Dr. Kenessay Albert Hospital, Balassagyarmat, the deputy director of a psychiatric department at Nyirö Gyula Hospital in Budapest, and the Director of the psychiatric department at Bajcsy Zsilinsky hospital. MDRI teams interviewed medical school authorities at the Semmelweis Medical School, and toured the psychiatric wards of Semmelweis, Kenessay Hospital and Nyirö Gyula hospital. In September 1995, MDRI associate Judith Klein toured a locked ward at Lipot. The November 1995 team also toured the Ludányhalászi social care home near Balassagyarmat. MDRI teams visited the AAwakenings@ community mental health program of Semmelweis medical school, and met with staff seeking to establish a community-based home in Budapest. In March and November 1995, the MDRI teams met with mental health system consumers and family members, including representatives of two consumer organizations. In March 1996, MDRI investigators observed a civil commitment hearing at Semmelweis medical school and visited three out-patient clinics in Budapest. On visits to psychiatric programs, team members toured facilities, visited therapeutic and residential wards, and interviewed administrative authorities, staff, and consumers.

At most locations, MDRI teams received full access to facilities, staff and clients without restrictions. MDRI was met with great openness and candor, and many people gave generously of their time. Almost without exception, they expressed concern about the need to improve services and the protection of rights of people with mental disabilities. This report - and the difficult reform process that lies ahead - would not have been possible without their support. The observations published in this report and the conclusions reached are those of the authors alone.

The findings of this report represent the views of its authors and of Mental Disability Rights International. Affiliations of the authors are listed for purposes of identification only. This report does not represent any position on the part of the Washington College of Law or American University.

<sup>&</sup>lt;sup>7</sup> Judges conducting psychiatric commitment hearings at Nyirö Gyula hospital would not permit team members to observe the hearings on the grounds that no prior consent had been obtained from persons subject to the commitment hearing. At the Bajcsy Zsilinsky Hospital, the MDRI team was not permitted to visit the psychiatric department. The department director said that permission from the hospital director was required, and for reasons he would not explain, the director declined to request this permission.

#### I. Introduction

#### Mental Disability Rights: An International Concern A.

The universal recognition of the rights of people with mental disabilities is a growing international concern. For years, however, the linkage between human rights and mental health was overshadowed by the abuse of psychiatry for political purposes. While the abuse of political dissidents received extensive international press, the concerns of the vast majority of people in mental health systems around the world have received very little international attention. United Nations special rapporteurs on human rights have found that people with mental disabilities are excluded from society and segregated in closed institutions in many parts of the world, and these individuals are especially vulnerable to discrimination and abuse.<sup>9</sup>

<sup>&</sup>lt;sup>8</sup> In the 1970's and >80's, courageous dissidents and mental health professionals in the Soviet Union documented the political abuse of psychiatry in the Soviet Union. Together, professional associations of psychiatrists and human rights organizations in the Soviet Union and abroad publicized these abuses and put pressure on the Soviet government to release dissidents improperly detained in psychiatric institutions. See, e.g. US Delegation, National Institute of Mental Health (NIMH), Report of the U.S. Delegation to Assess Recent Changes in Soviet Psychiatry, 15 SCHIZOPHRENIA BULL. (1989).

United Nations, Economic and Social Council, Commission on Human Rights, Sub-Commission on prevention of Discrimination and Protection of Minorities, Human Rights and Disability, U.N. Doc. E/CN.4/Sub.2/1991/31 (prepared by Leandro Despouy); United Nations, Economic and Social Council, Commission on Human Rights Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Principles*, Guidelines, and Guarantees for the Protection of Persons Detained on Grounds of Mental Illness or Suffering from Mental Disorder, U.N. Doc. E/CN.4/Sub.2/1983/17 (prepared by Erica-Irene Daes).

The international recognition of the rights of people with mental disabilities was preceded by legal reform and enormous changes in practice at the domestic level in many countries. These domestic developments (described in section 1 below) helped establish the consensus for the development of international human rights law regarding people with mental disabilities through the United Nations and the European Human Rights System (described in sections 2 through 4).

### 1. Transformation of national laws, policies, and practices

Advances in the legal recognition of disability rights are one part of a larger, interconnected set of social, medical, economic and political developments leading to great improvements in the lives of people with mental disabilities. Today in the Americas, <sup>10</sup> Europe, <sup>11</sup> and other parts of the world, <sup>12</sup> many countries have adopted laws against discrimination on the basis of disability. These laws have been critical in permitting people to obtain employment, housing, and access to public services and accommodations that permit people with mental disabilities to live a full life in the community. <sup>13</sup>

A constellation of important legal rights and public benefits were developed in different countries as principles of individual autonomy and community integration for people with mental disabilities began to take hold in the 1950's, >60's and >70's. In the United States, early efforts focused on basic constitutional rights of people in institutions, who were recognized to be especially vulnerable to improper treatment or harm. A key to the enforcement of these rights has been the establishment of oversight and advocacy systems to monitor conditions within institutions and to ensure legal representation and advocacy for people with mental disabilities. Civil commitment laws were developed in the 1960's and >70's to protect against arbitrary or improper commitment to psychiatric hospitals and to promote policies that increasingly favored community treatment over institutionalization. Yet community integration would not have been possible without the creation

<sup>&</sup>lt;sup>10</sup> The most important anti-discrimination law in the United States is the Americans with Disabilities Act (ADA), 42 U.S.C. '12101 et seq. *See* THE AMERICANS WITH DISABILITIES ACT: FROM POLICY TO PRACTICE (Jane West, ed. 1991).

<sup>&</sup>lt;sup>11</sup> See World Health Organization, WHO Regional Publications No. 29, IS THE LAW FAIR TO THE DISABLED? A EUROPEAN SURVEY (Geneviève Pinet, ed. 1990).

 $<sup>^{12}</sup>$  Despouy Report, *supra* note 9 (reviewing anti-discrimination laws in domestic legislation around the world).

Despite recent progress, protection against discrimination is not uniformly guaranteed or enforced, and community integration is lacking in many countries. Thus, A[e] ven the most carefully drafted legislation will be ineffective if the political will is lacking to translate it into action. WHO (1990), *supra* note 11, at 9.

<sup>&</sup>lt;sup>14</sup> Michael Perlin, LAW AND MENTAL DISABILITY 169(1994). Legislation to protect rights institutions was developed in many Western European countries in the 1970's and early >80's. WHO (1990), *supra* note 11; World Health Organization, Public Health in Europe, *Mental health services in Europe: 10 years on* 75 (1985).

<sup>&</sup>lt;sup>15</sup> Clarence Sundram, *Patient Advocacy in the United States*, 23 INT=L. J. MENT. HEALTH 3 (1995). WHO (1985), *supra* note 14, at 76 (describing legal oversight programs in Norway and Sweden).

of service and support systems, including income supplements and disability benefits for people unable to work.<sup>17</sup> The development of independent advocacy organizations has also been important in many countries, including advocacy organizations made up of people with mental disabilities<sup>18</sup> and their families. 19

 $<sup>^{16}</sup>$  See John Q. La Fond and Mary L. Durham Back to the Asylum: The Future of Mental Health LAW AND POLICY IN THE UNITED STATES (1992) (reviewing changes in commitment laws in the United States and analyzing the link to systemic changes in mental health services).

<sup>&</sup>lt;sup>17</sup> *Id.*, at 88.

<sup>&</sup>lt;sup>18</sup> See Judi Chamberlin, ON OUR OWN (1980); Ed Van Hoorn, Changes? What Changes?, 38 The Views of the European Patients = Movement, INT=L J. SOCIAL PSYCHIATRY 30 (1992); Loren Mosher & Lorenzo Burti, COMMUNITY MENTAL HEALTH: A PRACTICAL GUIDE (1994); Helmut Spudich, How Self-Advocacy Came About in the ILSMH [International League of Societies for People with Mental Handicaps], in NEW VOICES: SELF-ADVOCACY BY PEOPLE WITH DISABILITIES (Gunnar Dybwad & Hank Brsani, Jr. eds., 1996).

<sup>&</sup>lt;sup>19</sup> La Fond and Durham, *supra* note 16, at 112. Rosemary F. Dybwad, PERSPECTIVES ON A PARENT MOVEMENT: THE REVOLT OF PARENTS OF CHILDREN WITH INTELLECTUAL LIMITATIONS (1990).

## 4 | Human Rights and Mental Health: Hungary

The public recognition that people with mental disabilities have the right to protection against discrimination and the right to integration into society has been accompanied by enormous changes in the structure of mental health systems. The development of psychotropic medications in the 1950's fueled the first wave of deinstitutionalization in the late 1950's and >60's in the United States. Since then, advances in psychosocial rehabilitation have permitted people with mental disabilities to live, work, and achieve a higher level of integration and success than was previously thought possible. Once left to languish without hope in psychiatric institutions or other asylums, large numbers of people with mental disabilities have proven that they can live full lives in the community.

WHO, supra note 14, at vii.

<sup>&</sup>lt;sup>20</sup> In a retrospective study of thirty countries from 1972 to 1982, the World Health Organization (WHO) characterized the changes in mental health services:

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 programmes, policies and legislation have been developed in many countries, and continue to be developed in others....Institutional psychiatry has given way to community psychiatry with, first, an emphasis on extramural facilities such as out-patient clinics, day hospitals, after-care hostels, mental health centers, units in general hospitals, emergency crisis intervention centres and their like.

<sup>&</sup>lt;sup>21</sup> Lafond and Durham, *supra* note 16, at 87. The Mental Retardation Facilities and Community Mental Health Center Construction Act of 1963 promoted a new national policy in the United States to provide community-based services. *Id.* at 90.

As a matter of policy, the World Health Organization has found Aa remarkable degree of common ground@ among countries in Europe regarding the importance of shifting away from a reliance on large psychiatric institutions and promoting community-based services that permit the maximum possible integration into the community.<sup>22</sup> The transformation of mental health services to meet the ideal of community integration has been slower than expected in Europe<sup>23</sup> and the United States.<sup>24</sup> In the United States, cutbacks in social programs in the 1980's also led many people to associate the growing problem of homelessness with the failures of community-based services.<sup>25</sup> Despite these set-backs, there is still widespread consensus about the goals of communityintegration, and there has been progress in the development of better community-based mental health services. Throughout the 1980's and into the 1990's, there has been a steady shift toward community-based services in the United States and Europe.<sup>26</sup>

#### Recognition through the United Nations human rights system 2.

The Universal Declaration of Human Rights (1948) and the international human rights conventions developed after the Second World War have long provided individuals with mental

<sup>&</sup>lt;sup>22</sup> WHO (1985), *supra* note 14, at 4.

The ten year study by the World Health Organization comparing rates of in-patient and out-patient care in Eastern and Western Europe between 1972 and 1982 found Aslow and limited progress@ toward communitybased care. WHO (1985), supra note 14, at 71. Overall, WHO found that A[t]he evidence from the present report is that there is, throughout Europe, a declining role for the larger psychiatric institutions, that patients with acute mental illnesses are increasingly being dealt with by the out-patient services and general hospitals and that community services are becoming a reality. @ Id. at viii. The most dramatic finding of the study was a 50% decline in large hospitals with over 1000 beds. Overall, the study found Asome evidence of a movement toward a >normative= provision of about 0.5 - 1 [in-patient beds] per 1000 [population].@

<sup>&</sup>lt;sup>24</sup> Lafond & Durham, *supra* note 16, at 100.

<sup>&</sup>lt;sup>25</sup> Problems with community-based mental health systems in the United States were greatly compounded in the 1980's by broad cutbacks in social programs for people with and without disabilities. Increased unemployment and a decline in low-cost housing combined to create a widespread problem of homelessness. In the 1980's, the problem of homelessness was widely associated with deinstitutionalization. Yet most analysts now agree that the problem of homelessness in the United States is primarily due to economic and political factors beyond the mental health system. The great majority of the people who are homeless need support in the community and would not be appropriate for placement in a psychiatric institution. Even the most severe critics of the way community programs had been implemented did not abandon the principle of community-integration. Lafond & Durham, supra note 16, at 104

<sup>&</sup>lt;sup>26</sup> Jim van Os and Jan Neeleman, *Caring for Mentally Ill People*, 309 British Med. J 1218 (1994). Even in countries where there are significant differences in psychiatric practices, such as France and the United Kingdom, there has been a similar move toward community-based treatment since the early 1970's. Jim van Os, Poloma Galdos, et. al. Schizophrenia sans frontiers: concepts of schizophrenia among French and British psychiatrists 307 BRITISH MED. J. 489, 491 (1993).

A recent survey of twelve Western European countries found a significant decrease in the number of beds in in-patient facilities. This survey also found that the average length of stay in a psychiatric facilities declined significantly. W. Rössler et. al. Stand und Entwicklung der Psychiatrischen Versorgung: Ein Europäischer Vergleich, 64 NERVENART 427, 428-9 (1994).

disabilities with the same general rights as other people. Yet it has taken years for the international community to recognize the specific application of these rights to people with mental disabilities. In 1971, the United Nations adopted the *Declaration on the Rights of Mentally Retarded Persons*, and in 1975 adopted the *Declaration on the Rights of Disabled Persons*. In 1982, the United Nations brought international attention to the concerns of people with disabilities by declaring the ADecade for Disabled Persons, leading to the AWorld Programme of Action on Behalf of Persons with Disabilities.

The Universal Declaration of Human Rights, for example protects against discrimination on the basis of sex, race, religion, or Aother status. It was years before the international community explicitly recognized that this provision protected people with disabilities. At the World Conference on Human Rights in Vienna, the international community reaffirmed the universality of human rights under existing international human rights conventions and declarations. At the same time, the Conference emphasized the need for increased attention to especially vulnerable populations, including people with disabilities. Art. 1, ' 22, in Center for the Study of the Global South, American University, *Evaluating the Vienna Declaration: Advancing the Human Rights Agenda* 98 (1993)(conference proceedings)(ASpecial attention needs to be paid to ensuring non-discrimination and the equal enjoyment of all human rights and fundamental freedoms by disabled persons, including their active participation in society. (9)

<sup>&</sup>lt;sup>28</sup> G.A. Res. 2856, U.N. GAOR, 26th Sess., Supp. No. 29, at 99, U.N. Doc. A/8429 (1971).

<sup>&</sup>lt;sup>29</sup> G.A. Res. 3447, U.N. GAOR, 30th Sess., Supp. No. 34, at 92, U.N. Doc. A/10,034 (1975).

One of the most important products of the United Nations Decade for Disabled Persons was the adoption of the *Principles for the Protection of Persons with Mental Illness and the Improvement* of Mental Health Care (the MI Principles). 30 Due to their increased detail, the MI Principles are an important development over the United Nations declarations of the early 1970's on rights of people with mental retardation and people with disabilities. They are a useful tool for international human rights documentation, because they provide a fair and consistent standard for the evaluation of human rights practices in mental health systems around the world.<sup>31</sup> The MI Principles can also serve as a guide for governments with regard to the legal and policy reforms that may be needed to bring a country=s mental health system into conformity with international human rights law.

After adopting the MI Principles, the United Nations General Assembly adopted one more important resolution to promote the rights of people with mental disabilities, the December 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities (hereinafter the Rules on Equalization). The Rules on Equalization call on states to initiate a national planning process for the implementation of human rights and "to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities."<sup>33</sup> The planning process must be inclusive, involving people with disabilities in policy decisions affecting them.<sup>34</sup>

<sup>&</sup>lt;sup>30</sup> G.A. Res. 119, U.N. GAOR, 46th Sess., Supp. No. 49, Annex, at 188-92, U.N. Doc. A/46/49 (1991).

Human rights declarations of the United Nations are frequently used by international human rights organizations as an objective standard to assess human rights conditions. Eric Rosenthal and Leonard S. Rubenstein, International Human Rights Advocacy under the APrinciples for the Protection of Persons with Mental Illness@ 18 INT=L J. L. & PSYCHIATRY 257, 270. This report relies primarily on the MI Principles to assess conditions in Hungary. The substantive requirements of the MI Principles are described further in section 4, infra.

<sup>&</sup>lt;sup>32</sup> G.A. Res. 96, U.N. GAOR, 48th Sess. (1993).

<sup>&</sup>lt;sup>33</sup> *Id.* rules 3, 4, 15.

<sup>&</sup>lt;sup>34</sup> *Id.* rule 14.2 (AStates should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social

8 🗆	Human Rights and Mental Health: Hungary
3.	Developments in the European Community
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As the United Nations has developed the rights of people with mental disabilities, a parallel set of changes has been taking place in the European Community. Over the past two decades, both European law and practice has shifted towards deinstitutionalization of mental health systems and an emphasis on the human rights of mental health consumers.<sup>35</sup> In 1977, the Council of Europe adopted recommendation 818 (1977) calling on States Ato take measures, as a long term policy, to reduce dependence on large institutions and to develop side-spread community based services, with conditions approximating to the normal environment of individuals....@ In addition, the Council of Europe called on states to review legislation governing the confinement of people with mental illness. <sup>37</sup> Building on that recommendation, the Council in 1983 enacted Recommendation R (83)2, a model civil commitment statute.<sup>38</sup> Similar to the *MI Principles*, Recommendation R (83)2 sets forth substantive criteria and due process protections for commitment that are to be used as a standard with which domestic laws should conform.

Since the late 1970's, the European Human Rights system has developed an important body of case law on the rights of people with mental disabilities under the European Convention of Human Rights.<sup>39</sup> In *Winterwerp v. Holland* the European Court of Human Rights found that the protection against arbitrary detention under article 3 of the European Convention requires independent review of any psychiatric commitment.<sup>40</sup> In a friendly settlement in A. v. United Kingdom, the Commission found that detailed guidelines to protect against improper seclusion in a psychiatric hospital satisfied the protection against inhuman treatment under article 3 of the convention. In *Herczegfalvy v. Austria* the European Court of Human Rights stated that Athe

<sup>35</sup> AEuropean law and practice has been converging in the area of mental health for some time,@ and while partly spontaneous, this development Ahas also been a deliberate one developed at the European regional level by the Council of Europe ....@ Gerard Quinn, Civil Commitment and the Right to Treatment under the European Convention on Human Rights, 5 HARV. HUMAN RIGHTS J. 1, 17 (1992).

<sup>&</sup>lt;sup>36</sup> The Situation of the Mentally Ill, Eur. Parl. Ass., 29th Sess., Rec. No.818 (Jul. 8, 1977), section 13, recommendation II(i). The Council of Europe cautioned states not to use such policies to undercut services for people with mental disabilities or to Adischarge from [the] hospital before an effective network of community care is established.@ Id.

<sup>&</sup>lt;sup>37</sup> *Id., section 13, recommendation I*(i).

<sup>&</sup>lt;sup>38</sup> Council of Europe=s Recommendation R (83) 2, Legal Protection of Persons Suffering from Mental Disorder Placed as Involuntary Patients, reprinted in COUNCIL OF EUROPE, COLLECTION OF RECOMMENDATIONS, RESOLUTIONS, AND DECLARATIONS OF THE COMMITTEE OF MINISTERS CONCERNING HUMAN RIGHTS 1949-87 at 100 (1989) [hereinafter Recommendation R (83) 2].

<sup>&</sup>lt;sup>39</sup> For a discussion of the development of case law relating to the rights of people with mental disabilities under the European Convention, see T.W. Harding, The Application of the European Convention of Human Rights to the Field of Psychiatry, 12 INT=L J. L. & PSYCHIATRY 245 (1989); Larry Goston, Human Rights, Judicial Review and the Mentally Disordered Offender, 1982 CRIM. L. REV. 779 (1982).

<sup>&</sup>lt;sup>40</sup> 33 Eur. Ct. H.R. (ser.A) at 7-12 (1979). See discussion in Rosenthal and Rubenstein, supra note 31, at 278.

<sup>&</sup>lt;sup>41</sup> App. No. 6840/74, 3 Eur. H.R.Rep. 131 (1980)(Eur. Comm=n H.R.). See discussion in Rosenthal and Rubenstein, *supra* note 31, at 276.

position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance@ in ensuring compliance with the convention. 42

<sup>&</sup>lt;sup>42</sup> Herczegfalvy v. Austria, judgement of the European Court of Human Rights, September 24, 1994, para. 82. See discussion in Manfred Nowak and Walter Suntiger, *The Right of Disabled Persons Not to be Subjected to Torture, in* Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments 117, 118 (Theresia Degener & Yolan Koster-Dreese, eds. 1995).

There are tremendous new opportunities for the oversight and enforcement of rights of people with mental disabilities under the European Convention for the Prevention of Torture (ECPT), which came into force in 1989. The ECPT established the European Committee for the Prevention of Torture (CPT) in 1994, an oversight body that monitors enforcement of the ECPT. The CPT has already begun to inspect conditions in psychiatric institutions, and it is likely to do so in a more systematic way in the future. 43 In 1994, the Council of Europe called for the establishment of an inspection system for psychiatric institutions similar to the one created by the ECPT. 44

Along with these legal developments, the EU has shown increasing concern for the human rights of people living in poor conditions in closed facilities within member States. The EU recently evaluated conditions in the mental health system of Greece and supported a project to integrate people with severe disabilities into the community.<sup>45</sup>

### 4. Requirements of the Principles for the Protection of Persons with Mental Illness

This report relies primarily on the MI Principles because they are the most detailed and comprehensive codification of rights of people with mental disabilities to date. The MI Principles recognize that certain practices will vary from country to country, and they protect the right of every person to Atreatment suited to his or her cultural background. <sup>46</sup> According to the United Nations

<sup>&</sup>lt;sup>43</sup> See discussion in Nowak & Suntinger, supra note 42, at 128. The CPT has indicated in a number of its reports that treatment practices and staffing in psychiatric institutions, particularly the use of seclusion and restraint, implicate rights found in the convention. *Id.* at 126-129.

<sup>&</sup>lt;sup>44</sup> Council of Europe, Recommendation 1235 (1994), *Psychiatry and Human Rights*, section 7(ii)(f).

<sup>&</sup>lt;sup>45</sup> See J. Tsantis et al., The Children of Leros PIKPA, BRIT. J. PSYCHIATRY 167 (supp. 28) 5 (1995)(forward by John H. Henderson)(discussing EC initiative to reform and deinstitutionalize Greek mental health system).

<sup>&</sup>lt;sup>46</sup> MI Principles, principle 7(3).

working group that developed the *MI Principles*, they are designed to Aadequately reflect and accommodate all legal and social systems and all stages of development without sacrificing the essential needs and basic rights of the individual human beings ultimately concerned. <sup>47</sup> At the same time, the working group made clear that the *MI Principles* Arepresent minimum United Nations standards for the protection of fundamental freedoms and human rights of persons with mental illness. <sup>48</sup>

<sup>&</sup>lt;sup>47</sup> United Nations, Economic and Social Council, Commission on Human Rights, *Human Rights and Scientific and Technological Reports: Report of the Working Group on the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care*, U.N. Doc. E/CN.4/1991/39 at 6.

<sup>&</sup>lt;sup>48</sup> *Id*.

The MI Principles provide protections against a broad array of abuses. The MI Principles prohibit discrimination on the basis of mental disability, <sup>49</sup> and they require that states ensure this and other rights under the MI Principles Athrough appropriate legislative, judicial, administrative, educational, and other measures....@50

The MI Principles provide protections against the most serious human rights abuses to which people are especially vulnerable in institutions, such as improper in-patient commitment, <sup>51</sup> harmful, including unjustified medication, 52 and improper use of seclusion or physical restraints. 53 They also

<sup>&</sup>lt;sup>49</sup> MI Principles, Principle 1(4).

<sup>&</sup>lt;sup>50</sup> *Id.*, Principle 23.

<sup>&</sup>lt;sup>51</sup> The *MI Principles* require that all persons committed involuntarily to an in-patient mental health facility have a diagnosis of mental illness and, "because of that mental illness" pose a "serious likelihood of immediate or imminent harm to that person or to other persons." Id. principle 16(1)(a). Commitment may also be justified when needed to prevent "serious deterioration" or to provide "appropriate treatment that can only be given by admission...." Id. principle 16(1)(b).

<sup>&</sup>lt;sup>52</sup> *Id.* principle 8. Treatment and care must be provided "based on an individually prescribed plan". *Id.* principle 9(2). Medication may be prescribed "only for therapeutic or diagnostic purposes and shall never be administered ... for the convenience of others." *Id.* principle 10(1).

provide the kind of detailed protections of rights that may take on enormous importance for people whose lives are subject to institutional control. Thus, in addition to providing a right to an Aenvironment and living conditions...as close as possible to those of normal life...,  $e^{54}$  they provide a right to privacy, a right to receive visitors, a right to freedom of communication, Aand freedom of access to postal and telephone services and to newspapers, radio and television.  $e^{55}$ 

The *MI Principles* protect individual autonomy, self-determination, and individual choice to the extent possible. The *MI Principles* provide that A[n]o treatment shall be given to a patient without his or her informed consent@ (except under special circumstances set forth in the *MI Principles*). <sup>56</sup> In addition, the Atreatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff.@ <sup>57</sup> Throughout mental health treatment, individuals have the Aright to be treated in the least restrictive environment...appropriate to the patient=s health needs and the need to protect the physical safety of others.@ <sup>58</sup>

<sup>&</sup>lt;sup>53</sup> *Id.* Principle 11(11).

<sup>&</sup>lt;sup>54</sup> *Id.* Principle 13(2).

<sup>&</sup>lt;sup>55</sup> *Id.* Principle 13(1)(c).

<sup>&</sup>lt;sup>56</sup> *Id.* Principle 11(1).

<sup>&</sup>lt;sup>57</sup> *Id.* Principle 9(2).

<sup>&</sup>lt;sup>58</sup> *Id.* Principle 9(1).

The MI Principles= protection for individual autonomy has far reaching implications for mental health policy. To avoid unnecessarily intrusive or restrictive services, positive efforts may be needed to provide community-based alternatives to in-patient hospitalization for individuals who are capable of living in the community. In addition to protecting against discrimination, supportive services may be necessary to realize such fundamental principles as the right of A[e]very patient ... to be treated and cared for, as far as possible, in the community in which he or she lives. @<sup>59</sup>

The MI Principles are a resolution of the United Nations General Assembly, and as such they establish the legal basis for international cooperation and scrutiny of the rights of people with mental disabilities. 60 As a matter of international law, the MI Principles establish that the treatment of people with mental disabilities raises fundamental human rights concern. Unlike an international human rights convention, <sup>61</sup> the *MI Principles* are non-binding. The *MI Principles* can, however, be used as a guide to the requirements of binding human rights conventions. <sup>62</sup> The MI Principles are extremely useful as a guide to the requirements of international covenants because covenants are written in broad language. The application of these broad conventional protections to people with mental disabilities requires reference to international consensus and interpretation. The International

MI Principle 9(1) states, "Every patient shall have the right to be treated in the least restrictive environment with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others." Additionally, Principle 3 protects the right of persons with mental illness "to live and work, as far as possible, in the community," and guarantees persons with mental illness treatment and care "in the community in which he or she lives." *Id*.

<sup>&</sup>lt;sup>60</sup> Rosenthal & Rubenstein, *supra* note 31, at 269.

<sup>&</sup>lt;sup>61</sup> International human rights treaties (or Aconventions@) are legal instruments to which countries bind themselves through ratification or accession. MARK W. JANIS, AN INTRODUCTION TO INTERNATIONAL LAW 9 (1988).

<sup>62</sup> Rosenthal & Rubenstein, *supra* note 31, at 270.

Covenant on Civil and Political Rights (ICCPR), for example, protects against discrimination, arbitrary detention, and inhuman treatment. Laws that arbitrarily deny a person=s rights protected under the *MI Principles* may constitute discrimination under international conventions. A broad failure to abide by the substantive standards and due process protections for people subject to commitment in a psychiatric facility, as set out in the *MI Principles*, may constitute arbitrary detention. Failure to provide the *MI Principles*= protections against improper physical restraints can cause the suffering necessary to constitute inhuman or degrading treatment under human rights conventions. Can be a convention of the conventions.

## **B.** Hungary's International Treaty Obligations

 $<sup>^{63}</sup>$  Id (describing the use of the MI Principles to interpret the requirements of the ICCPR with regard to arbitrary detention).

 $<sup>^{64}</sup>$  Id (describing the use of the MI Principles to interpret the requirements of the ICCPR with regard to inhuman and degrading treatment).

Hungary has ratified a number of international human rights treaties relevant to people with mental disabilities, including the *International Covenant on Civil and Political Rights* (ICCPR)<sup>65</sup> and the International Covenant on Economic, Social, and Cultural Rights (ICESCR)<sup>66</sup>. On November 6, 1990, Hungary became the first former East Bloc nation to join the Council of Europe, 67 and has ratified the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR),<sup>68</sup> the European Convention for the Protection Against Torture and Inhuman or Degrading Treatment or Punishment (ECPT), 69 and the European Social Charter (ESC). 70 the European counterpart to the ICESCR. Article 7 of Hungary=s Constitution recognizes the country=s obligations to conform to the requirements of these treaties as well as other aspects of international law.<sup>71</sup>

<sup>&</sup>lt;sup>65</sup> G.A. Res. 2200, 21 U.N. GAOR, Supp. (No. 16) 52, U.N. Doc. A/6316 (1966), ratified by Hungary Jan. 17, 1974, 999 U.N.T.S. 172, 296 (1974).

<sup>&</sup>lt;sup>66</sup> G.A. Res. 2200, 21 U.N. GAOR, Supp. (No. 16) 49, U.N. Doc. A/6316 (1966), ratified by Hungary Dec. 12, 1966, 993 U.N.T.S. 3 (1966).

<sup>&</sup>lt;sup>67</sup> 40 YEARS OF HUMAN RIGHTS PROTECTION BY THE COUNCIL OF EUROPE 13-5 (1994).

<sup>&</sup>lt;sup>68</sup> Enacted Sept. 3, 1953, 213 U.N.T.S. 222 (1955), ratified by Hungary May 11, 1992. Mark Janis. Richard Kay, & Anthony Bradley, EUROPEAN HUMAN RIGHTS LAW 29 (1995).

<sup>&</sup>lt;sup>69</sup> Enacted Feb. 1, 1989, 27 I.L.M. 1152 (1988), ratified by Hungary Mar. 1, 1994, 34 I.L.M. 349 (1995).

<sup>&</sup>lt;sup>70</sup> 529 U.N.T.S. 89 (1961), signed by Hungary Dec. 13, 1991, *Human Rights Information Sheet No. 29* at 4 (1992).

