Not on the Agenda:
Human Rights of People with Mental Disabilities in Kosovo

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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 around the world, and promotes international awareness and oversight of the rights of people with mental disabilities. MDRI advises governments and non-governmental organizations to plan strategies to bring about effective rights enforcement and service system reform. Drawing on the skills and experience of attorneys, mental health professionals, people with disabilities and their families, MDRI challenges the discrimination and abuse faced by people with mental disabilities worldwide.

MDRI is based in Washington, DC, with a regional office in Budapest, Hungary. MDRI Executive Director Eric Rosenthal, JD founded MDRI in 1993 as a joint project of the Bazelon Center for Mental Health Law and the Center for Human Rights of the Washington College of Law, American University. Since 1997, MDRI has been an independent organization. Dr. Éva Szeli directs MDRI’s Budapest office. MDRI has published three major reports on human rights in mental health systems: Human Rights and Mental Health: Mexico (2000); Human Rights and Mental Health: Hungary (1997); and Human Rights and Mental Health: Uruguay (1995). On behalf of UNICEF, MDRI published Children in Russia’s Institutions: Human Rights and Opportunities for Reform (2000). MDRI has assisted mental disability rights advocates in Argentina, Armenia, Azerbaijan, Bulgaria, the Czech Republic, Estonia, Hungary, Kosovo, Lithuania, Macedonia, Mexico, Poland, Romania, Russia, Slovakia, Slovenia, Ukraine, and Uruguay.

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Foreword

People with disabilities are among the human rights community’s most neglected victims. In recent years, the human rights movement has greatly expanded its embrace. What began as a cause concerned almost exclusively with the plight of political prisoners has now broadened to defend a wide array of victims. Women, children, refugees, displaced, migrants, workers, common prisoners, gays, lesbians, and all sorts of ethnic, racial and religious minorities now routinely find shelter under the protective umbrella of human rights organizations.

For the most part, people with disabilities who face official discrimination, abuse or neglect are still left outside, battling the elements on their own. There is little doubt that a disability is a “status” entitling one to protection under, for example, the anti-discrimination provisions of Article 26 of the International Covenant on Civil and Political Rights. In some cases involving children, the human rights movement has begun to take on the cause of people with disabilities. But an embrace of this broad sector of humanity has barely begun. Remedying this failure is a major challenge facing the movement.

Mental Disability Rights International has taken up this challenge. With much energy, dedication, and intelligence, it has produced some of the finest accounts available of the plight of people with mental disabilities before the indifference and callousness of state institutions. This latest report, on Kosovo, is a model of such work.

One would hope that respect for international standards would begin with the guardian of those standards: the United Nations. But as MDRI shows, UN operations in Kosovo have fallen far short of the mark. They have consigned people unnecessarily to lifetime institutionalization, and they have countenanced conditions of confinement that are abusive and inhumane.

The detailed accounts in this sober and carefully researched report are a powerful indictment. They should be a spur to action. They should lead us to vow no longer to tolerate silence the suffering so compellingly described. They should remind us all of the urgency of protecting and advancing the human rights of this vulnerable population.

Kenneth Roth
Executive Director, Human Rights Watch
Acknowledgments

The Mental Disability Rights International (MDRI) team of investigators who researched and prepared this report would like to acknowledge the assistance of the many people in Kosovo whose valuable insights and observations have made this report possible. To protect the privacy of individuals who spoke with us, most of the people MDRI interviewed are not named in this report. The people who assisted the MDRI investigators include people who use mental health and disability services in Kosovo, members of their families, staff at institutions, mental health professionals, and officials at the United Nations Mission in Kosovo (UNMIK), the World Health Organization (WHO), and the Organization for Security and Cooperation in Europe (OSCE). We also received extensive assistance from humanitarian relief workers in Kosovo. We would particularly like to thank representatives of the Norwegian Red Cross (Norcross) and Doctors of the World (DOW).

Clive Baldwin of the OSCE originally invited MDRI to Kosovo to advise him on the development of new mental health legislation. Mr. Baldwin introduced MDRI investigators to representatives of WHO and UNMIK. As part of Mr. Baldwin’s efforts to draft new mental health legislation, he provided MDRI numerous opportunities to review and comment on drafts and to meet with the committee drafting the legislation.

At the World Health Organization (WHO), Dr. Liliana Urbina and Devora Kestel spent many hours with MDRI and provided us with extensive information about WHO activities. Dr. Urbina assisted MDRI in making contacts with mental health professionals throughout Kosovo. Dr. Ferid Agani of the Ministry of Health, then advisor to WHO and UNMIK, also provided extensive assistance to MDRI in making visits to the psychiatric ward of Prishtina University Hospital. Dr. Agani also provided extremely helpful background information about the operation of Kosovo’s mental health system.

At UNMIK, Tanya Radocaj, Sandra Hudd, Dr. Hilbert Belksma, and Dr. Gabrielle Rutten provided extensive assistance to MDRI. They opened the doors of every UNMIK-administered institution and made MDRI fact-finding visits possible. They were generous with their time in answering questions and providing background information about UNMIK activities in Kosovo. Dr. Rutten and Dr. Belksma accompanied MDRI on a number of site visits and greatly assisted our research. We would also like to thank Kujtim Xhelili, the Director of Shtime, for providing us with access to his institution and information about its operation.

MDRI’s work in Kosovo would not have been possible without the extensive assistance of disability rights and women’s rights activists in Kosovo, as well as other health professionals. We would especially like to thank Halit Ferizi, President of Handikos; Igballe Rogova, coordinator of Motrat Qiriazi, and Board Member of the Kosovo Women’s Network; and Dr. Gani Demolli, founder and Coordinator of Health Services of the Mother Teresa Society.

Diana Beth Hoover of Doctors of the World has provided extensive background information to MDRI about the operation of the DOW Children’s Program. Marta Schaaf, Dr. Mary Hayden, Dr. Harriet Epstein, and Isabel Marti have also provided valuable background information about the children’s program and about the operation of service systems in Kosovo that they observed. Dr. Hayden has also reviewed and commented on the draft of this report.
Deb Benko, Communications Officer at Mental Disability Rights International, provided extensive assistance reviewing and editing the text, providing background research, and formatting the report for publication. Elizabeth Bauer and Clarence Sundram, members of the Mental Disability Rights International Board of Directors, reviewed the text and provided extensive comments on the draft.

Irving and Suzanne Rosenthal and Bud and Grace Newman reviewed numerous drafts, assisted with formatting, and provided many hours of babysitting time during MDRI missions to Kosovo and drafting phases of the report. Sheila Geist provided a base of operations for MDRI’s advocacy work in New York. Njomeza Pallaska provided extensive logistical assistance in Kosovo. The contributions of all these individuals have been invaluable to the development of this report.

Eugene Richards of Many Voices, Inc. traveled to Kosovo as a volunteer to provide photographic portraits of people living in Kosovo’s institutions. Both Eugene Richards and Janine Altongy have demonstrated great dedication to MDRI’s mission and this project by donating many hours of their time to help document the human rights conditions of people with mental disabilities in Kosovo.

Lisa Newman provided strategic advice, copy-editing, and emotional support on every step of this project – during her pregnancy and in the first six months of the life of Eliana Sofia. Without Lisa’s endless patience and deep commitment to MDRI’s work, this report would not have been possible. Eliana Sofia brought great joy to the final six months of work on this project. May each child from Shtime have a chance some day to grow up with the comfort of a loving family.