<sup>&</sup>lt;sup>71</sup> CONSTITUTION Art. 7(1)(Hung. 1949), as amended Oct. 18, 1989, translated in Gilbert H. Flanz, Ed., CONSTITUTIONS OF THE WORLD (1995)(hereinafter HUNG. CONST.). Cf. Vienna Declaration and Program of Action,

С.	Political and Economic Context
<i>supra</i> no	ote 27, at Art. 1, ' 26 (urging states to ratify all international human rights instruments without reservations).

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The Republic of Hungary is a nation of 10.4 million people located in the heart of Central Europe. Hungary=s transition from Communist one-party rule to parliamentary democracy is often described as one of the smoothest in the former East Bloc countries.<sup>72</sup> The constitution of 1949 was significantly revised in 1989, paving the way for free multiparty elections in 1990. The opposition, Hungarian Democratic Forum (MDF) won the 1990 election with 43% of the vote for Parliament. In the 1994 election, the formerly Communist MSZP won 54% of the seats in Parliament, <sup>73</sup> and Gyüla Horn became Prime Minister of the new government.

<sup>&</sup>lt;sup>72</sup> See Eric Stein, International Law in Internal Law: Toward Internationalization of Central-Eastern European Constitutions? 88 AM. J. INT=L L. 427, 429 (1994)(AHungary ... [was] in the forefront of the former Communist states seeking to establish a democratic pluralist and free market order and to >rejoin= Western Europe as quickly as possible.@)

<sup>&</sup>lt;sup>73</sup> BUREAU OF PUBLIC AFFAIRS, U.S. DEP=T OF STATE, BACKGROUND NOTES: HUNGARY 1 (1994). The MSZP formed a coalition with the Alliance for Free Democrats (ADF). Together, the coalition commands 74 percent of the seats in Parliament. Id.

Hungary is a member of the Council of Europe<sup>74</sup> and ratified the ECHR in 1992.<sup>75</sup> Upon ratifying the Convention, Hungary signed two optional protocols, submitting itself to individual complaints before the European Commission of Human Rights and to the jurisdiction of the European Court of Human Rights.<sup>76</sup> Since becoming a member of the Council of Europe, Hungary has recognized its obligation to conform its domestic laws to the requirements of the ECHR and European human rights law.<sup>77</sup>

<sup>&</sup>lt;sup>74</sup> The Council of Europe is the organization of European countries established after World War II to protect human rights and fundamental freedoms among its member states. Among the requirements for membership are that a State be European and Arecognize the rule of law and respect for fundamental freedoms. Mark Janis, Richard Kay & Anthony Bradley, European Human Rights Law 97 (1995). *See* A.H. Robertson, The Council of Europe: Its Structure, Functions and Achievements 18 (1956).

<sup>&</sup>lt;sup>75</sup> See supra note 68.

The Convention established the European Commission to which individuals could petition and the European Court to which both the Commission and member States could refer cases. EUROPEAN HUMAN RIGHTS LAW, *supra* note 74, at 23. However, the Convention made optional member States= recognition of both the individual right of petition to the Commission and the jurisdiction of the Court. The optional protocols are Articles 25 and 46 of the Convention, respectively. Hungary is not alone in ratifying these protocols; in fact, as of March 1995 every member of the Council of Europe had adopted the two optional protocols. EUROPEAN HUMAN RIGHTS LAW, *supra* note 74, at 27 & n. 94.

<sup>&</sup>lt;sup>77</sup> In a 1995 interview, a Council of Europe official noted that while Hungary joined the Council of Europe in November 1990, it Aneeded almost two years to ratify the Convention ... Hungary set up an inter-departmental

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commission within the Ministry of Justice that scrutinized Hungarian law and practice in relation to the requirements of the European Convention and case-law of the Commission and the Court. Upon parliamentary approval of the commission=s work, A[i]t is only then that the Convention was ratified ... Francoise Roth & Claudia Martin, Drzemczewski Discusses the System in Motion, HUMAN RIGHTS BRIEF 7 (Winter 1995)(interview with Andrew Drzemczewski, Secretary of the Committee of Experts for the Improvement of Procedures for the Protection of Human Rights of the Council of Europe).

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On March 31, 1994, Hungary applied for membership to the European Union. Although primarily an economic union, the EU has regarded respect for international human rights law as a requirement for membership. Article F2 of the 1992 Treaty of Maastricht, which created the EU, requires that the EU respect fundamental rights as guaranteed by both the European Convention of Human Rights and the constitutional traditions of member states. Furthermore, the European Court of Justice has held that it will use international human rights instruments that EU member states have signed when deciding the human rights requirements of the EU.

[I]t is well settled that fundamental rights form an integral part of the general principles of law whose observance the Court ensures. For that purpose, the Court draws inspiration from the constitutional traditions common to the Member States and from the guidelines supplied by international treaties for the protection of human rights on which the Member States have collaborated or of which they are signatories ... Respect for human rights is therefore a condition of

<sup>&</sup>lt;sup>78</sup> TREATY ON EUROPEAN UNION/TREATY ESTABLISHING THE EUROPEAN COMMUNITY 25 Art F(2)(1993)(AThe Union shall respect fundamental rights, as guaranteed by the European Convention for the Protection of Human Rights and Fundamental Freedoms ... and as they result from the constitutional traditions common to the Member States, as general principles of Community Law@).

<sup>&</sup>lt;sup>79</sup> The court wrote:

Hungary=s transition to a market economy has been more difficult than its political changes. A privatization effort, begun under the former regime and continued under both post-communist governments, has led to the sale of most state industries, the reduction of economic subsidies, and the deregulation of prices.<sup>80</sup> Despite a large infusion of foreign investment, Hungary=s gross national product declined in the first two years after the fall of communism.<sup>81</sup> In 1995, the government estimated that the unemployment rate rose from 10.9 percent to between 12.5 and 12.9 percent: 82 the rate in some parts of the country is much higher. 83

the lawfulness of Community acts.

1996 E.C.J. 2/94 at 23. See e.g. Europe and the Challenge for Enlargement, Bulletin of the European Communities Supp. 3/92, at 11 (1992)(includes respect for human rights as a criteria for EU membership). The EU has even evaluated the human rights conditions in the mental health systems of recent member states. See Tsantis, supra note 45, at 5.

- <sup>80</sup> BUREAU OF PUBLIC AFFAIRS, U.S. DEP=T OF STATE, BACKGROUND NOTES: HUNGARY 15 (1994).
- 81 *Id.* at 1 (annual growth rate declined 2.3%).
- <sup>82</sup> Government of the Republic of Hungary, *Mid-Term Economic Strategy of the Hungarian Government* (1995).
- <sup>83</sup> Unemployment ranges from 5% in Budapest and the western counties to nearly 20% in the northeastern part of the country. HUNGARY: INVESTMENT CLIMATE STATEMENT (Mar. 21, 1995).

In March 1995, the Socialist-Liberal coalition government in March 1995 announced an austerity program designed to cut Hungary=s \$28 billion foreign debt. The program proposed a \$1.4 billion reduction in public spending and a 28% devaluation of the forint to boost imports. By 1995, inflation and austerity measures combined led to a decline in real wages of over ten percent. These forces also led to a precipitous decline in the real income for individuals reliant on fixed incomes, including old age pensions, unemployment pay and disability benefits. 86

The transition to a market economy has necessitated enormous changes in social welfare policies in Hungary. One commentator described this as a Atask of creating a *sui generis* social policy hitherto unknown under state socialism. Social policies under the communist government had not been linked with governmental revenues, and the system of financing social expenditures was left in disarray. The government=s March 1995 austerity program included a commitment to make major changes in social policies. Many of these proposals, including proposals to establish a new system for financing mental health care and disability benefits, are currently under consideration.

### **D.** Structure of Mental Health Services

Hungary is divided into nineteen counties or districts, each of which administers its own health care programs, including mental health programs. The National Institute of Psychiatry and

Opposition parties charged that the austerity measures would push most Hungarians into poverty. *Hungary: Radical at Last.* THE ECONOMIST, Apr. 1, 1995, at 45.

<sup>&</sup>lt;sup>85</sup> Hungary Personal Income Fell 10.5% in 1995, REUTERS, Feb. 6, 1996; Real Wages Down 10.6PC in 1995, MTI-ECONEWS, Feb. 6, 1995; Hungary Parliament Approves Tough 1996 Budget, REUTERS, Dec. 21, 1995.

<sup>&</sup>lt;sup>86</sup> Péter Gedeon, *Hungary: Social Policy in Transition*, 9 EAST EUROPEAN POLITICS AND SOCIETIES 433, 445-449 (1995).

<sup>&</sup>lt;sup>87</sup> *Id.* at 433.

<sup>&</sup>lt;sup>88</sup> *Id.* at 447.

Neurology (OPNI in Hungarian, the Országos Pszichiátriai ès Neurológiai Intézet), under the authority of the Ministry of Health and Social Welfare, is responsible for national mental health planning and regulation of local mental health programs.

In most cities in Hungary, in-patient services are provided at a psychiatric institution or in the psychiatric ward of a general hospital. There are approximately 10,000 in-patient beds in Hungary.<sup>89</sup> The OPNI also operates the largest psychiatric institution in Hungary, also referred to as OPNI (or informally as ALipót@). Opened in 1868, OPNI is the second largest building in Budapest after the national parliament. It currently has approximately 1,000 beds, down from 1,600 in the mid-1980's. 90 In the cities, each psychiatric ward serves people who live in its particular geographic Acatchment area. @ Voluntary patients who do not wish to go to a particular psychiatric ward in their area can choose to go to OPNI. 91 More than half of all in-patient psychiatric beds are located in Budapest though the city accounts for approximately one-quarter of the 10.5 million people in the country. Thus, some people from underserved areas travel to Budapest to receive in-patient psychiatric care.

According to authorities at OPNI, approximately 70,000 people receive some form of outpatient services at OPNI annually. Out-patient services consist almost entirely of psychotropic medications, though a limited number of people receive psychotherapy. There are almost no supported living or employment programs to help people with mental disabilities to live and work in the community. Out-patient clinics in Budapest are administered through psychiatric institutions or hospitals in their catchment area. Despite this administrative link, there is little coordination of inpatient and out-patient services. Case management systems do not exist, and there are no programs to assure that an individual receives a continuity of care once he or she leaves a psychiatric institution.<sup>92</sup>

Ironically, people thought to have the most severe disabilities are placed in institutions not officially recognized as part of Hungary=s mental health system. These institutions, called

<sup>&</sup>lt;sup>89</sup> In March 1995, the Director of the National Psychiatric Institute reported that there were 12,000 inpatient beds. Since then, there have been budget cuts and the number of in-patient beds has declined. See Judit Sandor, Judicial Monitoring of Psychiatric Confinement and Therapy, 4 E. Eur. Const. L.Rev. 83, 86 (1995)(discussing trends in the rate of institutionalization in Hungary since 1960).

<sup>&</sup>lt;sup>90</sup> MDRI investigators received varied reports from staff about the current number of beds, ranging from 1,300 to 800. In March 1995, the Director of the National Psychiatric Institute reported that there were 900 beds, but he said that his goal was to bring the total down to 800 beds.

<sup>&</sup>lt;sup>91</sup> Human rights conditions in these facilities are described *infra* Chapter III sections D. E & F.

<sup>&</sup>lt;sup>92</sup> The structure of Hungary=s mental health system, and the lack of community-based services, is described infra Chapter III section A.

As described further in Chapter II, some of the people in the social care homes actually have little or no mental disability. This is the product of the lack of legal procedures in the commitment process and the failure to control quality of care in the institutions.

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Asocial care homes,@ are located in remote areas, often on Hungary=s borders. <sup>94</sup> The structure and administration of the social care homes reflects the view that its residents are beyond rehabilitation. Once a person is placed in a social care home, he or she is considered hopeless. Thus, the state provides no rehabilitation and outplacement programs at social care homes. As a result, the vast majority of residents remain there for life. According to government authorities, social care homes designated for people with mental illness currently house at least 7,000 people. <sup>95</sup>

The Director of the National Psychiatric Institute explained that social care homes are not part of the mental health system because the skills of mental health professionals are not needed for this population. The National Institute of Psychiatry has no authority to regulate practices in social care homes, which are administered and funded by the local governments from which the people originate. The living conditions and custodial nature of the social care homes are described in part IV of this report.

<sup>&</sup>lt;sup>95</sup> This report examines only social care homes designated for adults with mental illness. A separate system of social care homes also exists for children with mental disabilities. Another system of institutions also exists for elders and people with other disabilities. Institutions for people with mental retardation are reported to house 14,000 children and adults. The human rights implications of this segregated system, and the living conditions within social care homes, are described *infra* Chapter II.

Although the great majority of mental health services remain available only in state-run institutions, the national health care system is in the process of being privatized. As a result, private mental health services are now being established on a small scale. <sup>96</sup> Most private care is provided on the side by individual practitioners who have a full time job at a state-run institution or clinic. 97

<sup>&</sup>lt;sup>96</sup> Some private practitioners did provide services under the former communist government.

 $<sup>^{97}</sup>$  The privatization of the health care and insurance system is described *infra* Chapter V.

## **II.** Social Care Homes

MDRI teams visited two social care homes, Fövárosi Szociális Otthon Szentgotthárd and Elmeszociális Otthon Ludányhalászi. Szentgotthárd is located on the Austrian border and houses 720 people from Budapest. The other, Ludányhalászi, is located near the Slovakian border, housing 400 to 500 people from the north western part of the country. Szentgotthárd is administered by the district authorities in Budapest from which its residents originate, and Ludányhalászi is administered by the local government of Balassagyarmat. The two institutions visited by MDRI represent approximately 1,100 of the 7,000 people in social care homes in Hungary.

As described below, MDRI finds that the system of social care homes violates many fundamental rights of the people who live within them, including the right to be free of arbitrary detention<sup>99</sup> and the right Ato be treated in the least restrictive environment...appropriate to the patient=s needs. <sup>100</sup> Within institutions, conditions are often Ainhuman and degrading. <sup>101</sup> Certain treatment practices, such as the detention of people in cages with minimal supervision, create great suffering and life-threatening dangers. <sup>102</sup>

## A. Arbitrary and Improper Detention

<sup>&</sup>lt;sup>98</sup> Together, Szentgotthárd and Ludányhalászi serve over one-thousand people. Thus, the institutions visited by MDRI account for slightly more than one-seventh of Hungary=s social care home population.

<sup>&</sup>lt;sup>99</sup> Article 13 of the ICCPR and article 5 of the ECHR protect against arbitrary detention.

<sup>100</sup> MI Principles, principle 9.

<sup>&</sup>lt;sup>101</sup> Article 7 of the ICCPR protects against Acruel, inhuman or degrading treatment or punishment.@ Article 13 of the ECHR provides similar protections.

<sup>&</sup>lt;sup>102</sup> In addition constituting inhuman and degrading treatment, *supra* note 16, such practices may be life threatening, in violation of ICCPR article 6 and ECHR article 2.

### Lack of due process or judicial review of commitment to social care homes 1.

The Hungarian law that governs civil commitment to a psychiatric institution does not apply to social care homes. 103 Commitment to a social care home is, instead, governed by the Social Care Act. 104 The procedures and standard for commitment under the Social Care Act do not provide the basic protections against arbitrary commitment required by international human rights law.

Under the MI Principles, standards adopted by the Council of Europe, and international human rights treaties, every psychiatric commitment must be approved by a judicial or other independent authority after a fair hearing. 105 Under the Social Care Act, no judicial process or independent review is required. Under the law, the decision is delegated to a legal guardian, and is thus considered Avoluntary <sup>106</sup> on the part of the person who is committed. As described by social care home administrators, commitment to a social care home is initiated by a family member or a legal guardian who brings a person to the attention of the social care home. In practice, social care home authorities report, the decision to approve placement is usually left to the discretion of social care home administrators.

The only time a person placed in a social care home may come before a court is during the procedure for appointing a legal guardian. Social care home authorities report that, until recently, everyone in a social care home was required to be under legal guardianship. 108 As described in

 $<sup>^{103}</sup>$  The commitment law of Hungary and the minimum requirements for commitment under international human rights law are described in detail in Chapter IV. Even if social care homes are not officially classified as mental health facilities, international human rights law requires protections against arbitrary detention. Detention in a social care home entails the same, or greater, deprivation of an individual=s personal autonomy as does commitment to a more conventional psychiatric institution. The commitment standards under the MI Principles apply to all Amental health facilities.@ Principles 15-17. A Amental health facility@ is defined as Aany establishment, or any unit of an establishment, which as its primary function provides mental health care. @ Id. Under the ICCPR, A[n]o one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law. @ ICCPR, supra note 65, article 9(1). In addition, [a]nyone who is deprived of his liberty by ... detention shall be entitled to take proceedings before a court....@ Id., article 9(4). The United Nations Human Rights Committee has specified in its General Comment=s on the ICCPR that article 9(1) Ais applicable to all deprivations of liberty, whether in criminal cases or other cases such as, for example, mental illness, vagrancy, drug addiction, educational purposes. immigration control, etc.@ General Comment 8(1), cited in UN MANUAL ON REPORTING, supra note 299, at 95.

<sup>104</sup> Act III of 1993 on Social Care.

<sup>&</sup>lt;sup>105</sup> See discussion of international standards in text accompanying and following note 227, infra.

<sup>&</sup>lt;sup>106</sup> *Id.* arts. 93-94.

<sup>&</sup>lt;sup>107</sup> Under the Social Care Act, a Guardianship Authority settles any dispute between a Guardian and Ward regarding placement in the social care home. The law provides no standard or procedures for settling this dispute. however, so the decision is left to the complete discretion of this administrative body. As described in Chapter IV, the Guardianship Authority does not meet the requirements of a Ajudicial or other independent authority, @ as required by international law.

According to social care home authorities, this is no longer required. At Szentgotthárd, authorities stated that there are a few people placed in the social care home at each institution who are not under guardianship.

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Chapter IV, however, the guardianship process may take place years before a social care home placement. The process of judicial review for the purpose of establishing a legal guardian looks narrowly at the question of whether a person can Amanage his or her affairs@ and may never examine whether institutional placement is appropriate. Once a person is placed under guardianship, there is no requirement that this legal status be reviewed over the course of a lifetime. The Social Care Act does not require the guardian to have a court approval in order to place his or her ward in the social care home.

At Ludányhalászi, everyone is reported to be under guardianship except a few people who are alcoholics and have no psychiatric disability.

<sup>&</sup>lt;sup>109</sup> See discussion in Chapter IV, Section B-2.

While most placements in a social care home have no legal time limit, there is a provision in the Social Care Act for some people to be committed for a Adefinite@ period of time. According to the Gönczöl Report, the expiration date of such a commitment is routinely ignored. <sup>110</sup> The finding of the Gönczöl Report is consistent with that of the MDRI investigators, who were consistently informed by social care home staff and authorities that people remain in the institution until they die.

### 2. Improper commitment standard

The standard for commitment set forth by the Social Care Act violates international law. Under the MI Principles, a person may be involuntarily committed if he or she is mentally ill and Athere is serious likelihood of immediate or imminent harm to that person or to other persons. @ 111 If a person is mentally ill but not dangerous, he or she may be involuntarily committed only if Afailure to admit or retain that person is likely to lead to serious deterioration in his or her condition or will prevent the giving of appropriate treatment that can only be given by admission to a mental health facility in accordance with the principle of the least restrictive environment. @ 112 Under the latter principle, A[e]very patient shall have the right to be treated in the least restrictive environment ... appropriate to the patient=s health needs and the need to protect the physical safety of others. @ 113

Under the Social Care Act, placement in a social care home is limited to those individuals who are mentally ill but *not* dangerous and Acannot be rehabilitated, cannot live independently, and

<sup>&</sup>lt;sup>110</sup> Katalin Gönczöl, A BETEGEK EMBERI ÉS ÁLLAMPOLGÁRI JOGAINAK ÉRVÉNYESÜLÉSE A PSZICHIÁTRIAI FEKVÖBETEG-INTÉZETEKBEN ÉS PSZICHIÁTRIAI OTTHONOKBAN 83 (1996) (hereinafter the Gönczöl Report).

<sup>111</sup> MI Principles, principle 16(a).

<sup>&</sup>lt;sup>112</sup> *Id.*, principle 16(b).

<sup>&</sup>lt;sup>113</sup> *Id.*, principle 9(1).

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require constant institutional care.  $0^{114}$  Thus, according to the Social Care Act, people in social care homes Ado not require considerable treatment.  $0^{115}$ 

Social Care Act, art. 71.

<sup>&</sup>lt;sup>115</sup> *Id*.

The terms of the Social Care Act violate the MI Principles, which permit the detention of non-dangerous individuals solely for the purpose of receiving treatment they cannot receive outside an institution. Under the MI Principles, everyone has a right to health and social care Aappropriate to his or her health needs@116 and Athe treatment of every patient shall be directed towards preserving and enhancing personal autonomy. @ 117 The Social Care Act precludes any effort at such rehabilitation because no one is permitted to be in the social care home if they could benefit from such treatment.

The Social Care Act=s standard for commitment is self-fulfilling, precluding any meaningful or realistic effort to provide rehabilitation or a return to the community. Authorities at both social care homes explained that individuals placed in social care homes are considered Abeyond rehabilitation.@ According to the Director of the National Psychiatric Institute, people are transferred to social care homes from psychiatric hospitals if they would not benefit from further psychiatric treatment within psychiatric institutions. Thus, as the Director of Szentgotthárd said, the social care home is for custodial Acare, not treatment.@

### 3. Wrongful detention of social care home population

Despite their official designation as a place for people who have no hope for rehabilitation or reintegration into the community, authorities at both social care homes observed that some of the social care home residents would be capable of living in the community. The director at Szentgotthárd estimated that at least ten percent of the social care home population could live in the community if families were interested in taking them in. The chief psychiatrist who consults at Ludányhalászi estimated that one third to one half of the population would be capable of living in the community with a family.

The actual number of people who are improperly detained is probably much higher than the informal estimates of social care home authorities would indicate. Without a process for periodic review of commitments, people placed in a social care home at a time of crisis are likely to remain in the institution for life. Even if a person=s mental illness goes into full remission, there is no procedure for a review of commitment. Evidence from around the world suggests that a majority of people diagnosed with a major mental disorder will experience significant improvements in their condition over time. 118

<sup>&</sup>lt;sup>116</sup> *Id.*, principle 8(1).

<sup>&</sup>lt;sup>117</sup> *Id.*, principle 9(4).

<sup>118</sup> Courtenay M. Harding, The Interaction of Biopsychosocial Factors, Time, and Course of

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4.	Promoting continued dependence and increased disability

Despite improvements in their underlying condition, people who remain in institutions for a long period of time gradually develop a dependency on the institution. 119 According to authorities at both Szentgotthárd and Ludányalászi, the majority of residents have what they call an Ainstitutionalized mentality. @ The director at Szentgotthárd said that, in many cases, Ait has been so many years, we have forgotten the original events that brought a person to the home. But now, they have lived in the institution so long that they do not know what life is like@ in the community. 120

Some of the deficits described by the director of Szentgotthárd are referred to as Aiatrogenic@ disabilities - disabilities caused by the treatment or context of treatment. <sup>121</sup> In Hungary, the problem of people with iatrogenic disabilities is compounded by the existence of a network of facilities that segregate people with mental disabilities from society starting at a very young age. Children placed in institutions are at a particularly high risk of developmental delays and iatrogenic disabilities. 122

MDRI investigators interviewed a number of residents at Szentgotthárd and Ludányhalászi with strikingly similar stories. These men and women were placed in institutions as children and lived their entire lives in one institution or another. At age eighteen, they were transferred from the childrens= home to the social care home. 123

 $<sup>^{119}</sup>$  People who spend many years in an institution for a very long period of time almost inevitably lose the psychological and social skills required of living in the community. WHO REVIEW OF EFFECTIVENESS, supra note 22, at 19. The classic explanation of the Ainstitutionalized mentality@ is portrayed in ERVING GOFFMAN, ASYLUMS: ESSAYS ON THE SOCIAL SITUATION OF MENTAL PATIENTS AND OTHER INMATES (1961). The iatrogenic effects of long-term institutionalization have since been well documented in the United States and abroad. See, e.g. J. Tsantis et al., The Leros PIKPA Asylum, Deinstitutionalization and Rehabilitation Project, 167 BRIT. J. PSYCHIATRY (supp. 28) 10,11 (1995).

As described infra Chapter II section A, the lack of rehabilitation or programs to maintain such skills reinforce this decline in level of functioning. People in the social care home are not provided the opportunity or responsibility to care for themselves or work, and such basic skills as cooking, cleaning, or showing up for a job are allowed to deteriorate.

 $<sup>^{120}</sup>$  Authorities at Ludányhalászi also agreed that a large portion of the population require care in the institution because they are unable to care for themselves in the community. Many of these people are elderly and have lived in the institution for ten, twenty, or thirty years. These people may once have had the social and personal skills to live in the community, but they have lost these skills over time. Other people have lived in the institution their entire life and know no other way of living.

WHO REVIEW OF EFFECTIVENESS, *supra* note 131, at 19.

<sup>&</sup>lt;sup>122</sup> Id.

<sup>&</sup>lt;sup>123</sup> The social care homes investigated by MDRI are reportedly only for adults over age eighteen. Some people are placed there at a younger age, however. At Szentgotthárd, MDRI investigators interviewed a girl who staff reported to be seventeen years old. She said she had been living at home and had been placed in the social care home after she had attempted suicide.

The stories of people who said they had been placed in social care homes at a young age are consistent with information MDRI received from family advocacy groups. In the absence of community-based services, families reported that they were often unable to support a mentally disabled child at home. Thus, families have been forced to place their son or daughter in an institution at a young age. Family members of people with mental disabilities reported to MDRI investigators that doctors would advise them to give up a child before the child Agrew too



Despite the severity of the mental disabilities that can result from long-term institutionalization, there is ample evidence to suggest that people with such disabilities, with appropriate training and support, can leave the institution and live safely in the community - with a vast improvement in quality of life. 124

### Detention of people with mental retardation or other disabilities 5.

In addition to people with iatrogenic disabilities, a large number of people are inappropriately placed in the social care homes for other non-psychiatric disabilities, such as mental retardation. 125 At Ludányhalászi, there is one ward for sixty-eight people with mental retardation. 126 According to staff on the ward, most of the people on the ward have mental retardation and no psychiatric diagnosis. It is now widely accepted that the great majority of people with mental

<sup>&</sup>lt;sup>124</sup> See, e.g. Tsantis, supra note 119, at 10. Courtenay M. Harding, supra note 118, at 667.

<sup>125</sup> Some social care homes designated for people with mental illness are reportedly careful not to include people with mental retardation. As a policy, many social care homes only accept people with mental retardation if they also have a psychiatric diagnosis. Without a system of quality assurance or review, however, people with mental retardation can easily be misdiagnosed with a mental illness and do not have the capacity to challenge their treatment or placement.

<sup>126</sup> Staff reported that the institution is also used for people with physical disabilities. MDRI investigators observed three people on the ward in wheelchairs. MDRI investigators were not able to determine whether these individuals had any mental disability.

retardation do not require institutionalization and can live and work in the community. The United Nations *Declaration on the Rights of Mental Retarded Persons* states that individuals with mental retardation have a right to Aeducation, training, rehabilitation, and guidance@ and Ashould live with his own family or with foster parents and participate in different forms of community life. In addition, the Council of Europe recommends that a Adistinction...be made between handicapped and mentally ill patients. <sup>129</sup>

Studies have shown that practically all such individuals could be placed in the community. A recent study in the U.S. state of Minnesota found that with appropriate community supports such as behavior management plans and follow-up consultation, even persons with mental retardation who displayed aggressive or severely destructive behavior could live successfully in the community. Josefina S. Colona & Norman A. Wiesler, *Preventing Restrictive Placements through Community Services*, AMER. J. MENTAL RETARDATION 100(2), 201 (1995). In Greece, a 1993 EU-funded pilot project successfully moved eleven residents of an extremely isolated institution into a community-integrated group home in Athens. Tsantis, *supra* note 119, at 31.

<sup>&</sup>lt;sup>128</sup> G.A. Res. 2856 (XXVI)(Dec. 20, 1971).

<sup>129</sup> Council of Europe, *Psychiatry and Human Rights*, Recommendation 1235 (1994), section 7 (ii)(a).

Placement in a social care home can be particularly dangerous for people with mental retardation because they lack the professional staff to serve such individuals. Neither institution visited by MDRI has education or behavior programs geared to the needs of people with mental retardation - either for reintegration into the community or to provide them with the basic living skills they need for day-to-day survival. As a result, as described below, many of the people with mental retardation are permitted to languish in the worst conditions in the institution. 130

At Szentgotthárd and Ludányhalászi a large group of people are reportedly placed in the institution because of a history of alcoholism and alcohol-related dementias. Research demonstrates that people with alcoholism will be better served in the community than in long-term psychiatric institutions. 131 People with alcohol related dementias can also be served in the community. 132

### В. **Degrading and Dangerous Conditions**

<sup>130</sup> See infra section B.

Long-term psychiatric institutionalization is not an accepted treatment for people with a history of alcoholism. The World Health Organization=s REVIEW OF EFFECTIVENESS cites studies showing that Ahospital services are of little value to the patient and are probably not cost-effective; virtually all treatment modalities are possible in an out-patient or day care setting...@ Lorenzo Burti and Vasily Yastrebov, AProcedures Used in Rehabilitation,@ in World Health Organization, TREATMENT OF MENTAL DISORDERS: A REVIEW OF EFFECTIVENESS 289, 298 (Norman Sartorius, Giovanni de Girolamo, Gavin Andrews, and G. Allen German, eds. 1993) (herein after the REVIEW OF EFFECTIVENESS).

<sup>132</sup> JOHN TALBOTT, ROBERT HALES & STUART C. YUDOFSKY, THE AMERICAN PSYCHIATRIC PRESS TEXTBOOK OF PSYCHIATRY 1124 (1988).

International law requires that A[a]ll persons with a mental illness, or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of the human person. a Council of Europe recommendation also stipulates that A[i]n all circumstances the patient=s dignity should be respected.... To fulfill this tenet, the *MI Principles* specify that individuals placed in psychiatric facilities, or similar institutions, have a right to Aenvironment and living conditions ... as close as possible to those of normal life of persons of similar age.... This includes a right to privacy, communication, and an environment in which treatment and enhancement of personal autonomy is possible. Conditions must protect individuals against harm or unjustified Amental distress or physical discomfort.