This project was funded primarily by the Open Society Institute. Additional support for MDRI has been provided by the Public Welfare Foundation and the Overbrook Foundation.
Executive Summary

*Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo* describes the findings of an investigation by Mental Disability Rights International (MDRI) on the human rights of people with mental disabilities¹ in Kosovo. MDRI conducted seven fact-finding missions to Kosovo between September 2000 and July 2002. MDRI teams investigated conditions at inpatient and community facilities, including: two social care facilities; two psychiatric wards at general hospitals; the psychiatric ward of the Lipljan jail; two group homes for children with disabilities; a special school for children with disabilities, and two recently established community mental health centers. The largest social care facility we visited is Shtime, a 285-bed facility designated for individuals with mental disabilities. Shtime currently has approximately 230 people under its authority. The other social care facility is known as the Elderly Home, a 165-bed facility housing people of all ages (as young as 17 when we visited). This report particularly focuses on Shtime and Prishtina University Hospital’s psychiatric ward, a 75 bed short-term facility.² In addition to documenting abuses within institutions, this report examines policies and programs for reform of the mental health and social service system adopted by the United Nations Mission in Kosovo (UNMIK) and inherited by the new government of Kosovo.

International intervention in Kosovo by NATO and the United Nations was inspired by the worthy goals of protecting the human rights of people in Kosovo. Despite extensive international funding for the development of democracy and the support for civil society in Kosovo, this report finds that people with mental disabilities have been left off the human rights agenda. Serious human rights abuses against people with mental disabilities are taking place in Kosovo and continue unabated. While some valuable community mental health programs have been established to serve a small number of individuals, internationally funded programs to refurbish Shtime are likely to perpetuate an outmoded and inappropriate system of services that segregates people with mental disabilities from society.

In Kosovo’s social care facilities and psychiatric wards, people are being illegally and improperly detained in institutions in violation of domestic and international law. Once detained, people are deprived of meaningful treatment and habilitation,³ and they are subject to physical, sexual and psychological abuse. For the great majority of patients, life in Kosovo’s facilities is one of mind-numbing boredom and inactivity in an environment devoid of privacy and dignity. Despite internationally funded programs to fix up buildings at Shtime, staff is inadequate to provide basic cleanliness or hygiene. Many residents live in filth, surrounded by the smell of urine or feces. Medical and psychiatric care is inadequate and unsafe; a cursory review of medical records at Shtime shows that non-professional staff is authorized to administer powerful psychotropic medications without review by a psychiatrist for months or years.

¹See discussion in the Preface, part C, describing the use of the term “mental disability.” The term includes individuals with psychiatric disabilities or intellectual disabilities (including developmental disabilities, such as mental retardation, or other cognitive disabilities).

²This facility is over capacity, reportedly holding up to 100 patients at a time. See Organization for Security and Cooperation in Europe, Mission in Kosovo, Department of Human Rights and Rule of Law, Kosovo: Review of the Criminal Justice System, September 2001-February 2002 (hereinafter the “OSCE Report on the Criminal Justice System.”) at p.54.

³“Habilitation” is the term used to describe the services needed by people with intellectual disabilities (or developmental disabilities, such as mental retardation) to maintain basic self-care and living skills.
MDRI received reports from international and Kosvar staff and patients about cases of sexual harassment, exploitation, rape, or other forms of violence at Shtime, Prishtina University Hospital, and the Elderly Home. Institution and UNMIK authorities have been informed about cases of abuse at Shtime, yet they have done nothing to remove known abusers from day-to-day contact with former victims. At Prishtina University Hospital, MDRI has received reports about sexual abuse of women by staff. There is no system at any institution MDRI visited to conduct independent investigations of abuses or to protect the privacy or safety of witnesses who may come forward. MDRI has encountered both staff and patients who are afraid to come forward with evidence about abuses they have experienced or observed.

Many people are inappropriately placed at Shtime, yet UNMIK continues to direct limited international resources to refurbishing Shtime rather than creating community-based alternatives. According to an analysis by UNMIK’s “Deinstitutionalization Team,” the majority of people at Shtime have no medical reason for being at the institution. UNMIK has stated that the main obstacle to their integration into the community is the lack of services and support systems in the community. Despite these findings, UNMIK has proposed a new program to the Dutch Government to rebuild and rehabilitate the Shtime institution. No funding has been set aside to create community alternatives for residents of Shtime.

The World Health Organization (WHO) and the Ministry of Health have created a program to provide community services to a small fraction of people with psychiatric disabilities in Kosovo. Adults with intellectual disabilities have been entirely left out of any plans for a community-based service or support system. Thus, policies and programs established under UNMIK authority will result in lifetime institutionalization for most people now detained in mental health facilities.

The great majority of individuals with mental disabilities – approximately 40,000 such individuals – live with their families or on their own and receive no support from the government. Anecdotal reports suggest that such individuals and their families live in impoverished conditions. Due to lack of resources, lack of accessible public services, and the stigma associated with mental disabilities, many of these individuals remain closeted at home and cannot participate in any form of public life. The failure to create an integrated system of community-based services and support for these individuals also leaves them abandoned and segregated from society.

We find that the lack of respect for human dignity, the danger due to unhygienic conditions, inappropriate medical care, and lack of protection from physical and sexual abuse renders detention in Shtime for anyone a form of “inhuman and degrading” treatment in violation of the United Nations’ International Covenant on Civil and Political Rights (ICCPR). Shtime is so dangerous and destructive to the mental and physical health of its residents that the UN should plan for its closure at the soonest possible date — as soon as alternatives can be created in the community. The lack of protections against physical and sexual abuse or exploitation at the Elderly Home and the psychiatric wards of general hospitals also constitute inhuman and degrading treatment under the ICCPR. The lack of protections against improper civil commitment in these facilities renders detention in these facilities a form of arbitrary detention under the ICCPR. For people capable of living in the community, the provision of services exclusively in the segregated and inappropriate environment of institutions is a form of discrimination under international law.
For any democracy to function effectively, people must be in a position to represent their own interests, to demand rights enforcement, and to advocate for responsive government policies. The United Nations’ own “Standard Rules on Equalization of Opportunities for Persons with Disabilities” (the “Standard Rules”) call on all governments to create opportunities for people with disabilities to participate in public life. In addition to developing social services and support systems that promote community integration, the Standard Rules call on all governments to include people with disabilities in policy-making and program implementation on matters that affect them. UNMIK programs in Kosovo do not conform to the UN’s own disability rights standards, given a service system that segregates them from society in institutions or abandons them in the community. International civil society programs have not provided training or support to organizations made up of people with mental disabilities or real opportunities for people with mental disabilities to participate in Kosovo’s democracy.

MDRI calls on the UN Secretary General to direct UNMIK to:

- Act immediately to protect people detained in institutions from further violence or sexual abuse, create safe living conditions, and separate abusers from patients;
- Create a system of human rights oversight and accountability to ensure rights enforcement in institutions and community-based programs; this should include the creation of a mechanism to investigate abuse that will protect the privacy and safety of witnesses and victims;
- Establish a comprehensive plan to create community-based services for people with mental disabilities that (1) does not exclude people with intellectual disabilities (2) provides services for people now detained in institutions who are capable of living in the community (3) builds on the support of Kosovar non-governmental organizations and families and (4) creates independent community supports for individuals without families or with abusive family situations;
- Create a time-table for the closure of Shtime as soon as community-based alternatives can be created for its residents;
- Ensure participation by organizations of people with mental disabilities in policy-making, human rights advocacy, and program implementation through the creation of targeted outreach, training, and civil society support programs for people with disabilities and their families;
- Report to the UN Human Rights Commission on steps taken to end abuses against people with mental disabilities in Kosovo, in accordance with the Human Rights Commission’s April 2002 resolution calling on the Secretary General to report on the enforcement of international human rights for people with disabilities by UN agencies.

MDRI’s specific recommendations to the United Nations Mission in Kosovo (UNMIK) and international funders are listed at the end of this report.
Preface: Goals and Methods of this Report

A. Goals

This report documents the treatment of people with mental disabilities in internationally funded public mental health and social services in Kosovo. The report relies on international human rights conventions to which the United Nations Mission in Kosovo (UNMIK) and local government authorities in Kosovo have binding obligations, with particular reference to the International Covenant on Civil and Political Rights (ICCPR)\(^4\) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).\(^5\) As a standard for assessing human rights enforcement in public policy-making and the operation of mental health services, this report also relies on specialized human rights standards adopted by the United Nations General Assembly, such as the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles)\(^6\) and the Standard Rules on Equalization of Opportunities for Persons with Disabilities (the Standard Rules).\(^7\) Based on this analysis, the report recommends steps needed to bring the mental health and social service system into conformity with international human rights law. The report draws on international experience with best practices to suggest strategies that would most effectively bring about enforcement of international human rights law given the limited professional resources, infrastructure and funding in Kosovo.