Physical conditions at social care homes vary widely, where new and old buildings and wards exist side-by-side. Szentgotthárd is located in a converted tobacco factory originally built in 1890, with extensive additions built between 1982 and 1992. Some social care homes are located within beautiful, rural settings in converted castles or mansions in the countryside. Despite this, the physical conditions observed by the MDRI teams are generally isolating, often barren, and almost universally lacking in privacy. In some areas, a great deal of attention is placed on providing a clean and orderly environment. In other areas, MDRI teams observed living areas that are unhygienic and dangerous.

The physical isolation from society is the most significant and all-pervasive factor affecting the quality of life in social care homes. The total segregation from society, combined with the lack

<sup>133</sup> MI Principles principle 1(2).

<sup>134</sup> Council of Europe, Recommendation (83)2, article 10.

<sup>&</sup>lt;sup>135</sup> *Id.* principle 13(2).

<sup>&</sup>lt;sup>136</sup> *Id.* principle 13(1)(b).

<sup>&</sup>lt;sup>137</sup> *Id.*, principle 13(1)(a).

<sup>&</sup>lt;sup>138</sup> *Id.* principle 8(1).

The *MI Principles* require treatment in Athe least restrictive environment ... appropriate to the patient=s health needs and the need to protect the physical safety of others.@ Principle 9(1). Within an institution, A[t]he treatment of every patient shall be directed towards preserving and enhancing personal autonomy.@ *Id.* principle 9(4).

<sup>&</sup>lt;sup>140</sup> *Id.* principle 8(2).

Both social care homes visited by MDRI teams, as well as a number of institutions for people with mental retardation, consist of a number of buildings located on walled or fenced in areas. Szentgotthárd is located in a converted tobacco factory built in 1890. The building and its grounds are well maintained, with manicured lawns and a fountain in the center. New buildings were added in 1992. At Ludányhalászi, there are extreme contrasts between old, decrepit and dirty buildings which co-exist with expensive, new well-furnished buildings.

of attention to rehabilitation or normalization, leads to an unnecessary loss of the personal and social skills needed to function in the outside community.

### **Remoteness from the community** 1.

The MI Principles require that people with mental illness be Atreated and cared for, as far as possible in the community in which he or she lives. 9<sup>142</sup> When it is necessary to place a person in an institution, he or she has the right Ato be treated near his or her home or the home of his or her relatives or friends...@ 143 Hungary=s system of social care homes does not even make the pretense of adhering to this principle. Szentgotthárd, for example, is administered by the city of Budapest, from which it draws its residents. Nevertheless, it is located on Hungary=s western border with Austria, approximately four hours by car from Budapest. A Ministry of Health regulation requires social care homes to be easily accessible by public transportation, 144 yet many social care homes, such as Szentgotthárd, are placed in the farthest reaches of the country.

It is difficult to visit such social care homes from Budapest and return the same day, whether a person uses public or private transportation.

<sup>&</sup>lt;sup>142</sup> MI Principles principle 7(1).

<sup>&</sup>lt;sup>143</sup> *Id.* principle 7(2).

<sup>&</sup>lt;sup>144</sup> Ministry of Health and Social Welfare Regulation No. 2/1993, Professional Tasks and Condition of Operation of Institutions Providing Personal Care, section 2(3).

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The placement of the social care homes at the most remote parts of Hungary, violates the right of people to receive care as close as possible to their home, family, and friends. Many of the homes cannot be reached by public transportation in one day. The unnecessary and potentially prohibitive expense of traveling from the city violates the right of patients to receive visitors. As the director of one social care home observed, the distance from the city makes it difficult for many social care home residents to maintain any ties with their home. As ties with the community are severed, it becomes more and more difficult for people to return home, even if they have the mental capacity to do so.

# 2. Poor physical conditions & lack of hygiene

All living arrangements at Szentgotthárd and Ludányhalászi are communal. Many residents complained to the MDRI team that there is no place to go to be alone or obtain privacy. Most residential areas contain a number of beds and little else. Ministry of Health regulations establish that no more than four people should be placed in one room, but these regulations are not enforced. At Szentgotthárd, the MDRI team observed rooms with up to nine beds (some rooms built for four beds had two small beds or cots added later). At Ludányhalászi, most rooms have six

<sup>&</sup>lt;sup>145</sup> *Id.* principle 13(1)(c).

Two couples at Szentgotthárd are married and have rooms of their own. In addition, staff report that there is one locked room that can be used by residents for sex. Residents must obtain the key to this room from staff, who try to protect against abusive or nonconsensual sexual relationships by limiting the use of the room to approved relationships. The room is not available for private use for any other purpose.

<sup>&</sup>lt;sup>147</sup> In some areas of Szentgotthárd and Ludányhalászi there are end tables and closets for people to put personal belongings. Where day rooms exist, they usually contain chairs, tables, and a television set.

<sup>&</sup>lt;sup>148</sup> Regulation No. 2/1994, section 43, Professional Tasks and Condition of Operation of Institutions providing Personal Care (1994).

to ten beds, and some have up to thirty beds. At both institutions, bedrooms feed onto a common hall. Even in the nicest sections of these institutions, people cannot create truly personalized living areas. 149

Living areas at both institutions are highly variable; some areas are cheerfully decorated, others are barren, undecorated, and filthy. In much of Ludányhalászi, and some areas of Szentgotthárd, there are no places for personal belongings. Next to the modern building recently constructed at Ludányhalászi, there is an old building where physical conditions are in a state of total neglect. There is no furniture in some areas except beds and cages. Rooms are lit with bare bulbs. Floors, walls, and sleeping areas are soiled. At the time of the MDRI visit, rooms and beds smelled of urine and feces.

At Ludányhalászi, some of the women complained about the lack of separation between men and women. In some living areas, separate bathroom and shower areas are not available. In the room filled with cages at Ludányhalászi, MDRI investigators observed partially naked men and women being given sponge baths in full view of one another.

In the mental retardation ward and in parts of the new building at Ludányhalászi, the lights are turned off in the evening. The MDRI team visited Ludányhalászi at 4:30 pm in November, and it became dark outside shortly after our arrival. In most of the institution, lights had been turned off before the arrival of the MDRI team. In most living areas, rooms were so dark that it was impossible to read or engage in any activity except watching television or sleeping. There are no reading lights in most rooms. Staff in the mental retardation ward explained that it was standard practice to turn the lights off at this time.

In stark contrast to the old building at Ludányhalászi, a new building has recently been opened with marble floors and modern furniture. The newest buildings at Szentgotthárd and Ludányhalászi have four or six beds to a room rather than ten or twenty, but they still constitute institutional living. Rooms are placed on long hallways, and there is little privacy or place for individuals to personalize their living areas.

The newer buildings do not necessarily reflect a better or safer physical space. At the center of the new building at Ludányhalászi, there is a light well open on four levels of the building. This open space at the center of the building offers no protection for people who might fall accidentally or attempt suicide.

 $<sup>^{149}</sup>$  In the mental retardation ward of Ludányhalászi, there is one room devoted to arts and crafts. The room is decorated with very impressive artwork from some of the social care home residents. Very little of this artwork had been placed in the common residential areas.

Within old and new buildings at Ludányhalászi, the personal hygiene of residents is not adequately maintained. In one room at Ludányhalászi, everyone is kept in a cage built over his or her bed (the special problems of people living in cages are described further at II-B-3.) People living in cages cannot leave the bed to go to the toilet, and residents were observed in bed sheets covered with urine and feces. In another room of the same building, there is almost total neglect of the residents= personal hygiene. One person was observed without clothing; many others were half-dressed. Most people=s clothes and sheets were filthy, covered in dirt and feces. Apart from the beds, the ward has no furniture. The residential areas smelled terribly.

In the better wards at Ludányhalászi (such as the ward for people with mental retardation and the new building), and in most of Szentgotthárd, buildings are kept clean but some individuals are not. Even in the best living areas, some people=s fingernails are black, as if their hands had not been washed in days or weeks. Many people wear old, worn, and socially inappropriate clothing that would not permit them to integrate into a non-institutional setting. Some people wear open robes or clothing missing buttons; many people lack appropriate underwear.

The MDRI team visited Ludányhalászi during dinner time and were offered the food provided to patients, a mix of mashed potatoes and cheese. The food was plentiful and tasted good, but no solid food was served. The lack of solid food may be necessary because of the large number of people without teeth. Ministry of Health and Social Welfare regulations requiring the provision of basic medical care in social care homes provide an exception for dental care, <sup>150</sup> and oral hygiene is apparently deficient at Ludányhalászi. The MDRI team observed people of all ages missing teeth. Decay and loss of teeth can create discomfort (in addition to toothaches, loss of teeth may lead to decreased saliva production, muscle spasms, and chronic headaches) and serious health risks. <sup>151</sup> By limiting individuals to eating soft foods, people suffering from a loss of teeth will often substitute carbohydrates for meat and vegetables, resulting in malnutrition. <sup>152</sup>

### 3. Detention in cages

According to the *MI Principles*, physical restraints Ashall not be employed except...when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose. <sup>153</sup> Due to the potential for suffering caused by physical restraints, a number of procedural protections are required. The personal representative or guardian must be given Aprompt notice of any physical restraint. <sup>154</sup>

<sup>&</sup>lt;sup>150</sup> Regulation 2/1992, *supra* note 148, section 51.

<sup>&</sup>lt;sup>151</sup> Carolyn Jarvis, PHYSICAL EXAMINATION AND HEALTH ASSESSMENT 405 (1992). Loss of teeth and the lack of saliva production that ensues is particularly dangerous for people on psychotropic medications, because many of these medications independently cause the mouth to be dry. In addition to the discomfort this causes, decreased saliva decreases the mouth=s self-cleaning properties. *Id.* 

<sup>&</sup>lt;sup>152</sup> *Id*.

<sup>153</sup> MI Principles principle 11(11).

<sup>&</sup>lt;sup>154</sup> *Id*.

Restraints must be employed only Ain accordance with officially approved procedures@ and A[a]ll instances of physical restraint...the reasons for them and their nature and extent shall be recorded in the patent=s record. <sup>155</sup> People under restraint Ashall be kept under human conditions...under the care and close and regular supervision of qualified members of the staff. <sup>256</sup> Recommendation 1235 of the Council of Europe is stricter than the MI Principles; it prohibits the use of mechanical restraints altogether. 157

In social care homes (and in psychiatric institutions, such as OPNI and the psychiatric ward of Kenessay Albert Hospital), MDRI investigators observed the restraint of people in caged beds. In Szentgotthárd and Kenessay Albert Hospital, the team observed two or three cages, some open and some locked shut. At Ludányhalászi, the team observed the extensive use of cages. In one room, approximately sixteen people were permanently kept in cages. In two other wards, the MDRI team observed three individuals detained in cages.

The cages observed in Hungary are uniform in construction. They consist of metal frames built approximately 2 to 3 feet over a bed with a wire or net mesh enclosing all sides and the top. The cage permits a person to roll over or sit up but not stand up. The side of the cage can slide open or can be shut with a padlock. In Ludányhalászi, at least nineteen individuals were held in padlocked cages of this kind.

The goals of detention in cages, the conditions of detention, and the procedures for determining when and how to place a person in a cage violate the *MI Principles*. The use of cages creates unnecessary suffering on the part of people with mental disabilities and constitutes inhuman and degrading treatment under the ICCPR and the ECHR.

#### Illegitimate use of restraints a.

Under the *MI Principles*, physical restraints must be limited to the special circumstances when Astrictly necessary@ to prevent Aimmediate or imminent harm.@ In Hungary, restraints are used routinely because of inadequate staff. At the ward at Ludányalászi with nineteen patients in cages, staff said that Awe have no choice but to put these people in cages. We have ninety patients on the ward and only three sisters to watch them. @ At Kennesay hospital, where cages are also used,

<sup>155</sup> *Id*.

<sup>&</sup>lt;sup>156</sup> *Id*.

Recommendation 1235, section 13, recommendation iii(c) (Ano mechanical restraint shall be used.@).

a psychiatrist explained that people with mental retardation are often placed in cages because staff are not trained in methods of behavior management.

In some wards, cages are used as a means of ward management and possibly for punishment. In the modern ward of Ludányalászi, for example, a man observed by the MDRI team had been placed in a cage a month earlier because he had escaped from the social care home. The stated reason for placement in the cage was to prevent a future escape. It is not clear why this individual could not have been placed on a locked ward or in a locked building.

Another man was reportedly held in a cage because of assaultive behavior related to alcoholism. Despite reports of assaultive behavior, all of the people held in the cages (apart from one woman who was self-abusive, described further below) were docile during the MDRI visit. None of these individuals appeared to have any immediate need for restraints.<sup>158</sup>

### b. Inhuman, degrading and dangerous conditions of detention

Placement in cages is inhuman and degrading. A person in a bed-cage can sit up, but the limited size of the cages does not permit a person to stand, move about and stretch. Almost all activity is limited except sleeping. More than short-term confinement in such conditions can cause great suffering.

Individuals locked in cages have no place to go to the toilet except on the bed. In a number of the cages at Ludányhalászi, the team observed that bed pans had been placed in the bed. Since the bed pans must sit on the bed itself, movement can spill the contents of the bed pan onto sheets and covers. At the time of the MDRI visit, Ludányhalászi staff had been sent ahead to change sheets and blankets. Despite this, a number of people were observed who had spilled the contents of their bedpan onto their sheets and onto themselves.

<sup>&</sup>lt;sup>158</sup> The team did not have an opportunity to confirm this impression through patient or staff interviews.

Placement in a cage is dangerous. People who cannot move are at risk of bed sores. <sup>159</sup> The MDRI team observed two individuals with red, open sores. Without adequate staff to supervise patients, it would be difficult or impossible for the limited staff of the social care homes to provide the close attention that would be necessary to prevent bed sores. To avoid bed sores, staff would have to regularly check each person around the clock to ensure that they does not remain in the same position for more than two hours, and they would have to make sure that bedridden individuals maintain an adequate diet and are kept clean. 160 Without proper attention, bed sores can be lifethreatening. 161 The individuals observed by the MDRI team, left without attention and covered in their own feces, are at a high risk of dangerous infections and serious bedsores.

The cages do not provide protections against self-abusive behavior that may be found among people with mental disabilities. People unable to control their movement have enough room within the cage to bite themselves or bang themselves against the metal frame of the cage. One young woman was observed banging her forehead against the metal frame of the bed. Despite open, bleeding wounds on her forehead, she was allowed to continue this behavior. After the MDRI visit, the lights were turned off in the room. This woman screamed out that she was thirsty and needed

Bedsores pose a serious danger to the health of any person confined to a bed or wheelchair. People in physical restraints are at a particularly great danger of bedsores. Lillian Sholtis Brunner and Doris Smith Suddarth, THE LIPPINCOTT MANUAL OF NURSING PRACTICE 66 (1982). Unless the bedridden person shifts body position to reduce pressure, Athe localized pressure continues and skin ulcers develop.@ Joseph Agris and Melvin Spira, Pressure Ulcers: Prevention and Treatment, in CLINICAL SYMPOSIA ANNUAL 2, 6 (1979).

<sup>&</sup>lt;sup>160</sup> Removing the pressure is the key to preventing bedsores. AA bedridden person must be turned on a regular schedule, every two hours around the clock. For this several attendants may be necessary.@ Id., at 6-7. Care must be taken to keep the Askin clean and dry at all times....Areas where perspiration or body fluids collect...must be washed several times daily with mild soap, rinsed with warm water and patted dry...Clothing and bedding must also be kept clean and dry at all times, and changed as necessary. @ Id.

APressure ulcers in early stages involve only superficial tissues; if not recognized and treated early, however, the damage may extend through fat and muscle, even onto the underlying bone. In extreme cases, bacterial infection of the ulcer may be life threatening. @ Id.

water, and she continued to bang her head against the metal frame of the bed in the dark room. After twenty minutes screaming in the dark room, she had still not received any attention.

According to staff at Ludányhalászi, some people are taken out of cages two or three times a day for exercise, toileting, or meals. Others, they say, may receive more sporadic breaks from the cage. One man observed by MDRI was reportedly held in a cage for two months with breaks only for toileting.

# c. Inadequate procedures for authorizing and monitoring restraints

The dangers of detaining people in cages are all the more serious because the lack of safeguards against improper, unnecessary, or excessive use of the cages. There are no national regulations regarding the use of physical restraints or cages, and no guidelines existed at either social care home (or the two psychiatric hospitals) where cages were observed. According to authorities at Ludányhalászi and Kennesay Hospital, the use of cages is left to the discretion of the psychiatrist or ward administrator. Regular monitoring, required by the *MI Principles* to avoid the dangers of placing a person in restraints, is not required or practiced. At Ludányalászi, people were observed in cages entirely without staff supervision.

### 4. Lack of rehabilitation

People placed in social care homes are detained for purely custodial purposes. As noted above, the Social Care Act limits placement in a nursing home to people who (in theory) cannot benefit from rehabilitation. While most people receive pharmacological treatments, there is little or no effort to provide the rehabilitation or support they would need to return to the community, or even to develop better living skills. Some treatment is referred to as Arehabilitation,@ but there is no meaningful possibility for people in social care homes to benefit from such treatment or improve their living conditions. Any effort at rehabilitation or self-improvement is further undermined by the widely held belief by staff that people placed in social care homes have no hope for rehabilitation.

Psychiatric detention for purely custodial purposes violates international human rights law. Every person in an institution has a right to treatment. Treatment must be Aappropriate to his or her health needs@163 and Adirected towards preserving and enhancing personal autonomy.@164 Facilities must be available for Avocational rehabilitation to promote reintegration into the community.@165 The European Social Charter also specifies that people with mental disabilities have the right to Avocational training, rehabilitation and resettlement....@166

<sup>&</sup>lt;sup>162</sup> *Id.* principle 8(2).

<sup>103</sup> Id

<sup>&</sup>lt;sup>164</sup> *Id.* principle 9(4).

<sup>&</sup>lt;sup>165</sup> *Id.* principle 13(2)(d).

<sup>&</sup>lt;sup>166</sup> ESC article 15(2).

#### Pervasive inactivity and boredom a.

Pervasive inactivity and boredom is the most common characteristic of life on the wards of both institutions observed by the MDRI teams (with the exception of the worst wards of Ludányhalászi, where people live in filth and cages and the level of suffering is much greater). Most patients observed by MDRI at both institutions were lying in bed, sitting alone in chairs, or sitting around tables on the ward. Even when patients sat together, few engaged in conversation. In most areas, there is no reading material or newspapers. There are no clocks or calenders on the walls to mark the passing of time. MDRI was shown numerous activity rooms, including a large auditorium at Szentgotthárd. All of these rooms were empty or unused at the time of MDRI visits.

#### b. Lack of outplacement

There is little or no effort to find outplacements for individuals who might be able to function in the community. At Szentgotthárd, authorities report that many patients receive no assistance in maintaining contacts with their family and friends because of the lack of staff to assist them. At the two social care homes visited by MDRI teams, there had been one outplacement in the past year out of a total of 1,200 people.

#### Lack of treatment or vocational planning c.

The treatment provided in social care homes is not provided as part of an individual plan for rehabilitation, as required by the MI Principles and Ministry of Health and Social Welfare regulations. 168 The staff is generally engaged in maintaining the patients= physical health and administering medications. Patient records observed at Szentgotthárd showed no individualized information except dosages of medications.

MDRI teams observed no active mental health programming or other programmed activities at either institution. The MDRI team observed one special education class in session for twenty people at Szentgotthárd. This was the only planned activity of any kind MDRI observed in either social care home. At Szentgotthárd, evening activities are reported to take place only twice per month due to the lack of staff. Authorities report that there are up to two and one half hours of structured activities per day between 2:00 pm and 5:30 pm on a daily basis. MDRI visitors were present during these times, however, and observed no activities.

MDRI investigators also found a lack of vocational support. At Szentgotthárd and Ludányhalászi, social care home staff report that many patients are capable of working in the community. None of the residents have such jobs, however, and the institutions have not developed

 $<sup>^{167}</sup>$  Under the MI Principles, A[t] he treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff.@ MI Principles principle 9(2).

<sup>&</sup>lt;sup>168</sup> Regulation 2/1992, *supra* note 148, section 50.

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programs to place people in real work positions. As unemployment rises throughout the country, staff at the institutions observe that people in institutions lose their jobs first.

Both Szentgotthárd and Ludányhalászi have what they call Ainternal@ vocational programs for social care home residents. Vocational programs are not linked with opportunities to obtain real employment, however, and are thus inherently limited. 170

At Ludányhalászi, there is one room on the MR ward reportedly used to make wooden brushes. At Szentgotthárd, there is also a vocational workshop. At the time of the MDRI visits to both institutions, no one was actively participating in vocational rehabilitation.

 $<sup>^{170}</sup>$  "Interest in hospital-based vocational rehabilitation programs has declined as lengths of in-patient stays

Very few people perform real work within social care homes. At Szentgotthárd, 120 to 130 of the 720 residents are reported to work in the institution, washing, cleaning, gardening, or helping in the kitchen. <sup>171</sup> On the ward for people with mental retardation at Ludányhalászi, staff report that

have decreased. Most authors examining the literature in this area have concluded that there is no relationship between involvement in in-patient vocational programs and successful postdischarge employment and that such programs may actually increase institutional dependency. @ J. Steven Lamberti and Marvin I. Herz, Psychotherapy, Social Skills Training, and Vocational Rehabilitation in Schizophrenia, in Contemporary Issues in the Treatment of Schizophrenia 713, 724 (1995).

<sup>171</sup> Individuals who can work four hours per day, receive 4 - 5,000 Hungarian Forints/month (about \$40 to \$50/month). People who cannot work these hours are paid 500 to 2,000 Hungarian Forints/month (\$5 to \$20/month). Anyone earning a salary can be charged for cost of care at the institution, a monthly fee of 7,100 forints/month (\$71.00). Authorities at Szentgotthárd report that each resident is allowed to keep a small amount of money and the institution does not charge patients as much as is permitted under the law. However, they say, people who work longer hours make approximately the same as people who work few hours. International standards permit people in institutions to be charged for the cost of their treatment as long as they receive Aa fair share of any

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Atwo or three@ of the 68 people help out with cleaning and maintaining the ward. Ward staff report that these people are usually not paid for this work.

### d. Inadequate staff

remuneration. A scale that does not allow people to benefit from longer hours of work deprives them of their Afair share and undercuts any incentive to work longer hours and develop important skills.

<sup>172</sup> On the MR ward, where the vocational program is placed, there are a number of highly functioning individuals who reported to MDRI visitors that they would like to work but are unable to find jobs. One thirty-year-old woman who had been in this institution for ten years said she missed her former work in a sewing factory. She said that she was not able to do this kind of work at Ludányhalászi.

Most studies refute this assertion and find that most people with mental retardation are capable of meaningful employment. They also find that work dramatically improves the social skills and accelerates the development of people with mental retardation. A Massachusetts study of two men with severe mental retardation and aggressive tendencies showed that when moved to jobs in the community, incidents of aggression declined 93%. T.L. Belcher, *Decreased Violence in a Day Program: Community-Based Endeavors*, 76 PSYCHOLOGICAL REPORTS 1201-2 (1995). *See* P.N. Walsh et al., *Supported Employment for Irish Adults with Intellectual Disabilities: The OPEN ROAD Experience*, 11 INT=L J. REHABILITATION RESEARCH 15, 15-24 (1994)(describing an Irish program that successfully placed people with mental retardation into financial, food service, and retail positions). Supported employment has also been found to be cost-effective as opposed to institutionalization or even institutionally-based sheltered workshops. A cost-benefit survey of two supported employment programs in rural Illinois that successfully placed people with mental retardation into jobs found that, as well as enhancing the lives of the participants, Asupported employment is both economically efficient and cost-effective over time for individuals with mild, moderate, or severe mental retardation. Wendy B. McCoughlin et al., *Cost Effectiveness of Supported Employment*, 31 MENTAL RETARDATION 41, 47 (1993).

Authorities at both institutions ascribe the lack of activities to a shortage of staff. Under the MI Principles, it is the responsibility of the government to ensure that A[q]ualified medical and other appropriate professional staff@ are available in Asufficient numbers@ to ensure A[a]dequate, regular, and comprehensive treatment.<sup>2173</sup>

At Szentgotthárd and Ludányhalászi, the low number and inadequate training of staff make it impossible to provide appropriate rehabilitation programs. As described by authorities at the institution, the staff of nurses is kept busy cleaning, dressing, and feeding patients, and assisting with administering medications.<sup>174</sup> Due to their heavy work load, they said that they were unable to stretch the staff to provide any additional activities (as described above, current rehabilitation programming is inadequate). At Ludányhalászi, an institution for 400 to 500 people, there are no psychiatrists or psychologists on staff. One psychiatrist comes to the institution two times a week. Despite the fact that they have a ward for people with mental retardation, they have no professional staff with expertise in habilitation or behavior programming for this population. In the worst ward, there are ninety people supervised by a staff of three. According to the staff on this ward, they are forced to place people in cages because they do not have adequate staff to supervise the ninety people who live on the ward.

While finances for increased staff may be limited, staff resources that are available are not adequately utilized. Neither social care home visited by MDRI has a psychologist on staff, yet both had funds to do so. Both institutions reportedly had openings for psychiatrists. The acting director at Ludányhalászi is the chief nurse, and she reports that the institution has been trying for over a year to find a director, with no success.

In part, the difficulty in hiring staff is a result of the low pay and remoteness of the social care homes from any major city. In addition, the view that the population is Abeyond rehabilitation@ has an invidious effect on the staff that are available. The psychiatrist at one institution observed that it is difficult to attract professional or non-professional personnel because Aworking conditions are depressing and the treatment is viewed as hopeless.@

Despite the poor working environment and low pay, many of the staff who work at each institution are very devoted to the work they do. As one staff worker at Ludányhalászi pointed out,

<sup>&</sup>lt;sup>173</sup> MI Principles, principle 14(1).

<sup>&</sup>lt;sup>174</sup> In March 1995, authorities reported that the staff consisted of 137 nurses, two psychiatrists, two general practitioners, one special education teacher, and six social workers. The authorities did not specify how many of the 137 staff designated as Anurses@ had professional degrees in this field.

Ano one would work here@ to advance his or her career, but the many people do so out of a Adeep commitment@ to the people they serve.

Staffing levels set by Ministry of Health and Social Welfare regulations are so low as to be nearly meaningless. The regulations require, for example, a psychiatrist to be available four hours per month in an institution of more than 200 beds. At an institution that houses 400 people (the size of Ludányhalászi, and about half the size of Szentgotthárd), this would mean about forty seconds with a psychiatrist per patient per month. At this level of staffing, it would be impossible to provide individualized mental health treatment, much less monitor psychotropic medications for basic issues of safety. In the institutions visited by MDRI, staffing levels for psychiatrists exceeded this legal minimum. According to the Gönczöl Report, staffing levels and professional qualifications in the social care homes often do not meet the minimum standards set by Hungarian law. 175

# 5. High rate of mortality

The limited data that MDRI has available suggest a high rate of mortality at the social care homes. According to authorities at Ludányhalászi, approximately 60 of 400 residents died over the previous year. At Szentgotthárd, authorities reported that 79 people died the previous year out of a total population of 720. Thus, the rate of mortality is more than 10% annually at both institutions.

For very old and severely disabled populations, a 10% mortality rate may not be high. At both institutions, however, people are placed in the facility at all ages and a wide range of disabilities. MDRI does not have sufficient information about the age range and condition of the patient population upon entry to determine how unusual it is to have such a rate of mortality at this level. This is information that the government of Hungary should routinely monitor. A rate of mortality this high warrants a thorough investigation.

<sup>&</sup>lt;sup>175</sup> Gönczöl Report, *supra* note 110.

<sup>176</sup> Other observers have noted the high rate of mortality in certain Hungarian psychiatric institutions. Psychiatrists working in the psychiatric ward of a general hospital in Budapest reportedly observed that there is a lack of intensive care for people with serious mental disorders. These psychiatrists estimated that 50% of the individuals with dementia who die in their unit could have been saved if adequate intensive care had been available. Ellen Mercer, Director, Office of International Affairs, American Psychiatric Association, Exploring Hungarian Psychiatry at 19 (unpublished report of mission to Hungary, May 10 - 18, 1992).

### C. **Human Rights Ombudswoman=s Report**

On July 17, 1996, the national Human Rights Ombudswoman, Katalin Gönczöl, released the report of findings and recommendations regarding human rights in social care homes in Hungary. 177 The report is the product of a fact-finding investigation by Katalin Gönczöl and a team of experts, including attorneys and at least one psychiatrist on Gönczöl=s staff. The team investigated conditions in five social care homes.

#### 1. Findings of the Gönczöl Report

The findings of the Gönczöl report are consistent with those of the MDRI team. The Gönczöl report finds numerous violations of rights under Hungary=s Constitution, as well as violations against the ECHR protection of the right to Aliberty and security of the person@ (article 5(1)) and the protection against Ainhuman and degrading treatment@ (article 3).

The Gönczöl report finds that people who enter social care homes generally remain there for life. In the social care homes visited by Gönczöl=s team, commitment was left to the discretion of psychiatrists. Even when commitment is ordered for a specific period of time, deadlines for review are ignored and commitment is considered final, until the death of the individual committed. In addition to the lack of judicial review of commitment, Gönczöl found that professional review of the need for continued treatment in the institution does not take place.

The Gönczöl report finds that the system of guardianship does not protect the interests of people in the social care home. According to the Gönczöl report, one public guardian may be responsible for 100 to 150 wards, making a personal relationship or in-depth knowledge of any particular case impossible. In addition, the report finds frequent conflict of interest between family members acting as guardians and their wards. For example, the Gönczöl report is critical of a law which permits a guardian to turn over only 20% of an old age pension to the ward, permitting family members the possibility of inheriting the additional money when the ward dies. Even when a person is committed for a definite period of time, guardians are reported to sell off the property and home of the ward, making it much more difficult for the ward ever to leave the institution. People living in social care homes are not notified of their rights, and they are not provided with information about how they may obtain help or seek review of their guardianship or commitment.

The Gönczöl report finds that conditions in the social care homes are poor and degrading. Furniture is scanty or worn out, clothing is inadequate or lacking, and some living areas are unhygienic. In at least one social care home, some people are kept in Anet-beds@ (presumably the same cages observed by the MDRI team). One of the five social care homes the Gönczöl team visited in Visonta was built for agricultural or mining purposes, and the Gönczöl report finds that the

<sup>177</sup> Gönczöl Report, supra note 110.

institution is not suitable for human habitation. Conditions are made worse by terrible pollution from a local power plant.

The Gönczöl report documents inadequate medical treatment, the lack of rehabilitation, and the lack of opportunities for employment for people in the social care homes. Social care homes lack the number of staff with the levels of professional training required by Hungarian law. Many patients are on the same medications for years at a time, without adequate attention to their potentially dangerous side effects. A large percentage of patients may be given medications Aas needed@ by staff not trained or licenced to prescribe medications. The right to informed consent is not recognized, and in some social care homes patients cannot obtain even minimal information about the medications they are taking. People with mental retardation and people with mental illness are mixed in the same institutions and wards. In some social care homes, half of the population is institutionalized on the basis of their mental retardation. There is effectively no independent oversight of living conditions or treatment practices in the institutions.

# 2. Recommendation in the Gönczöl Report

The Gönczöl report recommends a number of important steps the government of Hungary can take to protect the rights of people in social care homes and ameliorate the degrading living conditions. The Gönczöl report recommends that the guardianship law be amended and that a system for regular judicial review of commitment be adopted. The Gönczöl report also recommends an innovative new oversight body be created, called Acivil control boards@. These boards would permit individuals from the community who are independent of the institution to monitor conditions in the institution, treatment practices, and commitment. The proposed civil control board would also help investigate the possibility for individuals taking full opportunity to obtain employment, education, and leisure time activities.

The Gönczöl report=s recommendations differ in a number of important ways from the recommendations of MDRI. The Gönczöl report recommends that one of the five social care homes investigated (the Visonta social care home in Heves County) be closed and that funding should be significantly increased to end degrading conditions in the other homes. As described in the conclusions and recommendations of this report, MDRI finds that the social care homes unnecessarily isolate individuals from society and make it more difficult to provide rehabilitation and reintegration into the community. Thus, MDRI recommends that Hungary begin planning to close all social care homes. While some increases in funding may be needed to ameliorate dangerous living conditions, MDRI does not recommend investments be made in social care homes beyond what is necessary to protect the life and health of the individuals living there. Instead, MDRI recommends that new funding be provided to create community-based alternatives to the social care homes. MDRI=s full recommendations are described in the Conclusions and Recommendations section above and in Chapter VI, Planning and Financing Reform.

### III. **Hospital and Community Care**

Hungary=s Aofficial@ mental health services, administered by the National Psychiatric Institute, are made up of an extensive system of in-patient beds in psychiatric institutions and the psychiatric wards of general hospitals. The average length of stay in most psychiatric wards and institutions is reported to be one to three months, much less than in social care homes. There are people who spend years in psychiatric institutions and in psychiatric wards of general hospitals, however, including people who await transfer to a social care home.

As described in this section, psychiatric wards of general hospitals and psychiatric institutions offer little in the way of rehabilitation or training in skills that would help people reintegrate into the community. Large portions of the system, including wards for people with Aneurosis,@ provide care for people who would be better served in the community. The emphasis on in-patient over out-patient care is reinforced by an insurance reimbursement system that will fund only in-patient treatment and will not adequately fund alternatives that could be provided in the community. With the great majority of mental health funding directed at in-patient services, outpatient clinics are inadequate to meet the needs of people who wish to remain in the community.

As a result of the lack of community-based services, people are forced to seek treatment in in-patient facilities who would otherwise be able to remain in the community. Unnecessary inpatient care contributes to individual isolation, stigma, and the loss of family, friends, and employment opportunities in the community. In an environment in which unemployment is on the rise, in-patient treatment may cause the loss of a job. The mental health system is also increasingly used as a support system for people who have become unemployed, diverting mental health system resources away from people with more severe disabilities.

One of the potential strengths of Hungary=s psychiatric system is the extensive network of psychiatric wards in general hospitals. Psychiatric wards in general hospitals offer the possibility of integrating mental health treatment into general health care treatment as a whole. Located close to where people live, psychiatric wards of general hospitals offer the possibility of integrating inpatient services with out-patient treatment and support in the community. Given the lack of community-based service and support systems, however, psychiatric wards of general hospitals often operate in isolation, much like separate psychiatric institutions. There is reported to be little coordination and integration between treatment in psychiatric wards and out-patient programs, even when they are technically administered by the same general hospital.

The lack of community-based services, and the unnecessary reliance on in-patient care deprives people with mental disabilities of the right to live, <sup>178</sup> work, <sup>179</sup> and receive treatment Ain the community in which he or she lives.@180 A system of services that creates unnecessary

<sup>&</sup>lt;sup>178</sup> MI Principles principle 3.

<sup>&</sup>lt;sup>179</sup> *Id*.

<sup>&</sup>lt;sup>180</sup> *Id.* principle 7(1).

institutionalization misallocates scarce resources needed for community care and support and leads to increased iatrogenic disabilities. As such, the structure of Hungary=s mental health service system violates the right to Athe highest available standard of physical and mental health@ under the ICESR. 181

There is almost no regulation of treatment practices or conditions within psychiatric facilities, and conditions vary enormously. On some Aback wards@ of psychiatric institutions and psychiatric wards of general hospitals, where difficult or long-term patients are placed, people live without privacy in large dormitories, often in filth. Physical restraints are used without adequate supervision, and some individuals are held in cages. These conditions violate the right to protection against Ainhuman and degrading@ treatment under articles 7 and 10 of the ICCPR and article 3 of the ECHR.

# A. Inadequate Community-Based Services

### 1. Structure of services

There are few programs in Hungary designed to provide community-based alternatives to inpatient treatment. In Budapest, out-patient programs are administered by psychiatric institutions. Patients who have been discharged by the psychiatric institution may receive care as an out-patient through the same institution. There is also a network of out-patient clinics. MDRI

<sup>&</sup>lt;sup>181</sup> ICESCR, art. 12(1).

<sup>&</sup>lt;sup>182</sup> In areas where the in-patient psychiatric facility is a ward or a department of a general hospital, the outpatient program may be funded through the general hospital.

<sup>&</sup>lt;sup>183</sup> The majority of people who receive services as out-patients at Lipot are reported to be former inpatients. For the most part, this out-patient treatment consists of supervision of psychotropic medications. Some people receive more extensive out-patient treatment at OPNI.

investigators interviewed psychiatric staff at four such clinics. <sup>185</sup> Some clinics are dependent upon a particular in-patient facility for their funding and others receive direct funding from local governments or other sources. Whatever the funding source, directors at all four clinics visited report that there is little or no oversight of the treatment they provide. Thus, treatment practices are reported to vary considerably in out-patient clinics throughout the country.

### 2. Lack of services and support

<sup>&</sup>lt;sup>184</sup> In 1994, a total of 980,704 people are reported to have been registered at psychiatric out-patient clinics throughout Hungary. Sandor, supra note 89, at 86.

<sup>&</sup>lt;sup>185</sup> There is one out-patient program in each of the 23 districts of Budapest (free standing out-patient programs and programs located in hospitals or psychiatric institutions are both referred to here as Aout-patient clinics@). The out-patient clinics administered by the local government are reported to serve approximately 30,000 people per year. There are a few additional out-patient programs, including two visited by MDRI associated with Semmelweis Medical School. In addition, there are specialized out-patient clinics devoted to the treatment of people with alcoholism.

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For many patients, out-patient treatment consists almost exclusively of psychotropic medications. Due to the enormous case load of psychiatrists working in out-patient practice, meetings with psychiatrists are generally very short. Patients report that meetings often last three to five minutes. According to psychiatrists, visits may last up to fifteen or twenty minutes when difficulties arise. Some psychiatrists in out-patient practice report that when an individual starts a new drug regimen they see the patient once a week. Other psychiatrists report that visits are not always that common, even at the outset of treatment. In practice, psychiatrists and patients reported to MDRI that most patients see a psychiatrist every four to eight weeks. Some patients on medication are reported to visit the out-patient clinic once or twice a year. The limited time available with psychiatrists and the long periods of time between visits may undermine out-patient treatment and create dangers for patients on certain psychotropic medications that must be regularly monitored. The contraction of the psychotropic medications of the psychotropic medications are reported to visit the out-patient on certain psychotropic medications that must be regularly monitored.

<sup>&</sup>lt;sup>186</sup> At one clinic, staff psychiatrists report that, due to lack of staff, it is not always possible to schedule appointments every week. Thus, many patients have appointments at out-patient clinics every six to eight weeks. In Hungary, a prescription for psychotropic medications can only be granted for thirty days at a time. Thus, patients with longer periods of time between appointments come to the clinic and meet with a nurse, who reports back to the psychiatrist signing the new prescription.

Neuroleptic medications, widely used for controlling psychotic symptoms, must be monitored for neuroleptic-induced movement disorders, such as tardive dyskinesia. Tardive dyskinesia, a form of neuroleptic-induced movement disorder stemming from irreversible nerve damage, appears at a rate of approximately 5% a year among people on neuroleptics. WHO Review of Effectiveness, *supra* note 131, at 67 and 309; Harold I. Kaplan & Benjamin J. Sadock, Comprehensive Textbook of Psychiatry 2005 (Sixth edition, 1996). Other common neuroleptic-induced movement disorders are neuroleptic malignant syndrome, parkinsonism, acute dystonia, and acute akathisia. *Id.* at 1910. Other common medications, such as lithium and clozapine must be monitored regularly, especially when patients start using them or when dosage levels are adjusted. WHO Review of Effectiveness, *supra* note 131, at 72. In order to change certain medications or adjust dosage levels, psychiatrists in out-patient practice report that they must occasionally refer patients to a psychiatric ward for in-patient treatment. With adequate resources for out-patient clinics, such in-patient treatment would not be necessary.

In addition to medications, a small number of people receive out-patient psychotherapy and Asocial help@ from the staff of out-patient clinics. The type and frequency of such services varies at each clinic, 188 but services are severely limited at every clinic because of the lack of staff and funding. Psychiatrists at OPNI report that, due to staff limitations, only a small percentage of the people receiving out-patient treatment receive more than the supervision of medications. Approximately 1,000 people receive out-patient psychotherapy at OPNI, provided by a staff of eight psychiatrists. 189 At one out-patient clinic, a staff of four psychiatrists provided services to 8,433 people in 1995. 190 In addition to supervising peoples= medications, one psychiatrist reports that she can provide psychotherapy for up to ten people - a small percentage of her total caseload. 191 Outpatient clinics receive no extra funding for the psychotherapy, so there is no incentive for staff psychiatrists to put in more hours to provide therapy to their patients. <sup>192</sup> Some out-patient clinics are reported to provide no psychotherapy or treatment other than the supervision of medications.

Social care provided at the out-patient clinics consists largely of assistance in obtaining government benefits and pensions. On occasion, it may include meetings with families and neighbors to Aavoid disturbances. @ Out-patient clinics receive no funding for social care, and staff at some clinics reported to MDRI that they do not provide any such assistance to their clients. At the clinic where they do provide this assistance, it is provided by nurses in their Aextra@ time. With case loads of 300 to 400 each, even the most dedicated nurses can provide only a limited form of such care.

Out-patient programs in Hungary do not provide the supported living, supported employment, psychosocial rehabilitation, case management, peer-support, or advocacy services that are essential for many people to function in the community. Pharmacotherapy alone, as most

<sup>&</sup>lt;sup>188</sup> In the absence of standards or centralized oversight, psychiatrists provide the kind of treatment they prefer. In one clinic, a psychiatrist reported that she was trained in psychoanalysis, so she provides psychoanalytic psychotherapy to her clients. Her colleague at the clinic prefers cognitive behavioral treatment, so that is what she provides. Patients are assigned to one or the other psychiatrist based upon their address within the district. Thus, the treatment a patient receives depends on his or her address rather than his or her particular needs.

These people see a psychiatrist an average of once every three weeks.

 $<sup>^{190}</sup>$  This district has an official census of 90,000 people. Staff psychiatrists report that the actual population is probably much larger, because it is a poor district with many homeless people and many Roma (gypsies) who are undercounted by the official census.

<sup>191</sup> At another clinic, a psychiatrist reported that she is able to provide Apsychotherapy@ to almost 50% of her clients. This therapy is probably a form of supportive counseling. The psychiatrist explained that she is not trained in psychotherapy, and visits for therapy usually last 20 to 30 minutes. She reported that, on average, visits take place five times a year.

<sup>&</sup>lt;sup>192</sup> In theory, the national health insurance program provides payments for psychotherapy. However, these payments are reportedly made to the hospital or psychiatric institution administering the out-patient program. Staff at out-patient programs report that they never see the funds paid for the provision of psychotherapy, and additional hours of psychotherapy do not result in an increased budget for the out-patient program.

<sup>&</sup>lt;sup>193</sup> Successful community support systems for people with mental illness combine several services designed to negate the need for re-hospitalization. These include: client outreach to ensure client follow-through on

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people receive through Hungary=s out-patient mental health programs, is not sufficient to support rehabilitation and community living. Psychiatrists in out-patient practice report that if they had a larger staff, they would be able to provide care for many people who are now served in in-patient programs.

### 3. Institution-based services

psychiatric referrals; health and dental services; mobile crisis teams that can respond quickly to a psychiatric emergency; affordable housing; income support; legal protection and advocacy; family and/or peer support; and effective case management. Italy and some areas in the United States have implemented this model. *See* Lorenzo Burti and Vasily Yastrebov, AProcedures Used in Rehabilitation,@ in WHO REVIEW OF EFFECTIVENESS, *supra* note 131, at 303-321.

AFrom a rehabilitation perspective, drug therapy is a useful intervention but rarely an entire rehabilitation program. Likewise, practitioners of drug therapy may view rehabilitation as supportive in increasing drug compliance, determining the initial need for drug therapy, and or decreasing drug dosage. A. Anthony, M. Cohen, M. Farkas, PSYCHIATRIC REHABILITATION 72 (1990).

Within some psychiatric institutions, including OPNI, there are day programs, known as Aday hospitals, where people who live in their own homes can spend up to twelve hours on the ward during the day. 195 The day hospitals represent an advance over other institutional programs because they permit some people to remain at home. However, the programs are limited by the lack of a network of services and support in the community. Thus, individuals may remain in day hospitals longer than necessary once they are capable of living and working more independently. In addition to day hospitals, there are some psychosocial rehabilitation and skills training programs within institutions. Like the day hospitals, these programs are limited because there are no community programs to which people may progress. The institutional setting of in-patient rehabilitation units and day hospitals also tend to reinforce dependence. As one psychiatrist observed. 196 rehabilitation is difficult in an in-patient setting because Ait is hard to motivate patients when everyone else is just sitting around.@

#### 4. Lack of integrated services

<sup>&</sup>lt;sup>195</sup> At OPNI, there is a day hospital (where people live at home and come in during the day) and a night program (where people come at night who do not have a home - many of these people function well enough to hold a job outside of the hospital). There is also a sheltered workshop and a rehabilitation for people who reside in the institution. MDRI team members heard many positive things about these programs because they permit some independence on the part of people who would otherwise remain fully within the institution. The same programs could provide even more independence, however, if they were located outside the facility and were fully accessible to people who are able to remain outside the institution.

<sup>&</sup>lt;sup>196</sup> At the time of the MDRI visit in March 1996, this psychiatrist worked at an out-patient clinic of Semmelweis University Medical School that specializes in psychotherapy. Hospital administrators had recently made the decision to close the out-patient program and transfer services to an in-patient facility, where it would operate as a day program. Staff protested on the grounds that it would be much more difficult to run an effective program within an in-patient setting. Despite their limitations, day hospitals can be an improvement over other twenty-four hour in-patient treatment. Burti and Yastreboy, AProcedures Used in Rehabilitation, @ in WHO REVIEW OF EFFECTIVENESS 289, *supra* note 131, at 312.

A number of psychiatrists working in the area of out-patient treatment stated that the greatest problem in their work is the lack of integration in the service system to ensure a continuity of care for their patients. When a person has a crisis and seeks treatment in the psychiatric ward of a general hospital or a psychiatric facility (or is involuntarily detained), the psychiatrist providing out-patient care may not be informed. Even when the out-patient clinic is aware that a person has been institutionalized, there is rarely communication between the care providers. The lack of communication between providers creates a danger of a patient Afalling through the cracks@ of the service system, or receiving inconsistent and ineffective care. As one psychiatrist working in community care pointed out, inconsistent care undermines trust between the client and the care provider, Aif I send a patient to the hospital...I worry about what the hospital will do with him....[t]here=s low compliance anyway. But these problems are made worse by the fact that the doctors don=t talk to one another.@ 197

### 5. Model Community Programs

A few model community-based programs have recently been established. The National Institute of Psychiatry administers a group home providing supportive services for five people in Budapest. The Awakenings Foundation, based at the Semmelweis Medical School in Budapest, has recently established an experimental program that serves sixty-five people in the community. The program is currently seeking private funding to expand the program.

# **B.** Unnecessary In-Patient Treatment

The psychiatrist further observed, AWe need a network of care for the patients. We need communication among ourselves. We owe at least that much to the patient....there=s no real contact between outpatient programs and the hospital. I could always call them on the phone, but that is no guarantee that it would have any effect. I can=t control the treatment of my patients once they leave my office. If I send a patient to the hospital because I know his situation is dangerous, I worry about what the hospital will do with him. The hospital may decide to discharge, and then the patient gets angry at me for letting him down.@

MDRI: Does the opposite ever happen - you send the patient to the hospital for short term treatment and they won=t let the patient out? Can your patients be transferred to social care homes?

AYes, that can happen. I have the same lack of control, and I=m never informed about what the hospital does. But the biggest danger is that the hospital won=t treat my patient at all. The patient gets even more ill because they won=t renew treatment. There=s low compliance anyway. But it=s made worse by the fact that the doctors don=t talk to each other.@

Due to the lack of community-based services, large numbers of people with mental disabilities unnecessarily become in-patients. According to the director of the National Psychiatric Institute, the 25% of people in Hungary=s psychiatric institutions are Aneurotic@ and do not have a major mental illness. In addition, many other psychiatric patients have other problems with substance abuse (mostly alcoholism). At Kennesay Hospital, the director of one psychiatric department estimated that only 30% percent of patients are diagnosed with what is considered a Amajor mental disorder@ (schizophrenia, major depression, and bipolar disorders). All other people in the institution, according to the director have Aneuroses, personality disorders, or problems with alcohol.@

Psychiatrists at OPNI, Kennesay Albert Hospital, and Semmelweis Medical School agreed that a large portion of patients served as in-patients could be provided with the same or better treatment in the community. Informal estimates by psychiatrists and program directors in in-patient practice varied widely from about 10% to as high as 90%. Most psychiatrists interviewed agreed that 90% of people in Aneurotic@ wards could be served in the community. A psychiatrist at Kennesay Hospital said that 100% of the neurotic patients on his ward could be treated in the community. At Nyirö Gyula Hospital, the deputy director of one ward estimated that eighty to ninety percent of all patients are capable of living in the community. Psychiatrists at Semmelweis Medical School estimated that 30-50% of people institutionalized for Apsychosomatic@ problems could also be returned to the community. Even among people being served for acute care, psychiatrists estimated that 10% could be treated in the community.

International human rights law specifies that every person has a right to Abe treated and cared for, as far as possible, in the community in which he or she lives. <sup>198</sup> A mental health system that offers no real alternative to in-patient treatment for individuals who would be better served in the community violates the rights of these individuals.

#### C. **Improper Incentives for In-Patient Care**

Hungary=s mental health system creates a number of economic incentives for in-patient rather than out-patient care. These incentives contribute to the problem of people receiving unnecessary in-patient care. These policies not only contravene international human rights law, and undermine public health, they also constitute poor public policy. The unnecessary treatment of people in a costly in-patient setting limits funding for better, less expensive, community-based alternatives.

#### 1. In-patient bias of insurance and pension systems

Psychiatrists at OPNI, Semmelweis Medical School, Kennesay Hospital, and Nyirö Gyula Hospital report that patients frequently seek treatment in an in-patient facility in order to qualify for health insurance benefits or a disability pension that would be difficult or impossible to obtain outside the institution. A number of psychiatrists reported that they frequently exaggerate diagnoses

<sup>&</sup>lt;sup>198</sup> MI Principles principle 7(1).

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to help patients qualify for benefits or pensions. Psychiatrists report that the insurance system will pay for certain forms of treatment in an in-patient setting that will not be reimbursable in the community for the same client and the same treatment. This is true, they say, even when outpatient treatment would be more effective and in-patient treatment is more expensive. Similarly, psychiatrists and patients report that it is easier to qualify for a disability pension for a person who receives in-patient rather than out-patient care. With unemployment and the cost of living on the rise in Hungary, an increasingly large number of people seek treatment on a psychiatric ward as a way of obtaining basic housing and food.

Psychiatric institutions have an incentive to cooperate with patients seeking unnecessary or extended in-patient care because their level of funding may depend on keeping in-patient beds filled. Hungary=s health insurance program uses a system of Adiagnostic related groups@(similar to programs in the United States that refer to diagnostic related groups as ADRG=s@). The system provides a set amount of money for the treatment of a particular diagnosis. One of the problems with any DRG program is that it creates an incentive for the institution to provide a person with a more serious diagnosis, so that the institution may receive the higher level of payment.

# 2. Medicalization of social problems

<sup>199</sup> It is also important to note, however, that the insurance system would provide for many forms of care in the community that are simply not available because of inadequacies in the community mental health system. In some cases, insurance payments for out-patient care will be made to the hospital that administers the out-patient program. Staff at the out-patient programs report that the hospital will keep this additional money and will not pass it on to the out-patient program. *See supra* note 192.

MDRI investigators received different viewpoints about the use of psychiatric institutionalization for people with social or economic difficulties. Psychiatrists have reported and studied what they describe as a long tradition of the somatization of mental disorders.<sup>200</sup> Psychiatrists in Hungary have struggled for the recognition of emotional disorders against a biologically oriented tradition of neurology and a widespread cultural practice of the somatization of mental ailments. Psychiatrists have begun to gain ascendancy over neurologists since the early 1980's, but the practice of in-patient treatment for the stress and anxiety associated with social problems (now diagnosed as Aneuroses@ rather than organic brain disorders) is still a well established practice in Hungary.

As a result of these practices, the growth of unemployment in recent years has put particular stress on Hungary=s mental health system. Many psychiatrists reported that people who experience unemployment or social dislocation as a result of recent economic changes have shown up at hospitals presenting physical ailments or mental ailments. As one psychiatrist described, the loss of a job during the communist era carried with it great social stigma and personal blame. Thus, he observed, people experience this dislocation as an illness. Frequently, these individuals are diagnosed as Aneurotic. @ Being labeled as Amentally ill@ may itself be stigmatizing, but it removes the sense of blame from the individual. Many psychiatrists report that they admit people to a psychiatric facility because their clients (or the community) would not believe they are getting real Amedical@ care unless it is provided in an in-patient setting. In addition, a diagnosis of mental or physical illness may help a person obtain unemployment benefits.<sup>201</sup>

Whether or not service providers are well meaning, the unnecessary use of in-patient care perpetuates stereotypes about mental illness and health care and creates costs that Hungary can illafford. Misinformation provided by medical authorities may inhibit individuals from seeking

János Füredi and Béla Buda, Recognition Problems for Psychiatry as an Independent Discipline in Hungary, 7 AM. J. Soc. PSYCHIATRY 199 (1987). Neurologists would be more likely to diagnose an ailment as a brain or neurological disorder. As a cultural practice, anxiety or depression could be expressed as a somatic medical ailment, e.g. headaches, loss of sleep, heart problems, etc. See Gustave Batizy, Social Psychiatry in Hungary, INT=L J. Soc. Psychiatry 46, 51 (1976).

<sup>&</sup>lt;sup>201</sup> In 1987, psychiatrists reported that less than half the number of people who take off time from work for mental disabilities are identified as suffering from any form of mental problem. These psychiatrists explained this fact based on the observation that A[i]t is much easier to qualify somebody for sick pay with a >substitute= somatic diagnosis than with all sorts of vague complaints. Füredi and Buda, supra note 200, at 203.

appropriate responses to real problems. People who are drawn to institutions to receive Atreatment@ may make important sacrifices to place themselves in in-patient care - cutting off social ties with the community, possibly making it more difficult to return to family, friends, and work.

The treatment provided within psychiatric institutions further contributes to these misperceptions. At OPNI, Kennesay Hospital, and Nyirö Gyula Hospital, psychiatrists report that many people without major mental illnesses receive psychotropic medications or vitamins intravenously. Some psychiatrists explain that intravenous medications may be used because they have a quick-acting effect. In many cases, however, intravenous medications are used because this is what patients expect from Areal@ medical treatment. Whether or not there is a psychiatric indication for the medication, these psychiatrists at Kennesay and Nyirö Gyula Hospital hospitals explained that the placebo effect of the injection is beneficial. Where psychotropic medications are not called for, these psychiatrists report that they often inject vitamins.

## **D.** Inadequate In-Patient Care

As with out-patient treatment, there are no standards or oversight of in-patient treatment practices. As a result, there is enormous variation among in-patient programs. In most of the inpatient programs visited by MDRI teams, there was a lack of psychosocial rehabilitation and a lack of emphasis upon supporting the reintegration of people into the community. Without activities or rehabilitation programs, the in-patient setting can contribute to the loss of community living skills and can undermine the opportunity for active rehabilitation. As one psychiatrist observed, Ait is hard to motivate patients when others are sitting around. The lack of emphasis on return to the community can also lengthen the in-patient stay and contribute to the loss of ties with the community. Thus, programs that fail to provide rehabilitation and out-placement services for people who need them violate the right to services Adirected towards preserving and enhancing personal autonomy.

### 1. Inactivity on the wards

MDRI teams visited psychiatric wards at OPNI, Kennesay Albert Hospital, Nyirö Gyula Hospital, and Ludányhalászi Hospital. At each of these locations, there was a pervasive lack of

A psychiatrist at Ludányhalászi , who routinely administers anti-depressants by infusion, said that Apatients are socialized to believe that they need an infusion. They believe they=re getting >real= medical treatment if they get an injection....When we give oral treatment, patients complain that they are not getting proper treatment. This procedure creates small but unnecessary risks for patients. The Lippincott Manual of Nursing Practice 109-112 (1982) (describing risks of infection, circulatory overload, or air embolism associated with intravenous medication).

Like most other treatment in Hungary=s psychiatric system, the amount or rehabilitation or outplacement support appears to be completely a matter of discretion of the director of the department. At Nyirö Gyula Hospital, for example, two departments receive identical funds. According to the deputy director of one department, rehabilitation and psychotherapy are a major priority in his department. In the identical department upstairs, the psychiatrist reported that there is little or no support of this kind.

<sup>&</sup>lt;sup>204</sup> *MI Principles* principle 9(4).

activities, and a general lack of engagement among staff and patients. During visits to residential and treatment wards at each of these institutions, MDRI teams observed only one organized activity (a bible reading group at OPNI). The majority of patients were observed inactive and unoccupied sitting in hallways and around tables. At Kennesay and Nyirö Gyula Hospital, one third to two thirds of the ward residents were in bed during daylight hours.

Consistent with the Amedicalization@ of social problems described above, most in-patient care appears to consist of psychotropic medications and other Amedical@ treatment. Many psychiatric wards appear to function more as respite care facilities, where individuals come to escape from the pressures of the outside world, rather than places for active treatment or crisis management. On the Aneurosis ward@ at Kennesay Hospital, for example, there is no active treatment because the director stated that patients Ajust need a place to rest.@ At OPNI, the Director of the National Psychiatric Institute stated that skills training or vocational rehabilitation programs are not needed for the great majority of patients because they are Awell enough adjusted already.

#### 2. Neglect of Achronic patients@

People labeled as Achronic patients@ do not receive active psychosocial rehabilitation because they are considered Abeyond rehabilitation@ and without hope of returning to the community. The Director of the National Psychiatric Institute estimated that ten percent of all admissions at OPNI are people who are beyond rehabilitation. These individuals are designated for transfer to social care homes, for which there may be a waiting list of two or three years. As at OPNI, individuals labeled as Achronic@ patients at Kennesay and Nyirö Gyula hospitals are designated for transfer to social care homes (though some people remain as long-term patients). Once a person has been designated for life-long institutionalization, he or she receives very little attention and no assistance at outplacement.

#### 3. Lack of staff leadership

The lack of rehabilitation is, in part, a product of the lack of staff resources. As at social care homes, available resources are not fully used, and there is a lack of leadership from institution authorities to demonstrate the importance or urgency of return to the community. At Kennesay Hospital, for example, there are only three psychiatrists and one psychologist on staff to provide active treatment to a population of 200 people. However, there are many nurses or other technical people on staff. As the MDRI team walked through the wards, most of these staff were engaged in conversations among themselves at nursing stations and in closed rooms. No effort was made to organize activities among patients. The director of the department explained that the same staff had worked at the hospital before the new renovations, when it operated much like a social care home. They did not understand, he said, that staff were supposed to assist patients with rehabilitation. At the same time, no active programs had been designed to engage staff in these activities.

### 4. Lack of case management/outplacement services

At OPNI, there is a small social work staff responsible for assisting people in obtaining services they may need to leave the institution. There are only six social workers assigned to help close to 1,000 patients. One social worker reported that the social work staff is so overwhelmed that they cannot provide extensive assistance to any one person leaving the institution.

At Kennesay and at Nyirö Gyula hospitals, there are no social workers and there is no staff designated to assist with case management. At Nyirö Gyula Hospital, two nurses and some of the psychiatrists do what they can to assist patients to prepare to return to the community. Indeed, the psychiatrist complained that, without social workers, an enormous amount of his time was spent in activities that could have been provided by other staff. At Kennesay Hospital, people who leave the institution come back regularly for injections of psychotropic medications, but the out-patient program is not designed to assist in community placement. No services are available to help patients return to live with their families.

The director of the National Psychiatric Institute confirmed that most psychiatric institutions have limited staff devoted to case management. Traditionally, there was no specialization in psychiatric social work in Hungary. One university in Budapest established a social work specialty in the 1980s, but there is no sub-specialty in psychiatric social work. At Semmelweis University, authorities report that they have recently developed a program to train social workers, but medical school authorities report that there are no jobs for social workers once they graduate. New programs have also been established to provide psychiatric specialization for nurses.

# E. Neglect on Back Wards

The physical conditions at many psychiatric hospitals are clean and modern, and in some areas wards have been modernized at great expense (e.g. Semmelweis Medical School, Kennesay Albert Hospital). In other institutions, such as the psychiatric ward of Nyirö Gyula Hospital, physical conditions are poor and degrading. Within some institutions, such as OPNI, there is great variation among wards. Many areas of OPNI were kept clean, but in a locked ward observed by MDRI investigators, conditions were significantly worse - patients= clothes and bed sheets were soiled, and some patients were left to languish in their own feces. In this ward, a number of patients were also left in cages and other forms of physical restraint. Even in some of the cleanest and most modern institutions observed, such as Kennesay Hospital, some patients are kept in cages.

Whether or not physical conditions are poor, the worst treatment and living conditions in any institutions are on wards for people labeled Achronic@patients. Identification as a chronic patient can mean the end to any effort to provide rehabilitation and outplacement. Even where external

 $<sup>^{205}</sup>$  This ward was not included in the tour given to the March or November 1995 teams. MDRI associate Judy Klein visited this ward in September 1995.

Five individuals were observed in locked, cage-beds. One person was tied to a chair with pieces of cloth. According to ward staff, some residents of this ward were placed in restraints because of a shortage of staff over the weekend.

The Director of one psychiatric department at Kennesay Hospital said that he objected to the use of cages and had them removed when he first assumed his position. When he went away on vacation, the Director of the Hospital ordered the system reinstituted. The Department Director said that cages were often used because of a lack of trained staff to supervise difficult patients, or patients with mental retardation.

conditions are not worse than they are for other residents of psychiatric institutions, the effect of inactivity on the ward begins to mount over time, and people begin to lose the social skills and contact with the outside world that would give them hope of returning to normal life.

Many chronic patients are individuals who are designated for transfer to a social care home. These people are held for months or years until space is available for a transfer. Others who are unable to take care of themselves but are deemed inappropriate for the social care homes may be kept on the same ward, sometimes for life. 208 People who are considered to be Adifficult to manage@ can also be placed on locked wards. In locked wards, as in the wards for chronic patients, conditions are allowed to degenerate as patients spend longer periods of time without contact with the outside world

At Nyirö Gyula Hospital, the back ward for chronic patients is also one of the few locked areas of the institution. The MDRI team observed rooms with twelve and twenty-two beds, some areas with partitions between beds. Bedrooms lead onto a hallway with a table and chairs. There is no decoration on the walls in the bedroom area, and both bedrooms smelled of urine.

There are almost no activities on the ward. One woman asked to be allowed out to the day room with the other patients on the ward so that she could watch television. The woman=s request was denied, explained a member of the staff, because she was confused by alcohol related dementia, and she could not be properly supervised in the television area. A staff member explained that it had been their practice to bring all the ward residents out to a garden for one hour a day when the weather made this permissible. Because of construction on the hospital grounds, however, the staff person said that residents had not been brought outside in weeks.

At the time of the MDRI visit, twenty-six people sat in a row of chairs and around a table in inactivity and silence. Most residents of this back ward wore old, ill-fitting clothes or gowns, sometimes ragged and partially open. Many people on the ward do not have teeth and cannot eat solid food. Half the people on the ward are reported to be incontinent. Asked how people are cleaned, a staff person explained that they are usually given sponge baths. When there are not enough staff, however, she said that the patients are brought in groups to the bathroom area and hosed down together.

The deputy director of the department said that he had made great improvements since he arrived at the institution. A few years ago, he said, there were twice as many people on the ward and there were terrible problems of crowding. At that time, he said, two people were forced to share one bed. The deputy director has been making great efforts to reduce the number of people on the ward, almost entirely through transfer to social care homes. The deputy director said that most people on the ward require little more than supervision and could easily be cared for by their families. Social care homes, he explained, are the only place now available where appropriate supervision could be assumed.

 $<sup>^{208}</sup>$  At Nyirö Hospital, one such resident is a former member of the cleaning staff with no psychiatric diagnosis who is so old and physically infirm that she is no longer able to live on her own. She has avoided transfer out of the city to a nursing home or a social care home because she is friends with other staff members.

# F. Lack of Respect for Patient Choice/Rights

People who receive voluntary or involuntary psychiatric treatment in Hungary lose the opportunity to make basic decisions about their lives, including the course of their treatment. The loss of a person=s ability to make choices about his or her daily life is particularly serious for people receiving treatment in an in-patient setting, where the institution controls every aspect of daily routine.

# 1. Rights in institutions

People receiving treatment in institutions are not recognized to have rights to make choices about decisions - large or small - affecting their daily life. The concept of Apatient=s rights@ is not foreign to Hungary - numerous patients raised the issue with MDRI investigators, demanding that Aour rights as patients@ be recognized. Yet psychiatrists and ward staff interviewed by MDRI investigators explained that, in fact, almost every decision about a patient=s life is ultimately the

Ministry of Health and Social Welfare authorities explained that a draft law on patients= rights is being developed, but this would not be specifically adapted for the psychiatric setting. ATechnically,@ one official said that people who have not been placed under guardianship would have the Asame rights@ to make decisions as all others. However, he assumes that Amost people with mental illness lack the capacity@ to make decisions for themselves. Thus, as a practical matter, doctors regularly make decisions for their patients. Without specific legislation providing Aspecial rights@ for people with mental illness, he said, the treatment of people with a diagnosis of mental illness would likely remain the same under the new legislation.

<sup>&</sup>lt;sup>210</sup> "Every person with a mental illness shall have the right to exercise all civil, political, economic, social and cultural rights@ recognized by international law (*MI Principles*, principle 1(5)), nor shall there be discrimination under domestic laws (*id*, principle 1(4)).

<sup>&</sup>lt;sup>211</sup> *Id.*, principle 1(1).

<sup>&</sup>lt;sup>212</sup> *Id.*, principle 12(1).

<sup>&</sup>lt;sup>213</sup> *Id.*, principle 13(1) and (2).

<sup>&</sup>lt;sup>214</sup> *Id.*, principle 13(2).

responsibility of psychiatrists, administrators, or staff. The only statement of patients rights observed by MDRI investigators was at OPNI, where the legal advocacy service (Lipót Betegjogesély Alapitvány) of the Hungarian Civil Liberties Union has been permitted by the institution to place fliers.

Many of the most pressing concerns raised by patients interviewed by MDRI investigators regarded seemingly mundane issues - issues that take on vital importance when denied in an inpatient setting: access to a telephone to speak with relatives, the ability to wear personal clothing. the recognition of one=s privacy. Left to the discretion of ward staff, conditions vary tremendously by institution. As one woman described her experiences:

The first hospital I was in was awful. They controlled everything we did. We couldn=t even listen to the radio. There was no privacy. The nurses were awful....This place is much better. You have privacy. You have access to a refrigerator. We can listen to our own radio.

In one institution, MDRI investigators observed a woman plead with a psychiatrist to allow her to transfer from one ward to another, where she would have access to a television. She had been placed in long-term detention on a locked ward, at the discretion of a psychiatrist, who explained that she becomes disoriented and might wander about and hurt herself in the unlocked areas of the hospital.

#### 2. **Informed consent to treatment**

Hungarian law does not provide patients a right to informed consent. According to psychiatrists interviewed by MDRI, psychiatrists or other physicians are less likely to provide information to psychiatric patients than to their other clients. As one psychiatrist described, A[u]sually, it is not successful to explain to patients [what medications they are prescribed.] So, we just go ahead and administer drugs. When patients object to a particular form of treatment, Awe try to persuade them. If they refuse, we make a trick. We put it in their drink or give it to them by injection....Once they try it for a few days, they find it harmless and they stop objecting. This view was shared by many other psychiatrists interviewed by MDRI treating patients in in-patient and outpatient setting.<sup>215</sup>

 $<sup>^{215}</sup>$  Involuntary treatment outside of the institution is obviously much more difficult to enforce. As one psychiatrist reported, however, A[i]t is a small country, and we all know each other. We hear about it if a person is not taking medications outside the hospital. If non-compliant, we give them a depot injection.@

Decisions about all forms of treatment are left to the discretion of psychiatrists, even dangerous or controversial therapies such as insulin shock, ECT, or physical restraints. Psychiatric consumers reported to MDRI that ECT is occasionally administered without the subject=s knowledge. <sup>216</sup>

As one consumer reported to MDRI A[m]y friend in the hospital was not told he was being given ECT. He was told thirty times that he was put to sleep to receive an infusion. My mother received ECT and she was never told. I am her only living relative, and I was never told about it. When I finally saw the medical records, I found out that she had received ECT about 100 times. My mother had memory problems, but I did not know why. She changed so much [after going into the hospital], I felt that I had no mother.@

The MI Principles state that A[n]o treatment shall be given to a patient without his or her informed consent...@<sup>217</sup> The MI Principles permit involuntary treatment for individuals who have been involuntarily detained in a psychiatric facility, 218 if an independent authority finds that Athe patient lacks the capacity to give or withhold informed consent@ and Aunreasonably withholds such consent.@<sup>219</sup> The independent authority must also review a proposed plan of treatment and find that it is in the Abest interest of the patient=s health needs. <sup>220</sup> For individuals who are under guardianship (where a person is declared incompetent to make treatment decisions for him or herself), the MI Principles require the guardian to be fully informed about the treatment and to agree to such treatment.<sup>221</sup>

<sup>&</sup>lt;sup>217</sup> MI Principles, principle 11(1). Informed consent includes disclosure about (1) diagnostic assessment; (2) the Apurpose, method, likely duration and expected benefit of the proposed treatment@ (3) Aalternative modes of treatment, including those less intrusive@ and 4) A[p]ossible pain or discomfort, risks and side-effects of the proposed treatment. @ Id. principle 11(2).

<sup>&</sup>lt;sup>218</sup> *Id.*, principle 11(6)(a).

<sup>&</sup>lt;sup>219</sup> *Id.*, principle 11(6)(b).

<sup>&</sup>lt;sup>220</sup> *Id.*, principle 11(6)(c).

<sup>&</sup>lt;sup>221</sup> *Id.*, principle 11(7).

# IV. Civil Commitment and Guardianship

In December 1994, Hungary adopted a new law regulating voluntary and involuntary commitment to psychiatric institutions. The new legislation was intended to harmonize Hungarian law with European human rights standards, a condition of Hungary=s inclusion in the Council of Europe and ratification of the ECHR.

On its face, Hungary=s law is similar to the standards under international human rights law. Most important, the new legislation limits involuntary detention to people who are diagnosed as mentally ill and constitute an Aimmediate and serious danger@ to themselves or others or are in

Health Act of 1972, amendment no. LXXXVII/1994 (Dec. 22, 1994), entered into force February 1995, '35(5) (urgent commitment), '35/A(3) (involuntary commitment)(hereinafter Hungarian Commitment Law).

<sup>&</sup>lt;sup>223</sup> Ágnes Dósa, New Legislation on Civil Commitment in Hungary, 14 MED. & L. 581 (1985).

See supra text accompanying note 78. The support of the medical profession and legal scholars for amending the law also played a part in the passage of the new law. Dósa, supra note 223, at 581.

Aurgent need@ for treatment. Without further clarification in the law, the standard for determining dangerousness or urgent need is open to broad interpretation. 225 The standard is further weakened by the failure to provide adequate procedural protections, as required by international law. These procedural inadequacies are described further in part A of this Chapter.

The value of Hungary=s new commitment law is also severely limited by the exclusion of people detained in long-term facilities (social care homes) - the people who have the greatest need

Hungarian Commitment Law, supra note 222, ' 35(5) (commitment on the basis of Aurgent need.@). See Dósa, supra note 223, at 583. Hungary=s standard for commitment comes close to the requirements of international law, but it is somewhat broader than it should be. Under Hungarian law, a person may be subject to regular involuntary commitment, or they may be committed on the basis of Aurgent need@. Under the procedure for involuntary admission based on urgent need ( ' 35/A(3)), the law does not require immediate or imminent danger, contrary to the MI Principles principle 16(1)(a) (requiring Aa serious likelihood of immediate or imminent harm...@). The court must find only that:

due to the acute disorder of his/her mental condition, impose immediate and serious danger for his/her own or others= life or health, or for his/her environment, and this danger can be eliminated only by the patient=s immediate hospitalization.

' 35(5). Although close to the requirements of the MI Principles, Hungarian law diverges significantly by permitting commitment on the basis of serious danger to the Aenvironment.@ MI Principles allows commitment when one presents an immediate or imminent danger to Athat person or other persons@ (principle 16(1)(a)) (emphasis added).

The term Aenvironment@in Hungarian law is broad and could be construed to allow detention based on destruction of property.

Under Hungarian law, dangerousness can also be broadly interpreted to permit commitment Anot because of what he or she would actually do to himself or herself, but because what he or she would not do for himself or herself (passive harm standard).@

for the law=s protection. In most cases, people may be placed in social care homes by family members or other Alegal guardians@ without any judicial or independent review. As described in part B of this Chapter, Hungarian guardianship law fails to provide the protections required by international law. People placed under guardianship are stripped of all their rights, and their legal identity, making it very difficult to continue to live in the community. Once a judge appoints a legal guardian over a person, there is no requirement of review over the course of a lifetime.

Taken together, Hungary=s civil commitment and guardianship laws fail to provide the protections promised by the new legislation, nor do they provide the minimum standards required by international human rights law. In practice, large numbers of the 19,000 people in Hungary=s psychiatric institutions are arbitrarily detained, in violation of the ICCPR and the ECHR.

## A. Civil Commitment

The ICCPR and the ECHR both require that all people be protected against Aarbitrary detention. <sup>226</sup> The European Commission on Human Rights has found that, when any person is subject to psychiatric commitment, the ECHR provides a number of substantive and procedural protections, <sup>227</sup> including the right to review by a judicial or other authority independent of the

<sup>&</sup>lt;sup>226</sup> ICCPR art. 9; ECHR art. 5; see Quinn, supra note 35, at 20-22.

Winterwerp v. The Netherlands, 2 Eur. Ct. H.R. (ser. A) at 39 (1979). In addition to those protections found under the ECHR, Recommendation R (83) 2 of the Council of Europe guarantees, among other protections, the right to a judicial hearing, the right to have counsel present at the hearing, and the right of appeal. The Recommendation also provides that persons involuntarily or voluntarily placed do not lose legal capacity. See Rosenthal & Rubenstein, supra note 31, at 272-75 (describing the requirements of the ECHR with respect to psychiatric commitment).

admitting facility. 228 The MI Principles have set forth the internationally accepted minimum standards for psychiatric commitment in detail - including the right to attend and be heard personally at the commitment hearing, <sup>229</sup> a right to representation by counsel without payment, <sup>230</sup> and the right to periodic review of each commitment. <sup>231</sup>

 $<sup>^{228}</sup>$  In X. v U.K., 46 Eur. Ct. H.R. (ser.A) at 18 (1991), the European Court of Human Rights found that ECHR Article 5(4) requires independent review of psychiatric commitments. See discussion in Rosenthal & Rubenstein, supra note 31, at 278. Also, Council of Europe Recommendation 1235 (1994) section 7 (i)(b) similarly requires judicial review, frequent subsequent reviews and a right to appeal in the case of compulsory admission.

<sup>&</sup>lt;sup>229</sup> MI Principles principle 16(2) (right to a hearing); principle 18(2)(the right Ato attend, participate and be heard personally in any hearing.@).

<sup>&</sup>lt;sup>230</sup> *Id.* principle 18(1).

<sup>&</sup>lt;sup>231</sup> *Id.* principle 17(4).

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The new Hungarian commitment law provides two ways for a person to be involuntarily committed to a psychiatric institution: court ordered commitment and Aurgent need® for commitment. Under court ordered commitment, a court must conduct a hearing before a person may be detained in a psychiatric facility. Alternatively, the law allows a person to be detained immediately in an institution based on "urgent need" for treatment that cannot be provided outside the institution. A person may be sent to an institution based on Aurgent need® by either an outpatient clinic or by a physician. The court must review the urgent need commitment within eight days. In practice, court ordered commitment requiring review prior to detention rarely takes place. As enforced, many practical limitations in the implementation of the law deprive people the full opportunity to exercise meaningful rights in the commitment process. These limitations on commitment practice are described below.

AUrgent need for commitment@ is the literal translation of the Hungarian law. Other legal commentators have referred to this as Aemergency@ commitment. *See* Dósa, *supra* note 223, at 583.

<sup>&</sup>lt;sup>233</sup> Hungarian Commitment Law '35(4).

Judges and expert witnesses interviewed by the MDRI team said that Aurgent need@ was the basis for nearly all commitments, and they knew of few cases in which the law=s provisions for prior review had been invoked. Judges and experts expressed confusion about the law, saying that they could not conceive of a situation where a psychiatrist or physician would seek court-ordered commitment before sending that person directly to the institution. These observations are consistent with the prediction of one Hungarian legal scholar, who observed that the standard for urgent (emergency) commitment and court-ordered commitment were functionally similar. AOwing to this slight difference, and the procedural ability of emergency detention to avoid court in the first instance, it is likely that the emergency provision will be used most frequently.@ Dósa, *supra* note 223, at 583.

### 1. **Inadequate right to counsel**

Under the MI Principles, an individual subject to psychiatric commitment has a right Ato choose and appoint counsel. @ 235 If an individual cannot afford representation, counsel must be provided at the government=s expense. 236 Hungary=s new civil commitment law provides a right to counsel by what is called a Acasual guardian. @ As described below, the system for providing a legal representation under the new commitment law does not provide effective counsel for people subject to civil commitment.<sup>237</sup>

### Confusion about the role of the legal representative a.

Patients subject to involuntary commitment report to MDRI that they were never aware that they had a legal representative. A number of factors contribute to the confusion about the role of the legal representative on the part of people subject to commitment - and on the part of the people supposedly serving as their counsel.

<sup>&</sup>lt;sup>235</sup> MI Principles principle 18(1). The Council of Europe Recommendation 1235 (1994) section 7 (ii)(e) similarly requires that Apatients must have free access to a >counsellor= who is independent of the institution.@

<sup>236</sup> Id. Recommendation R (83) 2 of the Council of Europe also guarantees the right to counsel. See supra note 38.

An independent analysis of the civil commitment process by Central European University Professor Judit Sandor also finds that practices of providing legal representation fall short of the requirements of European human rights standards. See discussion in Sandor supra note 89, at 87.

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The language of Hungary=s commitment law creates confusion because it uses the term Acasual guardian@ to describe the person=s legal representative. The term Acasual guardian@ is undefined, and judges with whom MDRI spoke were not clear on the precise meaning of the term. In general usage, a guardian plays a very different role than a legal representative. The right to counsel is designed to ensure that someone is available to help an individual present their interests as effectively as possible. A guardian, in contrast, is a surrogate decision maker for an individual who is adjudicated to lack legal competence in certain areas.

If a person acts as a Aguardian, he or she is not necessarily representing that persons views. A guardian may also have a paternalistic relationship with his or her client, hindering the clients ability to present his or her own case. MDRI investigators observed one commitment hearing and interviewed the person designated as legal representative. In her opinion, and in the opinion of the judge who was present, the role of the legal representative is to represent her own best judgement - and not necessarily that of the patient.

The confusion about the role of the legal representative is exacerbated by the fact that, to save money, courts often hire retired judges to act as casual guardians. As a result, the legal representative may share the outlook of the court rather than as an advocate of the person subject to commitment. From the point of view of the person subject to commitment, the judge and the legal representative are often indistinguishable.

The law states that for anyone who "does not have a legal or authorized representative during the procedure, the court shall appoint a casual guardian.@ Hungarian Commitment Law ' 35/B(3).

Most judges and experts interviewed by the MDRI team also used the term "casual guardian" as the legal representative (though not necessarily an attorney) whose job it is to represent the wishes of the person subject to commitment at the hearing.

In one hearing that MDRI witnessed at Semmelweis University Psychiatric Clinic in Budapest, the legal representative said nothing, allowing the psychiatric expert to ask all questions. The judge later told MDRI that he recalled only one case where the legal representative/casual guardian protested a commitment. The legal representative also felt that the decision to protest the commitment was hers and not the client=s, an attitude contrary to the usual understanding of a legal advocate.

When a relative is available, some judges report that they will rely on that person as a legal representative/casual guardian.<sup>241</sup> The presence of a relative may worsen the situation. Courts usually defer to the relative to represent the views of the patient, and appoint no legal representative. When they are aware of a conflict of interest between the relative and the person subject to commitment, one judge said that a professional legal expert would be used. The judges interviewed by MDRI, however, said that they do not make a regular practice of inquiring into whether the relative might have a conflict of interest with the person subject to commitment.<sup>242</sup> Indeed, one judge said that she assumed that the individual "would not be able to communicate his or her views 99% of the time."

### b. Lack of rights to render effective representation

The right to counsel is further undermined by the lack of a right "to participate and be heard personally in any hearing."<sup>243</sup> The commitment law also fails to explicitly recognize the right to call witnesses of one=s own choosing, to present an independent mental health evaluation or other independent expert reports, and to have access to one=s own medical records.<sup>244</sup>

### Lack of communication and preparation for hearing c.

Other problems hinder a person=s ability to articulate his or her interests and desires at a commitment hearing. Legal representatives spend little if any time on pre-hearing investigations, and often learn the facts of the case only when the judge reads them in the hearing. 245 Furthermore. immediate hospitalization for eight days hinders a person=s ability to articulate his or her views at a hearing, particularly when the person has been forcibly medicated. Additionally, a court may not be able to evaluate that person=s capabilities absent the medication.

<sup>&</sup>lt;sup>241</sup> Judges hearing commitment cases at OPNI in Budapest reported that in 2 of the last 14 cases family members had served as legal representatives for the person undergoing a commitment hearing. This practice may violate the commitment law. The practice also suggests that the legal representative is being treated as a guardian. Under Hungarian guardianship law, a Guardianship Authority is mandated to select the nearest relative as guardian. See discussion in text accompanying note 264, infra.

The failure of the court and authorities to investigate conflicts of interest is also a problem in guardianship, discussed infra Chapter IV section B.

<sup>&</sup>lt;sup>243</sup> MI Principles principle 18(5). The Council of Europe Recommendation 818 (1977) section 13 (I)(iii) recommends member states Ato ensure that court decisions are not taken on the basis of medical reports only, but that the mental patient, like any other person, is fully given the right to be heard.... Also, the Council of Europe Recommendation (83)2 states that the Apatient should be informed of his rights and should have the effective opportunity to be heard personally by a judge except where the judge, having regard to the patient=s state of health, decides to hear him through sole form of representation.@

<sup>&</sup>lt;sup>244</sup> *Id.* principles 18(4-6).

<sup>&</sup>lt;sup>245</sup> Although legal representatives may visit their clients and review case records, a heavy case load often prevents them from conducting an adequate investigation. One legal representative told MDRI that she worked at eight hospitals and observed thousands of cases in one year.

# 2. Lack of financing for judicial review

Inadequate financing of judicial review contributes to the cursory nature of commitment hearings. When the new commitment law was adopted, the government provided the courts with no new funding to conduct the large number of hearings that the law requires annually. Every year, there are 9,500 admissions at Budapest=s National Psychiatric Institute alone, and each commitment in excess of thirty days requires periodic review. Without more judges to hear these cases, each judge has an overwhelming case load. Judges often hear as many as sixty hearings in one daily session, and commitment hearings last an average of four to five minutes each. This includes the time that it takes for the judge to review the facts in the written record and read out a summary of the individual's diagnosis. Under these constraints, judges cannot appropriately deliberate over each case. As described by one judge, Athe situation currently is awful. The patients fight with each other, and many court employees won=t go to the institution. We cannot afford to transport the patients to court. 

@ 246

# 3. Use of "voluntary" status to circumvent legal protections

Judges report that some psychiatrists and department heads label their patients as "voluntary" to avoid the civil commitment process. After a few months of experience with the new commitment law, the judges said that they noticed a few wards that classified every patient as voluntary. Many such wards, they observed, served the most disordered and potentially violent patients. The director of the National Psychiatric Institute in Budapest estimates that 90% of all admissions are classified as voluntary.

A number of psychiatrists told MDRI that they considered the commitment process a "hassle" and a "formality" and much preferred to classify individuals as voluntary patients. At the psychiatric department of a general hospital in Budapest, the department director told the MDRI investigators that he could convince any patient to accept "voluntary" treatment, and had never classified any of his patients as involuntary. <sup>247</sup>

Because Hungary's commitment law fails to provide substantive and procedural protections necessary for meaningful review, it is questionable whether all or even most of Hungary=s Avoluntary@ admissions are truly voluntary. Hungary's commitment law requires that the court be informed of a voluntary commitment within fifteen days and that the court review the necessity of continued hospitalization every thirty days. However, the law=s only standard for admission is when a person Ais constantly or periodically pathological due to his/her illness or addiction." The law delegates the decision to voluntarily admit a patient to the director of the facility. Besides the

<sup>&</sup>lt;sup>246</sup> See infra Chapter III section A.

According to one commitment judge, some department heads objected openly to the new law=s limitation of their discretion to detain individuals in the institution. One judge discussed this matter with department heads and with the Director of the National Psychiatric Institute, and she reported that more and more psychiatrists are slowly accepting the new law.

<sup>&</sup>lt;sup>248</sup> Hungarian Commitment Law ' ' 35(3), 35/F(2).

thirty days= review, the law does not outline the role of the court.<sup>249</sup> There is no right to counsel at the review.

In the absence of any legal clarification of the purpose of review, one judge said that, when she reviews voluntary cases, she seeks to find out (a) whether a person is competent to make a decision to commit him or herself and (b) whether that individual truly intends to remain voluntary. Despite these good intentions, the same judge appeared willing to accept a classification of voluntary unless there is vigorous and persistent objection by the person subject to commitment. As she describes, A[t]he usual scenario is that the patient objects at the beginning. But during the hearing, the patient hears the views of his psychiatrist, hears the expert opinions, and hears all the witnesses tell the court why the commitment is necessary. By the end of the hearing, the patient usually agrees.

A number of psychiatrists said that they found it easy to convince most patients to sign in to the institution voluntarily. Two voluntary patients interviewed by the MDRI team said that they were not aware that they had a choice about leaving the institution. One patient said that, without counsel representing them, many patients were afraid to speak out about their true desires. If they made trouble by seeking release from the institution, he said, patients were afraid that they would be punished by psychiatrists on the ward.

Not all judges report that they conduct such a review. Some are willing to accept as Avoluntary@ those patients who do not speak out against commitment. One judge observed that the vast majority of people subject to commitment are not capable of expressing their preferences, yet she had no objection to the approval of 90% of commitments as voluntary. One court-appointed psychiatric expert expressed his understanding that the Alaw does not distinguish between a patient who is unable to express his view and a patient who does not object@ to commitment.

### 4. Hearings held in institutions and hospitals

As described above, a lack of adequate funds forces Hungarian courts to conduct commitment hearings inside institutions, instead of in a courtroom. This situation may diminish the adversarial process necessary for a fair and impartial hearing. <sup>251</sup> For patients, institutions and psychiatric hospitals can be coercive environments. Patients may lack the confidence to express their desires openly before staff or other patients. Holding the hearing in a psychiatric facility may also reinforce the view among patients and staff that the commitment is a medical and not a legal decision.

### 5. Failure to protect people most at risk

Hungary's civil commitment law applies only to individuals committed to rehabilitation facilities or psychiatric facilities (including psychiatric wards of general hospitals and psychiatric institutions). 252 The law does not protect individuals in "social care homes," long-term facilities that typically house people for life. There are approximately 7,000 beds in Hungary's social care homes, representing approximately 39% of the beds for people with mental illness. <sup>253</sup>

Concerns about the setting of the commitment hearing in the United States led the American Bar Association to recommend that the hearing be held in a courtroom. Commission on the Mentally Disabled, American Bar Association, Involuntary Civil Commitment: A Manual for Lawyers and Judges 27 (1988) (Athe setting of the commitment hearing should be fit the seriousness of the issues and possible consequences. (2).

<sup>&</sup>lt;sup>252</sup> Hungarian Commitment Law '35(2).

<sup>&</sup>lt;sup>253</sup> Psychiatric facilities have approximately 11,000 beds.

Court-appointed legal guardians place people in social care homes. While there is some legal process associated with the appointment of the guardian, <sup>254</sup> Hungarian law requires no legal process to detain a person in a social care home. By contrast, the *MI Principles*= protections against arbitrary detention in a psychiatric institution create no exception for people under guardianship. <sup>255</sup> Failure to provide such protection for individuals detained in Hungary=s social care homes constitutes arbitrary detention under international human rights law.

# B. Guardianship

Hungary=s guardianship law and administrative process raise a number of serious human rights concerns by unnecessarily and arbitrarily depriving people with mental disabilities of their rights. Since Hungary=s law and process for determining competence and appointing guardians is complex, these procedures are described in detail below. An evaluation of the law under international human right standards follows.

The delegation of rights to a guardian can be important to protect an individual=s rights, when strictly limited to circumstances in which that person is truly unable to exercise his or her capacity to make decisions. Under international human rights law, people with mental disabilities retain their basic human rights, including their power to make decisions about themselves to the extent possible.

The *MI Principles* state that people with mental disabilities Ahave the right to exercise all civil, political, economic, social, and cultural rights@ recognized by international law.<sup>256</sup> The arbitrary denial of any right accorded to other citizens under domestic laws constitutes unlawful discrimination on the basis of mental disability.<sup>257</sup> Any decision that Aa person lacks legal

<sup>&</sup>lt;sup>254</sup> See supra Chapter IV section B.

<sup>&</sup>lt;sup>255</sup> *MI Principles* principles 15-6.

<sup>&</sup>lt;sup>256</sup> *MI Principles* principle 1(5).

<sup>&</sup>lt;sup>257</sup> Discrimination on the basis of mental illness is prohibited in Principle 1(4) (AThere shall be no

capacity@ and any decision to appoint a guardian on that basis, Ashall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. @ <sup>258</sup> A person subject to guardianship has a right to counsel, and any decision to appoint a guardian must be reviewed at reasonable intervals.<sup>259</sup>

### 1. Competence and Guardianship under Hungarian law

Hungary has a unique bifurcated process for appointing and administering guardianships: a family court judge determines whether guardianship is necessary, and a Guardianship Authority selects the guardian.

### Role of the judge: determination of competence a.

discrimination on the grounds of mental illness. ADiscrimination@ means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights.@). Id.

<sup>&</sup>lt;sup>258</sup> *Id.* principle 1(6).

<sup>&</sup>lt;sup>259</sup> *Id*.

The judge is responsible for determining whether or not a person meets the standard for guardianship, i.e. whether he or she has full competence, limited competence, or incompetence. The determination of competence is based upon whether that person is able to Amanage his or her own affairs. <sup>260</sup> If a judge finds a person to lack the capacity to manage his or her own affairs, the judge must determine whether to appoint a plenary (full) or partial (limited) guardian. After the court makes this determination, the administration and oversight of the guardianship is left entirely to a Guardianship Authority.

A judge may also appoint a temporary guardian, <sup>261</sup> for a set period of time, or a guardian *ad litem*, <sup>262</sup> who serves to represent an individual found incompetent for a particular legal proceeding.

# b. Role of the Guardianship Authority: choice and administration of guardianship

The Guardianship Authority, which has the power to select the guardian, <sup>263</sup> is part of the administrative structure of the local district government. In Budapest, a city of two million people, there is one guardianship authority in each of twenty-two districts. MDRI interviewed the chief of the family court for the Buda district, the Director of the Guardianship Authority in District 11, one of Budapest=s larger districts, and a woman who serves as a public guardian for twenty-six people

The standards for partial and full incompetence are very similar. Limited competence may be found where a person=s ability Ato manage [his or her] own affairs has significantly decreased, permanently or periodically, due to mental deficiency or pathological addiction.@ Law IV/1959, Law on Limited Competence, '13(2). Full incompetence is determined when a court finds that a person Afully lacks the decision making capacity necessary for managing [his or her] affairs due to mental illness or mental deficiency.@ *Id.*, Law on Incompetence, '16(2).

<sup>&</sup>lt;sup>261</sup> Art. 307(2), Act. No. III of 1952 on Civil Litigation. A temporary guardian may also be appointed during a regular guardianship proceeding if a court determines that there is probable cause to believe that the litigation will result in the establishment of a guardian. *Id*.

<sup>&</sup>lt;sup>262</sup> Law IV/1959, *supra* note 260, art. 72.

<sup>&</sup>lt;sup>263</sup> *Id.* art 11(2).

from District 11. MDRI also interviewed numerous people under guardianship living in long-term social care homes and in the community.

When a spouse or other relative is available, the Guardianship Authority is mandated to choose the nearest relative as the guardian. <sup>264</sup> If there is a conflict of interest with a relative, or if there is no relative available, the judge may appoint a Apublic guardian. In District 11, there are two permanent public guardians, each with 26 to 28 wards.

### Powers of the guardian and the ward c.

Guardians are responsible for all major legal and financial decisions of their wards. They also serve as representative payees on disability or pension benefits. Certain major decisions, such as the sale of a home, must be approved in advance by the Guardianship Authority. 265 The wards= funds must be maintained in a separate account, and the guardian is required to submit an annual financial report to the Guardianship Authority.

People under partial guardianship (the ward) may make small contracts and maintain control of current earnings. Individuals living under plenary guardianship do not have such rights. In addition to losing the power to make all legal contracts or decisions, they lose their identification card.<sup>266</sup>

While a Guardianship Authority must review questions regarding the Amaintenance@ of the ward, a guardian has almost complete power to decide where a ward lives or moves and can

<sup>&</sup>lt;sup>264</sup> Law on Limited Competence 'int.11(2).

<sup>&</sup>lt;sup>265</sup> *Id.* art. 61.

<sup>&</sup>lt;sup>266</sup> The total loss of rights under plenary guardianship makes it very difficult to function in the community. Many daily activities, such as taking a book from the library, require an identity card. Discrimination against people under plenary guardianship is described further in section 4, infra.

permanently place the ward in a social care home. <sup>267</sup> The Director of the Guardianship Authority in District 11 reports that a person under partial guardianship may challenge his or her commitment to a social care home. If a person under partial guardianship challenges the decision of the guardian to commit, the Guardianship Authority resolves the dispute. <sup>268</sup> If a person under partial guardianship refuses placement in a social care home, the guardian or Guardianship Authority may also return to the family court to seek plenary guardianship. A person under plenary guardianship does not have power to challenge his or her commitment to a social care home. According to social care home authorities, the vast majority of people placed in social care homes are under plenary guardianship.

# 2. Improper delegation of duties to administrative authorities

The bifurcation of power between the family court and the Guardianship Authority limits the value of judicial review and permits the deprivation of a persons= rights at the discretion of the Guardianship Authority. As described above, international human rights standards require that the rights of people with mental disabilities be limited only to the extent necessary and only by independent judicial authorities through a fair hearing.

The procedural protections in the process of appointing a guardian, required by the *MI Principles*, are only one specific example of the more general principle that people with mental disabilities retain all the rights of other citizens. The judicial decision to appoint a guardian must be justified by that individual=s lack of mental capacity, and only those rights that a person is incapable of exercising may be properly delegated to a guardian.

The scope of judicial review is limited under the Hungarian law, despite the fact that the effect of guardianship will have a wide-reaching limitation on a person=s rights. The law requires only that a judge determine whether a person can Amanage his or her own affairs. The chief of the family court observed that, in practice, the primary emphasis of the inquiry is on the person=s ability to manage his or her finances. The power of a full guardian, however, extends much farther. The guardian may decide to sell a person=s home in the city and move him or her to a social care home,

The guardianship authority must review matters that concern Athe maintenance@ of the ward. *Id.*, '19(1). According to one Guardianship Authority Director, the Guardianship Authority routinely must approve any placement in a social care home. Authorities at both social care homes felt that the decision to commit rested with them. The Social Care Act appears to delegate the decision to the Guardian. Act III on Social Care, arts 93-94. None of these sources defer to the viewpoint of the person subject to commitment.

<sup>&</sup>lt;sup>268</sup> Act on Social Care, arts. 93-94.

for example. The court is not required to be informed that a person is being detained in an institution.

As a result of the limited scope of review, the amount of information provided to the court about the proposed treatment of the ward is likely to be extremely limited. Because the law mandates the court to determine only the *necessity* for a guardian, and not who will serve as guardian, no judicial oversight exists to prevent potential conflicts of interest between the guardian and ward. The result is a transfer of power over a class of people to an administrative body that lacks the capacity to conduct hearings and gather evidence. The Guardianship Authority is not required to present the court with a plan for the treatment of a potential ward or the disposition of property.

The court does not have the power to define the exact powers of a guardian to ensure that the ward retains all rights for which he or she is competent. Even if the Court becomes aware of a specific problem or a specific desire of the ward, unrelated to the disability, the Court has no power to provide further direction to the Guardianship Authority to make the deprivation of rights inherent in a guardianship less onerous.

With the power of the court so limited, there is little a judge can do except to accept or reject a recommendation to appoint a guardian. At a certain point, judicial review becomes a mere formality. The chief of the family court observed that the decision to place a person under plenary guardianship is primarily a medical decision. She said she defers to the judgement of the court=s medical expert in such cases. The Director of the Guardianship Authority for the 11th District observed, AI never saw a case where the judge denied a guardianship over the recommendation of the expert. In theory, the court can make its own decision, but in my opinion that is all the judge relies upon.@

The limited scope of judicial review and the broad delegation of powers to the Guardianship Authority reinforce the view that guardianship decisions are medical and not legal. International law, which protects the equal rights of people with mental disabilities, requires that any decision to limit a person=s legal rights be made solely by a judicial body.

### 3. Lack of periodic review

One of the most serious problems with the Hungarian guardianship is the lack of a right to periodic review, required under the MI Principles. Under Hungarian law, a relative, guardian, Guardianship Authority, public prosecutor, or the person under guardianship may challenge a guardianship at any time. <sup>269</sup> However, no action is required by the guardian or others. In the absence of such assistance, the ward must initiate the legal process and must obtain relief from the same judge that granted the guardianship.

The right to appeal under Hungary=s law does not meet the MI Principles = requirement of periodic review. A person=s mental capacities may change over time, but that person may not have the knowledge of his/her rights or the resources, knowledge, or confidence to challenge the

<sup>&</sup>lt;sup>269</sup> Law on Limited Competence, int.13(2).

guardianship. People frequently become dependent on their guardian or upon the institution in which they live. Reliant on these outside structures, people under guardianship may be hesitant or afraid to challenge the authority of their guardian. In recognition of these common circumstances, the *MI Principles* explicitly require periodic review at Areasonable intervals. @ <sup>270</sup>

The lack of a legal requirement for periodic review of guardianship is particularly serious in cases where guardians place wards in social care homes. Social care homes are physically isolated, and people living within them lose contact with friends, family, and a vision of normal life. Many adults in social care homes interviewed by MDRI could not remember the last time they had seen their guardian. There is no legal requirement that a guardian visit his or her ward; the Guardianship Authority representative and public guardian interviewed by MDRI acknowledged that some guardians never visit.

Under these circumstances, a ward=s mental condition could change and improve without the knowledge of the guardian. Having lost contacts with friends and relatives, the requirement that institution residents seek a judicial hearing to challenge their guardianship is unrealistic. As a practical matter, contacting the court that established the guardianship years earlier in another part of the country could prove daunting even for individuals without disabilities.

<sup>&</sup>lt;sup>270</sup> MI Principles principle 1(6).

The procedure for appointing a temporary guardian, which is time delimited by the court at the time a person is found to be incompetent, would provide a vehicle under Hungarian law to ensure periodic judicial review. According to the Gönczöl Report, however, this provision of the law is routinely ignored.<sup>271</sup>

### 4. Lack of power to appeal decisions of the guardian

Although Hungarian law provides a right to appeal a decision to appoint a guardian, it provides no power to appeal a particular decision or action of a guardian or the Guardianship Authority. Indeed, major decisions can be made by the guardian and the Guardianship Authority without ever consulting with the ward. To reverse a specific decision made by the guardian, the ward must appeal to the original court that ordered the guardianship. At this proceeding, the ward must convince the court to overturn its previous decision to appoint the guardian by demonstrating that he or she is now fully capable of Amanaging his/her own affairs. @ If the court determines that an individual cannot manage his or her own affairs and requires a guardian, it does not have the power to provide further direction to the guardian or the Guardianship Authority.

### 5. Discrimination and denial of political rights

People living under guardianship are broadly deprived of rights not necessarily related to their specific disability. Individuals with limited competence cannot make Alegal statements@ of any kind. For example, a person under guardianship would not be able to make a will. Additionally, a person under guardianship loses all political rights and cannot vote. 272 The state takes away their identity documents, leaving them at risk of being arrested and detained until they can prove they are under guardianship. Without identity papers, a person cannot perform normal functions of independent living.

The unnecessary deprivation of rights itself constitutes unlawful discrimination on the basis of disability.<sup>273</sup> This discrimination is particularly serious, because it creates an additional burden on

<sup>&</sup>lt;sup>271</sup> Gönczöl Report, *supra* note 110, at 83.

ESC art. 13(2)(people receiving social or medical assistance Ashall not, for that reason, suffer from a diminution of their political or social rights.@).

<sup>273</sup> MI Principles principle 1(4).

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<sup>&</sup>lt;sup>274</sup> *Id* principles 3, 7(1).

### **Oversight** V.

### A. **Lack of Enforceable Standards**

The Hungarian National Institute of Psychiatry and Neurology (OPNI) is responsible for overseeing national mental health policies and practices that apply throughout the country, including psychiatric institutions in other cities and psychiatric departments of general hospitals. Psychiatrists throughout Hungary=s mental health system reported that, in practice, there is very little oversight or control. The directors of each psychiatric department (including the department directors within OPNI) have almost total discretion to determine what kind of mental health treatment they will provide.

The Ministry of Health and Social Welfare administers a Council of Psychiatry which has some power to establish recognized professional standards. The Council publishes a journal in which it discusses treatment practices and controversial new issues regarding psychiatric treatment. This Council does not establish regulations, however, and its findings are not enforceable.

The lack of medical standards results in great variability among departments and potential for abuse. Psychiatrists in Hungary=s mental health system report that good and poor psychiatric treatment may exist side by side in different departments within the same institution. At one general hospital, the deputy director of a psychiatric department reported that another department at the same hospital used unnecessary and potentially dangerous levels of electroconvulsive therapy (ECT).<sup>275</sup> Other psychiatrists reported the improper use of physical restraints<sup>276</sup> and insulin shock therapy.<sup>277</sup>

 $^{275}$  ECT can be dangerous if misused. Brain damage may occur when the ECT-induced seizures are frequent, not spaced properly and unmodified by oxygenation and muscle relaxation. Thomas G. Bolwig, Biological Treatments Other Than Drugs, in Norman Sartorius et al., TREATMENT OF MEDICAL DISORDERS 91, 104-5 (1993). Under conditions of modern, clinical practice, there is no evidence that unilateral ECT causes brain damage and side effects can be reduced. However, even under optimal conditions, Atime-delimited, spotty retrograde amnesia...may be long-lasting. @ D.P. Devand, Andrew J. Dwork, Edward R. Hutchinson, Tom G. Bolwig & Harold A. Sackheim, Does ECT Alter Brain Structure?, 151 AM, J. PSYCHIATRY 957, 958 (1994), For high-risk patients, the use of muscle relaxants and oxygenation becomes more critical. ECT can cause bone fractures, and for elderly patients with frail bones a higher dose of muscle relaxants is necessary. Kaplan & Sadock, supra note 187, at 2618.

The most common side-effect of ECT is short-term memory loss, and the risk of both retrograde and anterograde amnesia increases with the frequency of ETC. Electroconvulsive Therapy--Consensus Conference, 254 J.A.M.A. 2103, 2103 (1985). Significant, long-lasting memory loss secondary to ECT have also been documented. Larry R. Squire, Pamela C. Slater and Patricia L. Miller, Retrograde amnesia and bilateral ECT: Long-term followup, 38 ARCHIVES GEN. PSYCHIATRY 89-95 (1981); John R. Taylor, Racel Tompkins, Renee Demers and Dale Anderson, Electroconvulsive therapy and memory disfunction: Is there evidence for prolonged defects? 17 BIOLOGICAL PSYCHIATRY 1169-1193 (1982).

<sup>&</sup>lt;sup>276</sup> Physical restraints, in particular Afour-point@ restraints, when applied inappropriately or when prolonged, has been found to lead to shoulder and back pain, muscular-skeletal injuries and nerve damage, skin abrasion, and psychological trauma. Physicians for Human Rights, Cruel and Inhuman Treatment: The Use of Four-Point Restraint in the Onondaga County Public Safety Building, Syracuse, New York 47 (1993). Without adequate supervision, physical restraint can cause complications leading to severe injury or death; one study in New York State found that between 1979 and 1982, 17 people died as a result of being physically restrained. Elvn R. Saks, The Use of Mechanical Restraints in Psychiatric Hospitals, 95 YALE L. J. 1836, 1837 n. 4 (1986).

These treatments can cause great suffering and may be dangerous and life-threatening, particularly when used in violation of internationally-recognized standards. For insulin shock therapy, there is now a well established international consensus that the dangers of the treatment outweigh its potential benefits.<sup>278</sup>

The *MI Principles* require states to recognize and enforce human rights protections consistent with international standards for people with mental disabilities Athrough appropriate legislative, judicial, administrative, educational and other measures...@<sup>279</sup> States must not only ensure that people with mental disabilities are protected against extreme, life threatening abuses, they must also ensure that individuals receive Asuch health and social care as is appropriate to his or her health needs...@<sup>280</sup> Minimum health and human rights standards must be legally enforceable. <sup>281</sup>

# B. Lack of Human Rights Oversight

The human rights concerns documented in this report and the report of Hungary=s Human Rights Ombudswoman, Katalin Gönczöl, demonstrate the need for oversight of the rights of people in Hungary=s mental health system. Indeed, the widespread attention to the Gönczöl Report demonstrates the power of an independent oversight body to identify and focus national attention on abuses that have been long overlooked. The existence of a constitutionally mandated ombudsperson in Hungary is an important safeguard, but it is no substitute for the ongoing and systematic oversight mechanism that is needed. According to Ministry of Health and Social Welfare officials, there is no

Insulin therapy can cause permanent brain damage and cause a person to lapse into a prolonged coma or subcoma, resulting in persistent anterograde amnesia. Bolwig, *supra* note 275, at 115.

Bolwig, *supra* note 275, at 115. Insulin therapy has been abandoned as a treatment for schizophrenia in the United States. Kaplan & Sadock, *supra* note 187, at 2147.

<sup>&</sup>lt;sup>279</sup> *MI Principles* principle 23.

<sup>&</sup>lt;sup>280</sup> MI Principles principle 8(1).

<sup>&</sup>lt;sup>281</sup> *Id.* principle 22. The ICCPR and the ECHR also require states to create judicially enforceable remedies to protect any individual against the violation of his or her rights. ICCPR Art. 2(2); ECHR Art. 1.

ongoing, national system of governmental entity mandated to investigate allegations of abuse, document conditions in institutions, or ensure that treatment does not reach substandard or even dangerous levels.

Ministry of Health and Social Welfare regulations delegate the responsibility for monitoring conditions and quality of care to local governments. According to the regulations, the local government is empowered to appoint a Amethodological group@ to supervise the operation of the institution. 282 The Public Health Officer=s Service (ANTSZ), along with specialized medical professionals from the local level, are also authorized to supervise the quality of health care.<sup>283</sup> According to the Gönczöl Report, these supervisory bodies fail to serve this purpose in any systematic wav.<sup>284</sup>

The MI Principles require that appropriate mechanisms must be established Afor the inspection of mental health facilities, for the submission, investigation, and resolution of complaints and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient. @<sup>285</sup> The *Rules on Equalization* specify that States Aat regular intervals, collect ... information concerning the living of people with disabilities. <sup>286</sup> People with disabilities must be included in the process of reviewing and establishing relevant policies and practices.<sup>287</sup>

### C. **Insurance Reform without Public Participation**

Hungary=s mental health system is currently undergoing a major transformation as the country privatizes and reforms the insurance system. This change presents a valuable opportunity for the government to establish enforceable minimum standards of care to which insurers and service providers must adhere. As of yet, however, no such standards have been created.

As Hungary reforms its insurance system, a *de facto* system of standard setting is taking place in the mental health system. In *lieu* of publicly established standards, the national health insurance company has enormous influence in shaping mental health practices through the system of reimbursement that it establishes. Indeed, medical school authorities have reported to MDRI that

<sup>&</sup>lt;sup>282</sup> Regulation 2/1992, *supra* note 148, section 4(1).

<sup>&</sup>lt;sup>283</sup> Ministry of Health and Social Welfare, Regulation No.8/1993, Professional Supervision of the Curative-Preventative Institutions and Services (1993), section III, 31.

<sup>&</sup>lt;sup>284</sup> Gönczöl Report, *supra* note 110, at 84.

<sup>&</sup>lt;sup>285</sup> MI Principles, principle 22.

<sup>&</sup>lt;sup>286</sup> Rules on Equalization rule 13.

<sup>&</sup>lt;sup>287</sup> *Id.* rule 14(2)(AStates should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status.@)

reimbursement standards set by the insurance company will soon far outweigh the significance of standards established by medical schools as the most influential with respect to clinical practices.

The insurance company has consulted with psychiatrists and other health professionals to determine appropriate levels of reimbursable care. At present, however, the Ministry of Health and Social Welfare reports that there is no public oversight of this process, and no legally enforceable minimum standards have been established within which the insurance company must operate.

To ensure full enforcement of the rights of people with mental disabilities, legally enforceable minimum standards must be established within which the insurance system operates. <sup>288</sup> Under the *Rules on Equalization*, people with disabilities must be included in this public standard setting process. <sup>289</sup>

<sup>&</sup>lt;sup>288</sup> *MI Principles* principle 9(3).

<sup>&</sup>lt;sup>289</sup> See supra note 32.

### VI. **Planning and Financing Reform**

Reintegration of people with mental disabilities into society will require the creation of a comprehensive system of community-based mental health care. Creating such a system requires planning, financing and a continued commitment to implementation over a number of years.

Enforcement of fundamental human rights for people with mental disabilities creates costs that must be assumed by society at-large. By establishing disability rights as internationally recognized human rights, the international community has made clear that these concerns are an imperative in all countries - not merely a luxury affordable in wealthy parts of the world. <sup>290</sup> Thus. human rights enforcement for people with mental disabilities is never solely a matter of having adequate resources available. Enforcement of disability rights requires the commitment - and the political will - to make the best use of available resources to permit people with mental disabilities the opportunity to live as part of society like all other citizens.

Part A, below, identifies Hungary=s responsibilities under international law to take immediate action to remedy the human rights violations identified in this report. Part B describes some of the planning and financing issues that should be considered by Hungarian policy-makers and providers, and provides suggestions for this process based upon the experience of mental health service reform in other countries.

### **International Obligations to Plan and Finance Reform** A.

The MI Principles call on States to Aimplement these Principles through appropriate legislative, judicial, administrative, educational and other measures, which they shall review

 $<sup>^{290}</sup>$  The World Conference on Human Rights in Vienna in 1993 reconfirmed the universality of human rights, equally applicable in all parts of the world. Vienna Declaration, supra note 27. This understanding of human rights has been increasingly accepted by the psychiatric community to apply to the provision of mental health treatment. Norman Sartorius, former Director of the Division of Mental Health of the World Health Organization has written that A[t]oday, availability of appropriate care for all forms of mental disorders is seen as a human right that must be respected even if resources for health care are scarce. And this is not all; the fact that services should be made available to all who need them implies that they can no longer be provided exclusively, nor even mainly, through the psychiatric institutions. WHO REVIEW OF EFFECTIVENESS, supra note 131, at xvii (citation omitted).

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periodically. <sup>291</sup> The *Rules on Equalization* provide non-binding guidelines for national reform efforts to ensure appropriate public participation, including organized representation by people with disabilities.

International human rights conventions, to which Hungary is a State Party, create immediate obligations to remedy human rights abuses. These obligations are of two kinds: (1) immediate obligations of full enforcement under the ICCPR and the ECHR and (2) obligations of progressive implementation under the ICESCR. As described below, enforcement of the right of people with mental disabilities cannot be neatly divided between these two types of rights. Full enforcement of the rights of people with mental disabilities will require both immediate action on the part of the Government of Hungary and a commitment to bring about the long-term outcomes mandated by international human rights law.

# 1. Immediate obligations of full enforcement

<sup>&</sup>lt;sup>291</sup> *MI Principles*, principle 23(1).

The ICCPR creates a legal obligation of State Parties to Arespect@ and Aensure@ the full enforcement of their protections. 292 State Parties agree to take Alegislative or other measures as may be necessary to give effect to the rights recognized in the present Covenant. @ 293 The ICCPR makes no exception to the duty of full enforcement for rights that may require the investment of resources. Hungary must take action to bring about full enforcement of protections against discrimination, inhuman or degrading treatment, and arbitrary detention.

At times, enforcement of the ICCPR may require Hungary to finance immediate reforms. The major violations of the ICCPR documented in this report must be so remedied. For example, long-term, unsupervised placement of people in cages is a clear case of inhuman and degrading treatment. Failure to provide adequate hygiene to these and other individuals is dangerous and lifethreatening. Ending these abuses requires Hungary to outlaw such practices and provide the funding and staff necessary to ensure that these practices are avoided in the future.

Protections against arbitrary detention may also require the expenditure of resources. Legislative reforms are necessary to protect against arbitrary detention in social care homes and psychiatric facilities, but they are not sufficient. By requiring that these protections be Aensured, @ human rights conventions require sufficient funding for court administration and patient representation to make these rights enforceable in practice.

As described in this report, the lack of community-based alternatives to psychiatric hospitals and social care homes is the primary reason for many people to be detained in these institutions. A policy to promote community-based treatment and community integration would avoid improper and unnecessary psychiatric detention. Obviously, such programs cannot be immediately and fully implemented. But policies to develop services and promote community integration can be immediately adopted. The effort to ensure full enforcement of the ICCPR underscores the need, indeed the urgency, to adopt policies that promote community integration and support.

<sup>&</sup>lt;sup>292</sup> ICCPR, article 2(1).

<sup>&</sup>lt;sup>293</sup> *Id.*, article 2(2).

Like its counterpart, the ECHR mandates respect for human rights and creates immediate obligations to remedy abuses. As a State Party to the ECHR, Hungary Ashall secure@ to everyone in its jurisdiction Athe human rights and fundamental freedoms@ guaranteed by the Convention. After ratifying the ECHR, Hungary signed two optional protocols agreeing to submit itself to complaints before the European Commission on Human Rights and the European Court. The Commission and the Court are charged with the enforcement of the fundamental human rights defined by the ECHR. The Court=s decisions are binding on Hungary which Aundertake[s] to abide by the decisions of the Court in any case@ to which it is a party. The Commission and Court thus provide a useful enforcement mechanism to ensure that Hungary amends laws and modifies practices that violate the rights of people with mentally disabilities under the ECHR.

<sup>&</sup>lt;sup>294</sup> ECHR, article 1.

All persons who are victims of a violation of the ECHR may petition the Commission. The Commission determines whether the complaint should be submitted to the Court. If the Commission submits the complaint, the Court will enter its final decision only after a preliminary investigation, and after an attempt at reconciliation between the parties is made. Mark Janis, EUROPEAN HUMAN RIGHTS LAW 68 (1995).

<sup>&</sup>lt;sup>296</sup> ECHR, article 53.

### 2. **Progressive enforcement**

As a State Party to the ICESCR, Hungary guarantees its citizens the Ahighest attainable standard of physical and mental health. <sup>297</sup> Recognizing the need to develop programs to enforce rights of this kind, the ICESCR creates a duty of Aprogressive enforcement. @ Under the ICESCR, each State Party Aundertakes to take steps...to the maximum of its available resources, with a view to achieving progressively the full realization of the rights@ established in the Covenant. 298 Even though outcomes may only be achieved over time, Athe obligation >to take steps= is an immediate one...@ 299 The steps taken should be Adeliberate, concrete, and targeted@ to the full enforcement of rights. 300 This process may include Athe drawing up of a detailed plan of action for the progressive enforcement of the right. @ 301

<sup>&</sup>lt;sup>297</sup> ICESCR, article 4(1).

<sup>&</sup>lt;sup>298</sup> *Id.*, article 2(1).

<sup>&</sup>lt;sup>299</sup> United Nations Centre for Human Rights, Manual on Human Rights Reporting 46 (1991) (hereinafter UN MANUAL ON REPORTING).

<sup>&</sup>lt;sup>300</sup> *Id*.

<sup>&</sup>lt;sup>301</sup> *Id*.

The ICESCR=s requirement that a State take steps Ato the maximum of its available resources@ does not specify which of its national resources can be considered Aavailable@ for reform. At minimum, State Parties to the ICESCR must use resources currently available in mental health budgets to enforce policies that will uphold the rights established in the ICESCR. Even where resources are limited, the obligation to Adevise strategies and programmes@ for the promotion of rights established in the ICESCR Aare not in any way eliminated as a result of resource constraints. <sup>303</sup>

The ICESCR has major implications for the allocation of resources in Hungary=s mental health system. As described in this report, the long-term placement of people in social care homes because of a lack of community-based alternatives creates unnecessary dependency on the psychiatric institution, undermines the ability of people with mental disabilities to retain and rebuild ties with the community, and ultimately detracts from their physical and mental health. To the extent that community-based service and support systems would better serve the needs and protect the rights of people with mental disabilities, Hungary is under an obligation to shift available resources toward such goals.

# **B.** Strategies for Planning and Financing Reform

International human rights law obliges nations to remedy human rights abuses, but the law does not specify exactly how a country should plan, finance, or conduct mental health system reform. The *MI Principles* were constructed to permit every country to adapt human rights principles to local circumstances, respecting local culture and building on country-specific strengths.<sup>304</sup> Since the first community-based systems were developed, an enormous amount has been learned in the United States, Europe, and other countries about how to finance, implement, and reform community-based services.<sup>305</sup> Important lessons can be learned from successes and failures of mental health reform efforts in developed and developing countries. Building on such experiences, there is now a broad consensus about principles and practices that should guide mental health system planning and the community integration of people with mental disabilities.<sup>306</sup> By adapting models from abroad, Hungary can save scarce financial resources and many years of trial-and-error in bringing about reform.

<sup>&</sup>lt;sup>302</sup> As the United Nations= Manual on Reporting explains, A[t]he phrase >its available resources= refers to both the resources of the State party itself and to those which are available to it from the international community >through international assistance and cooperation. @ *Id.* At 46.

 $<sup>^{303}</sup>$  *Id.* at 45.

 $<sup>^{304}</sup>$  AEvery patient shall have the right to treatment suited to his or her cultural background. @ MI *Principles*, principle 7(3).

<sup>&</sup>lt;sup>305</sup> See, e.g., WHO REVIEW OF EFFECTIVENESS, supra note 131, at 278; Mosher & Burti, supra note 18 (summarizing lessons from the experience with mental health system reform in the United States and Italy); Robert Desjarlais, Leon Eisenberg, Byron Bood, & Arthur Kleinman, WORLD MENTAL HEALTH 38 (1995).

<sup>&</sup>lt;sup>306</sup> Id. at 269.

### Need for comprehensive services and planning 1.

A safe and effective transition from institutions to community-based treatment requires the creation of comprehensive, community-based service and support systems. 307 Any complete community-based mental health service should include: community in-patient and out-patient treatment and case management teams, supported housing, supported employment, twenty-four hour crisis services, respite care, consumer-controlled social clubs, as well as, consumer, family, and legal oversight and advocacy.<sup>308</sup> A system of income supplements (disability pensions) for individuals unable to support themselves is also essential. Such programs should be integrated into primary health care systems and adapted to take advantage of local cultures and community structures. 310

In the worst cases, deinstitutionalization without effective community-based services has led to Apatient dumping,@ homelessness, and the abandonment of people with mental disabilities.<sup>311</sup> More commonly, the failure to provide adequate community-based services leads to disconnected services that permit individuals to Afall through the cracks@ of existing programs. 312 Without adequate support in the community, people discharged from hospitals may quickly decompensate and return to in-patient treatment (the Arevolving door@ syndrome). 313 Well-planned, integrated, comprehensive service systems, however, can avoid or reduce these dangers. <sup>314</sup> In some areas where

While poorly planned deinstitutionalization did result in many abuses in the United States, these policies were also improperly blamed for many broader failings of economic and social policies. The problem of homelessness in the United States, for example, goes much beyond that of the mental health system to cuts in other social programs and a lack of low-cost housing. The great majority of people who are homeless are not the product of deinstitutionalization and would not be candidates for in-patient treatment under even the broadest commitment standards. Id. at 105.

WHO REVIEW OF EFFECTIVENESS. *supra* note 131, at 321.

<sup>&</sup>lt;sup>308</sup> See, id. at 304-321 (describing international experiences with the implementation of such programs). See also Mosher & Burti, supra note 18, at 99-224 (a guide to the development of community-based services drawing from experiences in the United States and Italy); Leonard I. Stein, Ronald J. Diamond and Robert M. Factor, A system approach to the care of persons with schizophrenia, in 4 HANDBOOK OF SCHIZOPHRENIA: PSYCHOSOCIAL TREATMENT OF SCHIZOPHRENIA 218(1990) (describing the need for a comprehensive Asystems approach@ to community mental health services).

<sup>&</sup>lt;sup>309</sup> *Id.* at 214. In the United States, the development of income supplements in the 1960's played an important role in the development of alternatives to in-patient treatment for many people. Lafond & Durham, supra note 16, at 88.

Desjarlais, Eisenberg, Bood & Kleinman *supra* note 305, at 269.

In some areas of the United States, poorly planned deinstitutionalization resulted in what has been called Apsychiatric ghettos@ in inner cities where people lived in poverty and neglect. Some people discharged from institutions ended up in the streets, others in jails, and still others were Atransinstitutionalized@ in nursing care homes. Lafond & Durham, supra note 16, at 100.

<sup>&</sup>lt;sup>312</sup> *Id.* at 109.

<sup>313</sup> Stein, Diamond, and Factor, *supra* note 308, at 213.

<sup>&</sup>lt;sup>314</sup> *Id*.

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).

Given the need for comprehensive community-based services, piecemeal efforts to reform service systems are often doomed to failure.<sup>316</sup> Improvements in in-patient programs will be of limited value for many people with mental disabilities if there is an incomplete system of community-based programs to which people may go once they are released from the institution.<sup>317</sup> Most countries cannot afford to provide comprehensive community-based services if they are also supporting an extensive network of large, expensive, in-patient facilities. Mental health systems will require additional funding during a time of transition. Over time, countries can reduce rates of institutionalization as they develop better and more comprehensive community care systems.<sup>318</sup>

### 2. Need for outreach and assertive treatment in the community

Stein, Diamond, and Factor, *supra* note 308, at 213.

WHO REVIEW OF EFFECTIVENESS, *supra* note 131, at 304.

As a general rule, Athe need to use hospital-based services varies inversely with the comprehensiveness of community-based services.@ Id. at 241.

One of the most important advances in the development of community-based services is the recognition that services must provide active outreach to people with mental disabilities. Programs that rely almost exclusively on weekly or monthly appointments to dispense medications have major limitations in providing support for people with severe mental disabilities in the community. The core of an effective community-based mental health program is the case manager (or case management team), responsible for coordinating the services provided by all government agencies. Experience with community mental health programs also demonstrates that service systems must be designed to provide ongoing, long-term support. 321

Assertive community mental health care programs that actively follow-up and seek out individuals living in the community have been demonstrated to be more effective than traditional aftercare programs in helping people remain in the community. 322 As part of a comprehensive

Leonard I. Stein & Mary Ann Test, *Alternative to Mental Hospital Treatment: A Conceptual Model, Treatment Program, and Clinical Evaluation*, 37 ARCH GEN PSYCHIATRY 392 (1980) In Dane Country, Wisconsin, researchers found a greatly reduced need to hospitalize patients in an assertive community treatment compared with individuals in a conventional aftercare program. As described by the authors of the study, A[c]hronically disabled patients are frequently passive, interpersonally anxious, and are prone to develop severe psychiatric symptomatology. Such characteristics often lead these patients to fail to keep appointments and >drop out= of treatment, particularly when they are becoming more symptomatic. Hence, the program must be assertive, involve patients in their treatment, and be prepared to >go to= the patient to prevent dropout. It must also actively insure continuity of care among treatment agencies rather than assume that a patient will successfully negotiate the often difficult pathways from one agency to another on his own.@ *Id*.

AThe case manager, whether this is an individual clinician or an entire core service team, assumes responsibility for all aspects of the care that the patient may require in order to live satisfactorily in the community. We have found the more stable patients with schizophrenia can be well served by an individual clinician functioning as the case manager, more difficult patients with more pressing needs and more frequent crises require an entire team to share case management responsibilities. These responsibilities include either providing all the services needed, or arranging for missing services to be provided by another agency. In all cases, the case manager remains responsible for making sure that needed services are provided. This broadly based care...includes psychiatric treatment, rehabilitation, housing, finances, etc.@ Case management alone, however, is of limited value without the existence of comprehensive community-based services. *Id. at 216*.

When assertive community-based programs are terminated, rates of recidivism return to those in traditional aftercare programs. Thus, psychiatrists have observed that Auntil we are able to prevent or cure chronic psychiatric disease we should change our treatment strategy from *preparing* patients *for* community life to *maintaining* patients *in* community life. Stein & Test, *supra* note 319, at 392.

 $<sup>^{322}</sup>$  The problems with traditional out-patient care of this kind are not limited to Hungary. The following critique of such mental health care programs in the United States raises many of the same issues about the Adiscontinuity@ of care described by psychiatrists in Hungary (see discussion a p40.40):

Despite these ... programs, large numbers of persons with schizophrenia continue to experience frequent relapses and have a poor quality of life even when in remission. One can ask whether this problem is due simply to a lack of sufficient resources to provide greater numbers of these specific interventions and programs. We believe that lack of resources may contribute to the problem; however, we also believe there are some major problems with how these programs are organized: they are uncoordinated, they are non-collaborative, and they often compete with one another. Together, they comprise a >non-system= of mental health care where a few patients get more than they need, many patients get less than they need, and some get nothing at all. Patients may get lost in this non-system, and no one feels obliged to look for them....Patients are moved from the community into the hospital and from the hospital back into the community in such a way

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community-based mental health system, intensive case management has been shown in the United States to reduce overall rates of hospitalization.<sup>323</sup>

### 3. Consumer and family advocacy and support

that the hospital, the community, the patient, and the family all feel mistreated. A major problem with this non-system is that it is episode-oriented rather than oriented to providing continuous care. This non-system fails the patient and undermines the potential effectiveness of the professionals working in it.

Stein, Diamond, and Factor, supra note 308, at 213.

<sup>&</sup>lt;sup>323</sup> WHO Review of Effectiveness, *supra* note 131, at 308; Quinlan, *et. al. Service Utilization and Cost of Care for Severely Mentally Ill Clients in an Intensive Case Management Program*, 46 PSYCHIATRIC SERVICES 365 (1995).

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Consumers (also known as psychiatric survivors or users of mental health services<sup>324</sup>) and family members can play an important role in the development and operation of community mental health services. In the United States and Western Europe, consumers and families have established advocacy organizations that have played an important role in promoting their rights and interests. Consumers and family members have worked closely together as part of the same organizations or coalitions, and at times each group has felt the necessity to have independent advocacy organizations. Organizations of psychiatric survivors and family members of people with mental disabilities have become powerful political forces in the United States in matters relating to mental health policies.<sup>325</sup>

Consumer-controlled self-help organizations have been established to promote advocacy, services, and support.<sup>326</sup> Consumer-controlled drop-in centers provide a place for mental health system users to gather for meals, social events, mutual support, and peer counseling. Consumers have established telephone hotlines, resource libraries, and other information networks. Programs of this kind provide invaluable assistance to people with mental disabilities to remain in the community

<sup>&</sup>lt;sup>324</sup> As used here, the term Aconsumer@ refers to a person who uses or once used mental health services. Some people prefer to be called users, expatients, or psychiatric survivors.

Consumer (or psychiatric survivor) organizations have been politically important in the United States, even though they have never successfully had the political influence that their representation in the population as a whole would indicate. Organizations of family members, such as the National Alliance for the Mentally III (NAMI), have been very powerful. Organizations of family members and psychiatric consumers have often taken different positions in the political arena and it can be important to distinguish between these two types of advocates. *See discussion in* Lafond & Durham, *supra* note 16, at 112.

<sup>326</sup> See Chamberlin, supra note 18.

and avoid unnecessary hospitalization, and these programs are very low in cost. A number of consumer-controlled projects have been established in Hungary, and they deserve recognition and support.

Consumers can also take an active part in the operation of psychosocial rehabilitation programs in the community. 327 These programs are usually work focused, providing job skills and supporting people with mental disabilities to obtain and keep real jobs in the community. Mental health professionals and consumers work together collaboratively in these programs, designed to foster consumer independence and to promote a supportive community.<sup>328</sup>

#### 4. **Decentralization of authority**

 $<sup>^{327}</sup>$  Judi Chamberlin described a number of different models of consumer controlled or operated services, stressing the need to distinguish between consumer controlled and consumer operated services. Id. See also Van Hoorn, supra note 18 (describing the view of consumer activists who work within the structure of the mental health system despite reservations about this system).

Mosher & Burti, *supra* note 18, at 152 (describing the Fountain House model, Aan intentional community designed to create a restorative environment within which individuals who have been socially and vocationally disabled by mental illness can be helped to achieve or regain the confidence and skills necessary to lead vocationally productive and socially satisfying lives.@).

The creation of community-based mental health services involves an extensive decentralization of authority. To be effective, community based services must actively build on the strengths of the communities they serve. Thus, the development of local service options, as well as day-to-day decisions about individual treatment, should be made on a local level. Local authorities should be able to make spending decisions based on local needs rather then centralized mandates. In such a decentralized system, however, it is essential to create centralized oversight and advocacy programs to ensure that minimum standards of care are provided and that resources are not removed from mental health care. As long as minimum standards and oversight are guaranteed, local authorities will be in the position to assess local needs, take advantage of local community structures, and maximize the efficiency of mental health and social service budgets. With decentralized authority and centralized oversight and advocacy, Hungary will be in a position to avoid many of the pitfalls of deinstitutionalization experienced in the United States when people were discharged from institutions without appropriate services and protection in the community.

The mental health system of Hungary, as in most formerly-communist countries, has historically been highly centralized with regard to major decision making, including budgeting. At present, psychiatric institutions and social care homes receive fixed budgets, whether or not they are able to return an individual patient to the community. Administrators report that they have a limited ability to create more out-patient programs because this would mean taking funds away from fixed costs within the institution (such as staff and building maintenance).

Administrators at out-patient community programs also reported that their budgets are fixed, and they are not currently provided with extra payments for serving more clients or providing better services. This creates a disincentive for community programs to provide better community-based services (and it creates a financial incentive for them to refer difficult clients to in-patient programs).

Hungary=s experiences with mental health system budgeting are strikingly similar to those of community mental health programs described by service providers in the United States and Italy.<sup>331</sup> In successful cases, these problems have been avoided by allocating funds to one core community mental health authority within each regional service system.<sup>332</sup> The community mental health authority should optimally have control of all public funds relevant to the treatment and support of people with mental disabilities (including mental health, rehabilitation, housing, and other social services).<sup>333</sup> Thus, funds can be allocated by the community mental health authority based on actual needs of clients within the community system. The best system of finance is one in which Athe dollar follows the patient.<sup>©</sup> As people move into the community, more funding is made available for community services.

<sup>329</sup> Stein, Diamond, and Factor, supra note 308, at 217.

<sup>&</sup>lt;sup>330</sup> Jochen Neumann, *Psychiatry in Eastern Europe Today: Mental Health Status, Policies, and Practices*, 148 Am. J. PSYCHIATRY 1386, 1389 (1991).

<sup>331</sup> Stein, Diamond, and Factor, *supra* note 308, at 239; Mosher & Burti, *supra* note 18, at 101-105.

<sup>&</sup>lt;sup>332</sup> *Id*.

<sup>&</sup>lt;sup>333</sup> *Id. at 215*.

One of the advantages of giving authority to a core agency within each locality is that the community mental health authority can promote cooperation among social services agencies in that area, assuring continuity of care, and preventing needless bureaucratic competition among agencies. Case managers and case management teams should optimally report to the community mental health authority.

The emphasis on providing community-based services should not detract from the importance of certain functions that should remain centralized, however. Standards of treatment and minimum guarantees of quality should be established on a national basis to ensure clear and consistent enforcement. Human rights oversight and quality assurance must be maintained independent of local service systems. Independent advocacy programs must be available to individuals with mental disabilities in institutions and in the community.<sup>334</sup>

#### 5. Financing community services

Effective planning for community integration will permit the mental health system to use available resources more widely and more efficiently. Phasing down institutions and social care homes must not, however, be viewed as a way to save on the overall cost of mental health care. Indeed, a significant new investment of resources will be necessary to create a comprehensive community-based service system. A portion of this new investment will be temporary, since the current level of institutional care needs to be maintained during the period when new community services are beginning to be developed. Some of the increase in cost, however, will be permanent. In part, the increase in cost is due to the fact that community-based mental health programs provide more and better services to a portion of the population that was not receiving appropriate (or any) services when only traditional inpatient and outpatient services were available. The per capita cost of care in the community is likely to be lower than in the institution, but the overall cost of mental health care may go up.

Reform of Hungary=s system of health care financing will be critical to the development of a new community-based service system. The reform of Hungary=s insurance reimbursement system now taking place provides an opportunity to ensure that financing is available for community-based The new insurance system must make resources available for the full spectrum of community-based services, not just the traditional inpatient and outpatient care. The new financing system must also end current incentives for unnecessary inpatient treatment.

While the financing system is being reformed, start-up grants must be provided to local authorities to create the infrastructure and initial funding for community services. The new financing system should then be restructured to maintain and promote the development of these services. Once community-based services are created, the need for long-term institutional care will diminish. Some of the resources that are saved as a result of a declining institutional census should be used to improve conditions within these facilities. The balance of the savings should be

<sup>&</sup>lt;sup>334</sup> In the United States, Protection & Advocacy programs were originally created to protect individuals especially vulnerable to abuses in institutions. As more individuals are discharged from hospitals into the community, the need to provide ongoing advocacy services has become clear. Sundram, supra note 15, at 23.

reallocated to further the development of the community-based system of services. In this way, the quality of care in institutions can be improved and the full spectrum of community services can be simultaneously enhanced.

Another potential source of funding for community services may be derived from phasing down the Aneurosis wards@ of psychiatric institutions and general hospitals. Such wards represent an established and respected tradition in Hungary and certain other countries of Western Europe, but many other nations have found it unnecessary to institutionalize people for neurotic conditions where outpatient and supported residential services are established in the community. Given the cost of operating such wards, it would be useful to reexamine this form of treatment<sup>335</sup>

### 6. Human rights enforcement in a time of transition

As a country making the transition to a market economy, and as a new democracy committed to protecting human rights, Hungary faces the challenge of expending new resources for mental health system reform at a time when it is particularly difficult to do so. Hungary should not make the mistake, however, of postponing human rights reform until the transition to a new economic system is complete. In addition to the immediate imperative to enforce human rights, it will become politically more difficult and increasingly more expensive to transform the mental health system once other institutional changes have taken place in Hungarian society. If Hungary continues to invest in social care homes, large centralized psychiatric institutions, and other services that must inevitably be phased down, there will be fewer resources for community care.

Immediate economic realities may require austerity, but decisions made during this time of transition will have a long-term impact with significant human rights and economic consequences. Although difficult in the current economic climate, immediate investment in the creation of community-based mental health services are necessary to enforce human rights and end the current system of segregated services. With proper planning, this investment can increase the efficiency of the mental health system budget. By the same token, new investments in social care homes and other in-patient facilities will increase the economic burden of disability and leave fewer resources for future reform. The government of Hungary should avoid these mistakes by establishing, as an immediate priority, restructuring services and ending the segregation of people with mental disabilities.

<sup>335</sup> This could be accomplished by instituting a randomized experimental trial in which treatment on such wards is compared with an alternative form of non-hospital based treatment. In this way, the clinical value and cost-effectiveness of each approach could be examined and recommendations for future financing could be made.

#### Appendix A **Responses By Hungarian Service Providers & Advocates**

#### 1. Dr. András Veér

### Director, National Institute of Psychiatry and Neurology

This thorough report is the result of a second investigation conducted in Hungary=s psychiatric institutions within one year, the first having been conducted by the Human Rights Ombudsman of Hungary, Katalin Gönczöl. The two investigations resulted in many of the same conclusions, and their recommendations overlap in many areas. This fact, I believe, underscores the reality that MDRI=s findings are trustworthy and cannot be doubted. With such doubts set aside, we should accept these findings as contributions to earlier and current efforts of Hungarian psychiatry. No one becomes a prophet in their own land, and too many reports by Hungarians have ended up in desk drawers. The perspective of outsiders reflected in this report, however, will achieve much more than the previous efforts in disseminating and promoting recommendations for reform.

As in the case of all effective criticism, this report has created a great storm of controversy. Professionals who do their job well, people who are concerned about human rights, may be offended by a well-structured report like this one. A report of this kind must, by its very nature, make generalizations. However, the report=s recommendations are justified, and it offers convincing examples.

Stories we have heard about improper care and abuse in Western mental health systems provide some perspective on the situation here in Hungary. Recently, a person with mental disabilities of Hungarian origin was discovered in a mental hospital, outside of London, where he had been ironing clothes in an institution=s laundry for forty years. No judge had ever seen this man or assessed his rights. He also did not have a detailed case history, his status was never reviewed, and he had never received compensation for his work. It is unclear what a judge could have done with him anyway as he did not speak English. He was discovered because the hospital building was to be demolished and the patients relocated. Finally, after an adventurous journey, he returned home to Hungary and ended his days with his family - not in a mental hospital. There was ultimately no reason to hospitalize him. Based on this one example from England, however, it may be improper for us to try to generalize and make recommendations about improving conditions in England=s mental health system. We cannot make judgements on whether human rights are violated there.

This report, however, makes recommendations based on several months of investigations, and not just from one random example. Thus, the report can be accepted as accurate despite some minor errors. We are very much aware that we often violate rules regarding human dignity and liberty. These rules should be adhered to tenaciously as they facilitate treatment and enhance the relationship between clinicians and patients.

This report provides a cross-sectional view of Hungary=s mental health system. It does not reflect the changes achieved in Hungarian psychiatry in the past ten years. It cannot tell us, for example, the extent that the use of cages has already been reduced. Of course, it is a problem today that cages still exist at all. But it is also difficult to establish the consensus to banish the use of these devices forever. We have made progress in reducing the use of seclusion. For many decades, for

example, I have been questioned regularly about whether Hungarian psychiatrists use Apadded cells@ to seclude patients. Comedians have made fun of padded cells (in Hungarian they are referred to as Arubber rooms@) with guaranteed success. I always thought they were fiction until I was shown a padded cell in the United States as an example of success in the protection of human rights and liberty. At that same time, clozapine had been in use in Hungary for a decade and we have been able to decrease the use of seclusion and restraint of patients. I understand that it is only recently, after more than twenty years, that the United States is beginning to get over its aversion to drugs. Hopefully, the padded cells in the United States are now empty.

Let=s talk about Hungary, however, as we have enough to do at home. Patients= rights have not yet been defined in any law. As I understand, however, a bill of rights for patients will be submitted to Parliament this year. Of course, the mere enactment of this law will not change the poor conditions in the social care homes for people with mental disabilities. However, the law may put pressure on local governments to make slow but definite changes. I must point out that social care homes are not part of psychiatry and are not under the authority of the National Institute for Psychiatry and Neurology (OPNI). OPNI does not have the authority to make recommendations to the social care homes, as this report incorrectly asserts. Instead, these rights are enforced by the Professional Colleges which serve as advisory boards to the Minister of Health and Welfare (the authors of the report would have been well-served by reviewing recommendations made by these boards over the past decade).

Until the 1990's, OPNI was responsible for the professional supervision of human rights, legality of treatments, and especially treatment using restraints. During this period, closed wards were reduced and abolished. In addition, the number of cages decreased. Community psychiatry, complemented by new drugs, was established and made more efficient. Perhaps for this reason - and because of the conscientiousness of Hungarian psychiatrists - there were no significant political abuses of psychiatry in Hungary. International opinion has recognized this. I hasten to offer this defense of Hungarian psychiatry, even though I am aware that the report does not criticize the psychiatrists for such political abuses.

Hospital wards and social care homes have unfortunately become Aownerless@ in the past few years. These institutions are now governed inordinately by local governments. The authority given to chief medical officers within these wards and institutions, particularly their supervisory functions, is inappropriate. Local governments with insufficient financial resources cannot improve the conditions of these institutions. The OPNI, the College of Psychiatry, and the Hungarian Association for Psychiatry are therefore forced to Aact blindly@ as we seek to enhance the quality of treatment, retain beds, and establish more humane provisions for enforcing human rights. The Ombudsman=s detailed report did not help us achieve the goals of improving conditions. Although profound breakthroughs cannot be expected as a result of this report, its recommendations to the Government can be supported by Hungarian psychiatrists. Perhaps changes should not be based on the example of the U.S. It is necessary for the mental health system to be developed and adapted to Hungarian conditions, however, taking into consideration international recommendations.

One of the findings of the report is that social care homes are far from patients= homes. It should be noted that this is really only the case for Budapest. With the exception of Budapest, all social care homes were established within relevant counties, and are in proximity to patients=

homes as determined by municipal and county authorities. As for Budapest, I doubt quick changes can occur without the investment of substantial financial resources. When these social care homes were established, we raised objections but our complaints were not heard. What can be done now? The report says that the system of social care homes should be terminated. And what suggestions are offered instead? As a professional I am troubled by the prospects for change. I feel the good will and the truth in this report, however, and I believe that we ourselves must begin to find the solutions.

Finally, I would like to thank Mr. Rosenthal and the editors of *Psychiatria Hungarica* for the opportunity to have my reflections published.

2 Dr. Judit Harangozó Adjunct Professor of Psychiatry, Semmelweis University of Medicine Director, Awakenings Foundation

*Truths must be repeated because errors are also repeated.* 

Goethe

The activity of representatives of the MDRI in Hungary is of decisive importance for the reform of Hungarian psychiatry. The findings of the report shock many, if not all of us, inducing us to face the facts. Although we saw some of the irregularities to which they draw attention and we made some efforts to change them, we had come to accept the majority of things. This is why this exposé will have such an impact. Personally, I found it hard to sleep on the day I first read it. I kept pondering the reasons why I hadn=t seen things the same way. Why did I refer so many patients to social care homes? Why did I persuade them to go? Why do I have a mental image of these institutions as being in beautiful mansions in the country? Why is my first association the kindness of the staff when I visited? I remember the geraniums in the window, the idyllic summer afternoon, the jam buns they offered me? Of course, it was enough to glance at one or two of the inmates to see the damage done by long years spent in the home. The chief physician even spoke about this problem to me at Tápiógyörgye. But I never imagined that the whole set-up could ever be changed. Why not?

There is a more serious problem that I have discovered trough self-examination. I have come to realize that I myself identified with many of the unlawful practices described in this report. It is not foreign to me to forget to notify the psychiatric outpatient unit that I recommend hospital treatment when this could be avoided; I have made decisions as the Aomnipotent therapist@ in matters where the patient=s own decision would be more lawful and authentic; I have failed to give full information to a patient and I have often felt that the court review of commitment is a waste of my time. In short, I was a hospital-orientated, somewhat paternalistic psychiatrist with little thought about the rights of the patient. Of course, this attitude changed a lot when I came to work in the day hospital. Nevertheless, after reading the study I am forced, at a number of points, to question what I had believed to be good qualities in my medical activity. It would have been easier, of course, to challenge the claims and conclusions of the study. But they were so clear and strangely obvious for me - it was like someone who had been wearing bad glasses being suddenly able to see properly again. Although the Gönczöl Report had already led me to begin self-examination, it was really after reading the MDRI study that I found myself in conflict with my earlier professional identity.

I have described my own emotions because I suspect that the study is having the same disturbing impact on others too. People whose identity is even more closely associated with common practices, here criticized on the basis of international legal norms, may be in a far more difficult position. However, as we tell our patients, a crisis is an opportunity to re-evaluate our life and choices to seek new paths and learn new solutions. Lashing out, rejecting its findings and regarding the whole thing as invalid would be the wrong resolution to the crisis caused by the study. The solution is to face the facts. The profession must join efforts in seeking a new way forward. The first step towards resolution of the crisis has been taken by the leaders of the profession such as Dr. András Veér who recently expressed public support for the ARosenthal Report.@

We can gain strength for the future by looking back at the many great figures in Hungarian psychiatry who were guided by their humanitarian spirit in achieving great deeds. Mention should perhaps be made of Kalman Pandi who, in the early years of the century, reviewed experiences in 25 countries and adopted a position in favor of mental patients being cared for in host families. He introduced this practice in Hungary with great success. AMinimum standards@ were applied to the care of the patients and were regularly checked. Other major figures in Hungarian psychiatry, such as Erno Moravcsik, consistently called for the humane care of patients. In recent decades, people with alternative views grouped around the psychotherapy schools continued to foster this spirit and, in an environment that was not friendly to personal freedom, they created nests of democracy. In this regard, Dénes Goldschmidt and József Gerevich should be mentioned.

The main task for today=s experts, legislators and activists is the creation and operation of uniform high standard and accountable professional quality. The following principles should be incorporated into practice:

! psychiatric care should be provided with minimum quality standards everywhere,

! care should be accessible for all,

! laws and practices should be compatible with international law, and

! all care should be provided in the least restrictive environment (based on a system of community psychiatry). Patients must be treated as citizens with full rights, who can live a full life.

In Hungary we have been conditioned to learned helplessness, but we must nevertheless take charge of the possibilities we can use to advance psychiatry and human rights. We need:

! A more suitable social environment, more effective local democracy, real self-government. Greater possibilities should be open to civil organizations to create the context for community psychiatry through which psychiatric patients will no longer be subject to institutional exclusion but can enjoy responsible community participation and support.

! Legislation on health care and social services should be established.

International resources are available to assist the changes. Many countries have successfully introduced quality standards and community psychiatry can be implemented in a cost-effective way. We can learn a great deal from these experiences and draw on them. Work has begun in Hungary to establish professional quantity standards (protocols) which can serve as the basis for quality

assurance. There exist district services (principally psychiatric outpatient units) from which the development of community psychiatry can be launched immediately with only a small investment.

The leaders of the psychiatric profession have taken a position in favor of the need for changes. There are already effectively operating organizations and groups for the protection of patients= family interests. There are many specialists working in mental care who, even under very difficult circumstances, have preserved their openness and their insistence on standards. These people keep interests of patients in sight and see the limitations of the present care. Last but not least, we have the Gönczöl and MDRI reports. Together with them we have the basis for the first Hungarian initiative aimed at the creation of community psychiatry.

The prestige of the mental health profession in Hungary can only be improved with the introduction of quality standards in an appropriate legal environment for the protection of human rights. The new situation - in which we must all accept many new burdens and far greater risk - will also bring improved material and professional recognition for mental health care specialists.

#### 3. Gábor Gombos

Voice of Soul: Association of People with Mental Disabilities

Our current understanding tell us that people with schizophrenia face the same problems all of us struggle with during our entire life.

Manfred Bleuler

We are pleased that international civil rights organizations and psychiatric professionals have realized that to prevent the further deterioration of the situation of people diagnosed as people with mental disabilities - and to prevent the collapse of Hungarian psychiatry - it will be necessary to bring about great changes in the mental health system. This must include a reduction of beds in hospitals and the development of community-based mental health services. We welcome the report=s call for a collaborative approach to solving these problems; the best that all parties can do is to define and communicate their own true interests.

This report is a starting point for planning reform. All relevant parties now should assess their interests at this time and openly outline them. As soon as properly communicated interests are made, we should adopt a common platform for action. We should also come up with a common program for social change and for financing reform. The core of this program should be a common commitment to improve the psychiatric patients' quality of life and to enforce their human rights.

The following is an effort to identify and outline the interests of consumers of psychiatric services as we begin this process of organizing to bring about the recognition of patients= rights.

### **Benefits of Community Psychiatry for Consumers**

In an ideal society, everyone should have the opportunity to take part in the community and develop their own personality, within the limits of responsibility shared by all other citizens. Throughout human history, certain groups of people have been denied this opportunity. People with a diagnosis of chronic mental illness are the most excluded individuals in modern societies. The chronic psychiatric patient is the only person in modern society whose rights and freedoms can be restricted *prior to* taking any action that may endanger self or others. This is routinely what happens when psychiatric patients are involuntarily committed to a psychiatric institution or placed in physical restraints.

Everybody needs friends, family and community, and everyone should have the right to community life. The extent and kind of community participation should be determined by the individual. In psychiatric hospitals, however, patients cannot choose the people with whom they associate. Within an institution, community participation is not possible. Community mental health care provides the structure necessary for the opportunity to live, associate with others, and make basic choices about life. Thus, community mental health care, rather than in-patient institution-based care, creates the conditions necessary for enforcement of all human rights.

Community mental health services prevent the social isolation and marginalisation of patients so common among chronic patients, who are so often among the poorest segments of society. International experience shows that consumer-controlled programs are more suitable and effective for certain purposes, e.g. bringing consumers together for mutual support in drop-in centers and co-ops, than are programs run by mental health professionals. Consumer organizations, including advocacy organizations and self-help groups, can be readily integrated into community mental health care

### **Obstacles of Community Psychiatry: Consumers Point of View**

The major danger facing psychiatric consumers in Hungary is that no actual reform and no new community-based services will be created as hospital beds are reduced. With an overload of cases already, community clinics will be forced to continue to operate as they now do. For so many people, that means Aone depo injection in every three weeks@ and nothing else. This concern is not eliminated by the declaration by government officials that community services should be created. In Hungary today, it is easy to find examples of rights guaranteed by law that are not actually enforced.

The following are some key concerns for consumers:

1. We are concerned about the use of the terms Acommunity@ and Alocality@ by mental health professionals (and the authors of the MDRI report). One cannot assume that just by ending physical isolation and getting people out of a hospital, people will actually be integrated into the community. People can be excluded and destitute in their own district, and they can be as alienated from society near home as they are in the mental asylums. The idea of the case manager described in this report is highly welcomed. But the case manager described here will not necessarily solve the problem of community integration. To make true community integration possible, what we need in Hungary is "neighbor therapy" along the lines of family therapy.

- Many people with chronic mental disabilities also suffer from other social disadvantages. 2. Unless society solves the broader problems associated with poverty, it may be difficult to help people with mental disabilities. The failure to overcome these external problems may discredit community mental health and may further increase the social stigma associated with mental disability.
- 3. The detrimental effects of hospitalization are not caused merely by hospital beds. We are pleased that Dr. Judit Harangozó refers to this in her pamphlet. 336 We would go a step further: the negative effects of hospitalization are also caused by day hospitals and other segregated Aghettos of treatment.@ such as sheltered workshops. There are related dangers of over-reliance on the medical model of mental illness, which reduces a person to his or her medical symptoms and reinforces the societal role of the individual as a dependent Apatient.@ The Ahospitalization@ of the individual happens any place where a person is treated exclusively and permanently as a patient and not as a vulnerable person of full value who faces problems common to other people.

One system I observed in Britain can be helpful to counteract this problem. In that program, the consumers' direct contact with the mental health care system is composed largely of social workers or volunteers. They are much less influenced by the medical model of mental illness commonly found among nurses and psychiatrists. In the long run, however, it is essential that all medical and non-medical staff working in community services be trained to approach the medical model of mental illness in a critical way. They should also be exposed to other theories, many of which are currently much less popular.

Education and training of mental health professional should include programs to improve attitudes toward patients and improve knowledge about patients= lives. Staff training should include sensitization to the challenges and stigma faced by patients in integrating into the community. Such practical education should not be subordinated to any abstract scientific theories. Highly qualified (and well paid!) teams and case managers are needed with good organizational skills. These individuals will not be able to accomplish their professional duties, however, without better knowledge of their clients= lives. With proper training, social workers and case managers will be in a position to use their power to promote community integration - not just torture defenseless patients.

The new attitude of mental health professionals should be reflected in an improvement in the status of the local treatment centers. These centers should become the cornerstone of the community mental health care system. Local treatment centers currently have official, legallydefined responsibilities, however, which undercut their ability to function within a framework that is truly respectful of people with disabilities. The treatment centers are currently obliged to assess anyone who is said to have a confused mental status. The treatment centers are also obliged to register (and retain) the person who was detected to have a mental disability. The patient is obliged

 $<sup>^{336}</sup>$  See, Judit Harangozó, Pamphlet on Hungarian Psychiatry, 12 PSYCHIATRIA HUNGARICA 75 (1997) (published in a compilation of articles along with a summary of this report).

to show up for supervision upon the call of the treatment center. If the patient does not cooperate, the police may be called in. These bureaucratic requirements distort the relation between the treating clinician and the patient. The vast majority of the clinician=s time is spent with official and/or bureaucratic duties rather than treating the patient. The responsibility of the clinician to provide coercive care undermines patients' trust and voluntary compliance with treatment. Patients who might well benefit or recover from treatment are often driven away.

The consumer=s opinion should be taken into consideration when mental health services are evaluated and when quality standards are established. This should be guaranteed by law. This practice has been established in many countries, and this model can be readily adapted in Hungary. Without taking this step, consumers will continue to bear treatment passively, rather than participating as actively and productively as they can.

Rehabilitation should be initiated at the first episode of mental health treatment. Vocational rehabilitation, in particular, can be a liberating experience for a person used to being dependent on the mental health system, family, and others. Rehabilitation, however, should not be reduced to the ability to take any job. Chronic mental problems often start prior to leaving school before work skills are developed. It is not always advisable to force the person who has just had a failure to face the prospect of another failure by expecting him or her to start working immediately. Due to the trauma of experiencing mental illness and the side-effects of psychotropic drugs, the level of the patient=s performance is likely to decline significantly. He or she may only be able to take on demoralizing (and underpaid) work. Such work can lead to a decrease in the consumer=s self-esteem and may lead to him or her to be re-hospitalized. Rehabilitation should not always start with work and it should not be expected to end with work. A person needs to be a full member of society with full self-esteem. A psychiatric consumer may need to learn the skills necessary to solve his or her problems integrating into society. It would be a mistake to force the consumer to do a job that takes time away from his or her ability to cope with personal issues.

It is unavoidable that eventually people with mental disabilities will have to start working. "Normal" jobs in integrated settings are preferred to sheltered ones. A good example is the activity of Motivation Foundation, a supported employment program in Budapest that places people in integrated work environments. Obviously, the huge demand for integrated employment cannot be met by a single foundation and the government should fund this activity. The government should enact legislation promoting the employment of people with physical or mental disabilities in normal, integrated work settings by creating tax and other incentives for such employment.

When the patient works at a normal, integrated job there is a danger that the appearance of his or her case manager at the work-site can be a problem. The confidentiality of the patient is violated when the employer becomes aware of his/her disabilities. In case of jobs where the employment of people with mental disabilities is not prohibited by law, the employer should not be aware of the employee's mental disabilities. The certificate entitling the employer to a tax reduction can be signed by the general practitioner justifying that the employee suffers from a health problem. The certificate need not be more specific. Of course, if the patient wants the case manager's involvement, it may be necessary for these problems to be discussed among the relevant parties.

Next to the right to community services, the right of a consumer to choose the kind of treatment he or she desires should be established by law. The aim is to have a mental health care

system in which consumers are getting more of the services they desire. Apart from the rare occasions where immediate intervention is needed, the law should permit no action or treatment against the will of the patient. Obviously, this will require a thorough revision of the law regulating guardianship.

It will be a great challenge to break through stereotypes and long established ways of thinking about psychiatric practice. Psychiatry - and all of its participants - must break out of the walls of the ghetto in which we have been living. Perhaps one day the mental strait-jackets we have been living with can be removed; at present they still tie us both up - patients and staff.

4. Dr. Péter Szabó Chair, Human Rights Committee Hungarian Psychiatric Assocation

The investigation conducted by Mental Disability Rights International has ended. The report raises - and answers - important questions about the basic rights of the people in our society who are the least able to defend their own interests.

Reading the MDRI report does not make us feel good. Our national pride must be set aside. We can no longer avoid reflecting on the issues raised in the report - even if they are painful. We should not have turned our faces away up to now or permitted these issues to remain shrouded in silence. Continued silence on these issues now would only make us accomplices.

In 1960, more than 30 years ago, we knew that people with mental disabilities should not be isolated from their families and should be treated in their home environment. Policy directives were adopted that were supposed to have brought about change. Instead of isolated and remote insane asylums, psychiatric wards were to be integrated into general hospitals. Despite these directives, however, treatment still takes place in locations far away from the community. This is particularly true when patients are placed in social care homes, located far from Budapest along the borders of the country.

A small group of well-meaning Hungarian professionals and non-professionals have, over the years, rung the alarm-bell. They have described the horrific conditions in psychiatric institutions. What term other than Ahorrific@ can be used to describe the living conditions of patients who do nothing all day, every day? Living in institutions for years or decades inevitably results in the loss of social contacts, and impairments become fixed. Patients placed under guardianship are forgotten, and they receive the worst care. Patients deported/relocated to social care homes for people with mental disabilities cannot rely on the help of their families or friends.

Next: Do the facilities for personal care meet the standards or needs of patients? Would they meet the needs of the staff? What does poor dental hygiene do to a person? What is the effect of living with an untidy, slovenly and shabby appearance? And so on.

We all agree that people with mental disabilities who are not able to live a full life on their own deserve some form of accommodation. But treatment in social care homes is provided in large dormitories where there is no privacy. During dark autumn and winter evenings - and in the day -

patients are condemned to inactivity, waiting around to fall asleep. They wait in dark rooms becuse of some unknown regulation that says that lights are to be switched off at a specified time. Is it a surprise, under these circumstances, that the reality of the inner world would become more important than the outside world? So it is that the institution perpetuates peoples= disabilities. The following warning could be placed at the doorway of the institutions: "He who enters here, give up all hope!"

Hungary=s out-of-date system of institutions sustains a totalitarian form of control over patients. The environment within the institution is unnecessarily restrictive. The cagebed, described in the MDRI report, has survived the years. The very fact that the practice of caging people still exists is a symbol of the ongoing violations of human rights and dignity that continue today. The cage-bed is the incarnation of the humiliating treatment used in everyday practice. The picture is not much nicer with regard to the enforcement of human rights in psychiatric institutions or psychiatric wards of general hospitals.

One commonly stated reason for the survival of these detrimental practices is that old-fashioned health care conintues throughout Hungary. This is no excuse. The MDRI investigation reinforces our awareness that the old, customary practices prevail in the institutions, despite the existence of new international human rights standards, the establishment of democracy in Hungary, and the existence of new legal guarantees.

Given the current bureaucratic system for registering complaints, seeking legal remedies, and obtaining legal representation, the adoption of Alegal equality@ for people with mental disabilities does not have much chance of having an effect. The MDRI report points out the positive achievements of new mental health care programs and the opportunities created by a changing Hungarian health care system. It notes the importance of the new legislation harmonizing Hungarian law with international standards. These new laws and opportunities only serve to sharpen the contrast between current conditions and desired changes.

The legal recognition of human rights and civil rights will not be productive unless there is a parallel series of reforms in the structure of psychiatric services, including the establishment of a system of community psychiatry. Inevitably, this will cost money. Why should the reform of psychiatry not have a price? The investment that we must make is not just one of financial accounting. We must invest in changes of attitude. Creating reform requires a positive new vision a human investment that will be invaluable for all of us.

The MDRI report provides direction for change through a series of recommendations for reform. The report specifies how and where internationally agreed standards, declarations, and professional principles were violated. This analysis, based on international law, provides ammunition to those who would like to bring about change. With the exception of a few, small misunderstandings, the report provides a useful foundation for further action. The MDRI report challenges mental health professionals and political decision makers to take the next step.

Overall, the MDRI report does not tell us anything we did not already know about Hungarian psychiatry. Revealed by outsiders, however, we are forced to digest the facts all over again. The MDRI fact-finding investigation brings to light the shameful reality we already know in detail. With this report, Eric Rosenthal and his colleagues support the progressive majority of

Hungarian psychiatrists. Last but not least, the report provides hope for change for people with mental disabilities.

The rest depends on us.

### **Appendix BPrinciples for the Protection of Persons with Mental Illness**

Adopted by General Assembly resolution 46/119 of 17 December 1991

The General Assembly,

Mindful of the provisions of the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights and other relevant instruments, such as the Declaration on the Rights of Disabled Persons and the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment,

Recalling its resolution 33/53 of 14 December 1978, in which it requested the Commission on Human Rights to urge the Subcommission on Prevention of Discrimination and Protection of Minorities to undertake, as a matter of priority, a study of the question of the protection of those detained on the grounds of mental ill-health, with a view to formulating guidelines,

Recalling also its resolution 45/92 of 14 December 1990, in which it welcomed the progress made by the working group of the Commission on Human Rights in elaborating a draft body of principles for the protection of persons with mental illness and for the improvement of mental health care on the basis of a draft submitted to the Commission by the Subcommission on Prevention of Discrimination and Protection of Minorities.

Taking note of Commission on Human Rights resolution 1991/46 of 5 March 1991, in which the Commission endorsed the draft body of principles that had been submitted to it by the working group and decided to transmit it, as well as the report of the working group, to the General Assembly, through the Economic and Social Council,

Taking note also of Economic and Social Council resolution 1991/29 of 31 May 1991, in which the Council decided to submit the draft body of principles and the report of the working group to the General Assembly,

Taking note further of the recommendations of the Commission on Human Rights in its resolution 1991/46 and of the Economic and Social Council in its resolution 1991/29 that, on the adoption by the General Assembly of the draft body of principles, the full text thereof should be given the widest possible dissemination and that the introduction to the body of principles should at the same time be published as an accompanying document for the benefit of Governments and the public at large,

Taking note of the note by the Secretary-General, the annex to which contains the draft body of principles and the introduction to the body of principles,

Adopts the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, the text of which is contained in the annex to the present resolution;

- 2. Requests the Secretary-General to include the text of the Principles, together with the introduction, in the next edition of the publication entitled "Human Rights: A Compilation of International Instruments":
- 3. Requests the Secretary-General to give the Principles the widest possible dissemination and to ensure that the introduction is published at the same time as an accompanying document for the benefit of Governments and the public at large.

#### **ANNEX**

### Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care

### **Application**

The present Principles shall be applied without discrimination on any grounds, such as disability, race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, legal or social status, age, property or birth.

#### **Definitions**

In the present Principles:

- (a) "Counsel" means a legal or other qualified representative;
- (b) "Independent authority" means a competent and independent authority prescribed by domestic law;
- (c) "Mental health care" includes analysis and diagnosis of a person's mental condition, and treatment, care and rehabilitation for a mental illness or suspected mental illness;
- (d) "Mental health facility" means any establishment, or any unit of an establishment, which as its primary function provides mental health care;
- (e) "Mental health practitioner" means a medical doctor, clinical psychologist, nurse, social worker or other appropriately trained and qualified person with specific skills relevant to mental health care:
- (f) "Patient" means a person receiving mental health care and includes all persons who are admitted to a mental health facility;
- (g) "Personal representative" means a person charged by law with the duty of representing a patient's interests in any specified respect or of exercising specified rights on the patient's behalf, and includes the parent or legal guardian of a minor unless otherwise provided by domestic law;
- (h) "The review body" means the body established in accordance with principle 17 to review the involuntary admission or retention of a patient in a mental health facility.

General limitation clause

The exercise of the rights set forth in the present Principles may be subject only to such limitations as are prescribed by law and are necessary to protect the health or safety of the person concerned or of others, or otherwise to protect public safety, order, health or morals or the fundamental rights and freedoms of others.

### Principle 1 Fundamental freedoms and basic rights

- 1. All persons have the right to the best available mental health care, which shall be part of the health and social care system.
- 2. All persons with a mental illness, or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of the human person.
- 3. All persons with a mental illness, or who are being treated as such persons, have the right to protection from economic, sexual and other forms of exploitation, physical or other abuse and degrading treatment.
- 4. There shall be no discrimination on the grounds of mental illness. "Discrimination" means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory. Discrimination does not include any distinction, exclusion or preference undertaken in accordance with the provisions of the present Principles and necessary to protect the human rights of a person with a mental illness or of other individuals
- 5. Every person with a mental illness shall have the right to exercise all civil, political, economic, social and cultural rights as recognized in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and in other relevant instruments, such as the Declaration on the Rights of Disabled Persons and the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment.
- 6. Any 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 a counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. 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. Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision.

7. Where a court or other competent tribunal finds that a person with mental illness is unable to manage his or her own affairs, measures shall be taken, so far as is necessary and appropriate to that person's condition, to ensure the protection of his or her interests.

## Principle 2 Protection of minors

Special care should be given within the purposes of the Principles and within the context of domestic law relating to the protection of minors to protect the rights of minors, including, if necessary, the appointment of a personal representative other than a family member.

## Principle 3 Life in the community

Every person with a mental illness shall have the right to live and work, to the extent possible, in the community.

## Principle 4 Determination of mental illness

- 1. A determination that a person has a mental illness shall be made in accordance with internationally accepted medical standards.
- 2. A determination of mental illness shall never be made on the basis of political, economic or social status, or membership in a cultural, racial or religious group, or for any other reason not directly relevant to mental health status.
- 3. Family or professional conflict, or non-conformity with moral, social, cultural or political values or religious beliefs prevailing in a person's community, shall never be a determining factor in the diagnosis of mental illness.
- 4. A background of past treatment or hospitalization as a patient shall not of itself justify any present or future determination of mental illness.
- 5. No person or authority shall classify a person as having, or otherwise indicate that a person has, a mental illness except for purposes directly relating to mental illness or the consequences of mental illness.

### Principle 5 Medical examination

No person shall be compelled to undergo medical examination with a view to determining whether or not he or she has a mental illness except in accordance with a procedure authorized by domestic law.

### Confidentiality

The right of confidentiality of information concerning all persons to whom the present Principles apply shall be respected.

### Principle 7 Role of community and culture

- 1. Every patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives.
- 2. Where treatment takes place in a mental health facility, a patient shall have the right, whenever possible, to be treated near his or her home or the home of his or her relatives or friends and shall have the right to return to the community as soon as possible.
- 3. Every patient shall have the right to treatment suited to his or her cultural background.

### Principle 8 Standards of care

- 1. Every patient shall have the right to receive such health and social care as is appropriate to his or her health needs, and is entitled to care and treatment in accordance with the same standards as other ill persons.
- 2. Every patient shall be protected from harm, including unjustified medication, abuse by other patients, staff or others or other acts causing mental distress or physical discomfort.

### Principle 9 Treatment

- 1. Every 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 treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff.
- 3. Mental health care shall always be provided in accordance with applicable standards of ethics for mental health practitioners, including internationally accepted standards such as the Principles of Medical Ethics relevant to the role of health personnel, particularly physicians, in the protection of prisoners and detainees against torture and other cruel, inhuman or degrading treatment or punishment, adopted by the United Nations General Assembly. Mental health knowledge and skills shall never be abused.
- The treatment of every patient shall be directed towards preserving and enhancing personal autonomy.

### Principle 10 Medication

- 1. Medication shall meet the best health needs of the patient, shall be given to a patient only for therapeutic or diagnostic purposes and shall never be administered as a punishment or for the convenience of others. Subject to the provisions of paragraph 15 of principle 11 below, mental health practitioners shall only administer medication of known or demonstrated efficacy.
- 2. All medication shall be prescribed by a mental health practitioner authorized by law and shall be recorded in the patient's records.

### Principle 11 Consent to treatment

- 1. No treatment shall be given to a patient without his or her informed consent, except as provided for in paragraphs 6, 7, 8, 13 and 15 of the present principle.
- 2. Informed consent is consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:
  - (a) The diagnostic assessment;
  - (b) The purpose, method, likely duration and expected benefit of the proposed treatment;
  - (c) Alternative modes of treatment, including those less intrusive;
  - (d) Possible pain or discomfort, risks and side-effects of the proposed treatment.
- 3. A patient may request the presence of a person or persons of the patient's choosing during the procedure for granting consent.
- 4. A patient has the right to refuse or stop treatment, except as provided for in paragraphs 6, 7, 8, 13 and 15 of the present principle. The consequences of refusing or stopping treatment must be explained to the patient.
- 5. A patient shall never be invited or induced to waive the right to informed consent. If the patient should seek to do so, it shall be explained to the patient that the treatment cannot be given without informed consent.
- 6. Except as provided in paragraphs 7, 8, 12, 13, 14 and 15 of the present principle, a proposed plan of treatment may be given to a patient without a patient's informed consent if the following conditions are satisfied:
  - (a) The patient is, at the relevant time, held as an involuntary patient;

- (b) An independent authority, having in its possession all relevant information, including the information specified in paragraph 2 of the present principle, is satisfied that, at the relevant time, the patient lacks the capacity to give or withhold informed consent to the proposed plan of treatment or, if domestic legislation so provides, that, having regard to the patient's own safety or the safety of others, the patient unreasonably withholds such consent;
- (c) The independent authority is satisfied that the proposed plan of treatment is in the best interest of the patient's health needs.
- 7. Paragraph 6 above does not apply to a patient with a personal representative empowered by law to consent to treatment for the patient; but, except as provided in paragraphs 12, 13, 14 and 15 of the present principle, treatment may be given to such a patient without his or her informed consent if the personal representative, having been given the information described in paragraph 2 of the present principle, consents on the patient's behalf.
- 8. Except as provided in paragraphs 12, 13, 14 and 15 of the present principle, treatment may also be given to any patient without the patient's informed consent if a qualified mental health practitioner authorized by law determines that it is urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons. Such treatment shall not be prolonged beyond the period that is strictly necessary for this purpose.
- Where any treatment is authorized without the patient's informed consent, every effort shall nevertheless be made to inform the patient about the nature of the treatment and any possible alternatives and to involve the patient as far as practicable in the development of the treatment plan.
- 10. All treatment shall be immediately recorded in the patient's medical records, with an indication of whether involuntary or voluntary.
- 11. Physical restraint or involuntary seclusion of a patient shall not be employed except in accordance with the officially approved procedures of the mental health facility and only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose. All instances of physical restraint or involuntary seclusion, the reasons for them and their nature and extent shall be recorded in the patient's medical record. A patient who is restrained or secluded shall be kept under humane conditions and be under the care and close and regular supervision of qualified members of the staff. A personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient.
- 12. Sterilization shall never be carried out as a treatment for mental illness.
- 13. A major medical or surgical procedure may be carried out on a person with mental illness only where it is permitted by domestic law, where it is considered that it would best serve the health needs of the patient and where the patient gives informed consent, except that, where the patient is unable to give informed consent, the procedure shall be authorized only after independent review.
- 14. Psychosurgery and other intrusive and irreversible treatments for mental illness shall never be carried out on a patient who is an involuntary patient in a mental health facility and, to the extent

that domestic law permits them to be carried out, they may be carried out on any other patient only where the patient has given informed consent and an independent external body has satisfied itself that there is genuine informed consent and that the treatment best serves the health needs of the patient.

- 15. Clinical trials and experimental treatment shall never be carried out on any patient without informed consent, except that a patient who is unable to give informed consent may be admitted to a clinical trial or given experimental treatment, but only with the approval of a competent, independent review body specifically constituted for this purpose.
- 16. In the cases specified in paragraphs 6, 7, 8, 13, 14 and 15 of the present principle, the patient or his or her personal representative, or any interested person, shall have the right to appeal to a judicial or other independent authority concerning any treatment given to him or her.

## Principle 12 Notice of rights

- 1. A patient in a mental health facility shall be informed as soon as possible after admission, in a form and a language which the patient understands, of all his or her rights in accordance with the present Principles and under domestic law, and the information shall include an explanation of those rights and how to exercise them.
- 2. If and for so long as a patient is unable to understand such information, the rights of the patient shall be communicated to the personal representative, if any and if appropriate, and to the person or persons best able to represent the patient's interests and willing to do so.
- 3. A patient who has the necessary capacity has the right to nominate a person who should be informed on his or her behalf, as well as a person to represent his or her interests to the authorities of the facility.

# Principle 13 Rights and conditions in mental health facilities

- 1. Every patient in a mental health facility shall, in particular, have the right to full respect for his or her:
  - (a) Recognition everywhere as a person before the law;
  - (b) Privacy;
- (c) Freedom of communication, which includes freedom to communicate with other persons in the facility; freedom to send and receive uncensored private communications; freedom to receive, in private, visits from a counsel or personal representative and, at all reasonable times, from other visitors; and freedom of access to postal and telephone services and to newspapers, radio and television;
  - (d) Freedom of religion or belief.

- 2. The environment and living conditions in mental health facilities shall be as close as possible to those of the normal life of persons of similar age and in particular shall include:
  - (a) Facilities for recreational and leisure activities:
  - (b) Facilities for education;
  - (c) Facilities to purchase or receive items for daily living, recreation and communication;
- (d) Facilities, and encouragement to use such facilities, for a patient's engagement in active occupation suited to his or her social and cultural background, and for appropriate vocational rehabilitation measures to promote reintegration in the community. These measures should include vocational guidance, vocational training and placement services to enable patients to secure or retain employment in the community.
- In no circumstances shall a patient be subject to forced labour. Within the limits compatible with the needs of the patient and with the requirements of institutional administration, a patient shall be able to choose the type of work he or she wishes to perform.
- 4. The labour of a patient in a mental health facility shall not be exploited. Every such patient shall have the right to receive the same remuneration for any work which he or she does as would, according to domestic law or custom, be paid for such work to a non-patient. Every such patient shall, in any event, have the right to receive a fair share of any remuneration which is paid to the mental health facility for his or her work.

### Principle 14 Resources for mental health facilities

- A mental health facility shall have access to the same level of resources as any other health establishment, and in particular:
- (a) Qualified medical and other appropriate professional staff in sufficient numbers and with adequate space to provide each patient with privacy and a programme of appropriate and active therapy;
  - (b) Diagnostic and therapeutic equipment for the patient;
  - (c) Appropriate professional care;
  - (d) Adequate, regular and comprehensive treatment, including supplies of medication.
- Every mental health facility shall be inspected by the competent authorities with sufficient frequency to ensure that the conditions, treatment and care of patients comply with the present Principles.

Principle 15 Admission principles

- 1. Where a person needs treatment in a mental health facility, every effort shall be made to avoid involuntary admission.
- 2. Access to a mental health facility shall be administered in the same way as access to any other facility for any other illness.
- 3. Every patient not admitted involuntarily shall have the right to leave the mental health facility at any time unless the criteria for his or her retention as an involuntary patient, as set forth in principle 16 below, apply, and he or she shall be informed of that right.

## Principle 16 Involuntary admission

- 1. A person may (a) be admitted involuntarily to a mental health facility as a patient; or (b) having already been admitted voluntarily as a patient, be retained as an involuntary patient in the mental health facility if, and only if, a qualified mental health practitioner authorized by law for that purpose determines, in accordance with principle 4 above, that that person has a mental illness and considers:
- (a) That, because of that mental illness, there is a serious likelihood of immediate or imminent harm to that person or to other persons; or
- (b) That, in the case of a person whose mental illness is severe and whose judgement is impaired, failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition or will prevent the giving of appropriate treatment that can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative.

In the case referred to in subparagraph (b), a second such mental health practitioner, independent of the first, should be consulted where possible. If such consultation takes place, the involuntary admission or retention may not take place unless the second mental health practitioner concurs.

- 2. Involuntary admission or retention shall initially be for a short period as specified by domestic law for observation and preliminary treatment pending review of the admission or retention by the review body. The grounds of the admission shall be communicated to the patient without delay and the fact of the admission and the grounds for it shall also be communicated promptly and in detail to the review body, to the patient's personal representative, if any, and, unless the patient objects, to the patient's family.
- 3. A mental health facility may receive involuntarily admitted patients only if the facility has been designated to do so by a competent authority prescribed by domestic law.

Principle 17 Review body

1. The review body shall be a judicial or other independent and impartial body established by domestic law and functioning in accordance with procedures laid down by domestic law. It shall, in

formulating its decisions, have the assistance of one or more qualified and independent mental health practitioners and take their advice into account.

- 2. The initial review of the review body, as required by paragraph 2 of principle 16 above, of a decision to admit or retain a person as an involuntary patient shall take place as soon as possible after that decision and shall be conducted in accordance with simple and expeditious procedures as specified by domestic law.
- The review body shall periodically review the cases of involuntary patients at reasonable intervals as specified by domestic law.
- An involuntary patient may apply to the review body for release or voluntary status, at reasonable intervals as specified by domestic law.
- 5. At each review, the review body shall consider whether the criteria for involuntary admission set out in paragraph 1 of principle 16 above are still satisfied, and, if not, the patient shall be discharged as an involuntary patient.
- If at any time the mental health practitioner responsible for the case is satisfied that the conditions for the retention of a person as an involuntary patient are no longer satisfied, he or she shall order the discharge of that person as such a patient.
- 7. A patient or his personal representative or any interested person shall have the right to appeal to a higher court against a decision that the patient be admitted to, or be retained in, a mental health facility.

### Principle 18 Procedural safeguards

- The patient shall be entitled to choose and appoint a counsel to represent the patient as such, including representation in any complaint procedure or appeal. If the patient does not secure such services, a counsel shall be made available without payment by the patient to the extent that the patient lacks sufficient means to pay.
- 2. The patient shall also be entitled to the assistance, if necessary, of the services of an interpreter. Where such services are necessary and the patient does not secure them, they shall be made available without payment by the patient to the extent that the patient lacks sufficient means to pay.
- The patient and the patient's counsel may request and produce at any hearing an independent mental health report and any other reports and oral, written and other evidence that are relevant and admissible.
- 4. Copies of the patient's records and any reports and documents to be submitted shall be given to the patient and to the patient's counsel, except in special cases where it is determined that a specific disclosure to the patient would cause serious harm to the patient's health or put at risk the safety of others. As domestic law may provide, any document not given to the patient should, when this can be done in confidence, be given to the patient's personal representative and counsel. When

any part of a document is withheld from a patient, the patient or the patient's counsel, if any, shall receive notice of the withholding and the reasons for it and it shall be subject to judicial review.

- 5. The patient and the patient's personal representative and counsel shall be entitled to attend, participate and be heard personally in any hearing.
- 6. If the patient or the patient's personal representative or counsel requests that a particular person be present at a hearing, that person shall be admitted unless it is determined that the person's presence could cause serious harm to the patient's health or put at risk the safety of others.
- 7. Any decision on whether the hearing or any part of it shall be in public or in private and may be publicly reported shall give full consideration to the patient's own wishes, to the need to respect the privacy of the patient and of other persons and to the need to prevent serious harm to the patient's health or to avoid putting at risk the safety of others.
- 8. The decision arising out of the hearing and the reasons for it shall be expressed in writing. Copies shall be given to the patient and his or her personal representative and counsel. In deciding whether the decision shall be published in whole or in part, full consideration shall be given to the patient's own wishes, to the need to respect his or her privacy and that of other persons, to the public interest in the open administration of justice and to the need to prevent serious harm to the patient's health or to avoid putting at risk the safety of others.

## Principle 19 Access to information

- 1. A patient (which term in the present Principle includes a former patient) shall be entitled to have access to the information concerning the patient in his or her health and personal records maintained by a mental health facility. This right may be subject to restrictions in order to prevent serious harm to the patient's health and avoid putting at risk the safety of others. As domestic law may provide, any such information not given to the patient should, when this can be done in confidence, be given to the patient's personal representative and counsel. When any of the information is withheld from a patient, the patient or the patient's counsel, if any, shall receive notice of the withholding and the reasons for it and it shall be subject to judicial review.
- 2. Any written comments by the patient or the patient's personal representative or counsel shall, on request, be inserted in the patient's file.

### Principle 20 Criminal offenders

- 1. The present Principle applies to persons serving sentences of imprisonment for criminal offences, or who are otherwise detained in the course of criminal proceedings or investigations against them, and who are determined to have a mental illness or who it is believed may have such an illness.
- 2. All such persons should receive the best available mental health care as provided in principle 1 above. The present Principles shall apply to them to the fullest extent possible, with only such

limited modifications and exceptions as are necessary in the circumstances. No such modifications and exceptions shall prejudice the persons' rights under the instruments noted in paragraph 5 of principle 1 above.

- Domestic law may authorize a court or other competent authority, acting on the basis of competent and independent medical advice, to order that such persons be admitted to a mental health facility.
- 4. Treatment of persons determined to have a mental illness shall in all circumstances be consistent with principle 11 above.

Principle 21 **Complaints** 

Every patient and former patient shall have the right to make a complaint through procedures as specified by domestic law.

### Principle 22 Monitoring and remedies

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

### Principle 23 *Implementation*

- 1. States should implement the present Principles through appropriate legislative, judicial, administrative, educational and other measures, which they shall review periodically.
- 2. States shall make the present Principles widely known by appropriate and active means.

Principle 24 Scope of principles relating to mental health facilities

The present Principles apply to all persons who are admitted to a mental health facility.

Principle 25 Saving of existing rights

There shall be no restriction upon or derogation from any existing rights of patients, including rights recognized in applicable international or domestic law, on the pretext that the present Principles do not recognize such rights or that they recognize them to a lesser extent.

#### Appendix C **Declaration on the Rights of Mentally Retarded Persons**

Proclaimed by General Assembly resolution 2856 (XXVI) of 20 December 1971

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end.

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

- 1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
- 2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
- 3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
- 4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should

receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

- 5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.
- 6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.
- Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.