The lessons learned from the experience in Kosovo are of great value as the international community turns toward new post-conflict areas of the world. These findings are also applicable in the many developing countries that receive international aid and support in health, social services, civil society, and human rights. While the recommendations in this report are targeted specifically at the situation in Kosovo today, the approach MDRI recommends is of immediate relevance to other foreign assistance or human rights programs affecting people with mental disabilities.

Kosovo is now at a critical time of transition as new Kosovar government authorities take over responsibilities from UNMIK for the day-to-day operation of health and social services, as well as long-range planning for service reform. We hope that the recommendations in this report will be of assistance to the new government of Kosovo in shaping a strategy for human rights, mental health, and social services for people with mental disabilities. As the international community retains ultimate responsibility for human rights enforcement in Kosovo, our recommendations regarding the immediate action needed to protect rights are directed to the United Nations Mission in Kosovo (UNMIK) and the Organization for Security and Cooperation in Europe (OSCE).

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It is not our goal to cast blame on the many dedicated mental health professionals and staff who work within Kosovo’s service system who are committed to helping people with mental disabilities. We have met many staff who work long hours at low salaries. When we first arrived in September 2000, we learned that UNMIK delayed for months in paying any salaries at all to institution staff. Most important, we recognize that conditions that make life dangerous for patients also make the working situation dangerous for staff. The need for increased funds for mental health services, as well as the establishment of human rights protections, will ultimately benefit staff as well as people who receive services.

While MDRI calls for the closure of Shtime, there is no reason for any staff member dedicated to the well being of the patients to lose his or her job. The government of Kosovo would do well to build on the experience of current staff and to provide further training needed to assist these individuals to work in community service programs.

B. Methods

MDRI was invited to Kosovo in 2000 by the OSCE to provide advice on the reform of mental health legislation. WHO staff arranged site visits and transportation for MDRI’s first visit in September 2000. MDRI arranged all subsequent visits independently. MDRI sent investigative teams to Kosovo in September 2000, May, September and December 2001, and May and July 2002. In addition to visiting institutions, MDRI teams met with independent disability rights and women's rights activists, mental health professionals, people with disabilities, family members, and representatives of the UN and other international organizations. During each visit, MDRI investigators brought photographic equipment (still or video cameras) to record our observations.

This report is based upon observations within the public mental health and service system for people with mental disabilities in Kosovo. MDRI investigative teams were not able to visit all internationally funded mental health or trauma programs in Kosovo, and this report was not intended to be an assessment of all such programs.

Within the programs we visited, there are almost certainly a number of programs we did not observe or were not able to include in this report. Our report is intended to provide as accurate a picture as possible of the human rights concerns that exist in the mental health and social services system for people with mental disabilities. We circulated this report to UN and OSCE authorities as well as activists in Kosovo and have requested that they make any corrections of any element of this report that they find to be incorrect. We regret any errors or omissions that are material to our primary observations or conclusions. MDRI requests that readers bring any factual errors (or additional relevant information) to our attention, including comments, responses, or suggestions for future work. Such comments can be directed to:

8 The list of participants in MDRI’s site visits were as follows: September 2000 - Andrea Blanch, Brittany Benowitz, Emily Hoffman, Eric Rosenthal and Éva Szeli; May 2001 - Rosenthal, Szeli and Laura Prescott; September 2001 - Rosenthal, Szeli, Prescott, as well as Eugene Richards, Gabor Gombos, and John O’Gorman; December 2001 – Szeli, Gombos; May 2002 – Rosenthal, Szeli, Prescott, and Dr. Robert Okin; July 2002 – Szeli. Dea Pallaska served as an interpreter and a participant on all missions.

9 A video camera was made available to MDRI by Witness. MDRI’s videotapes are kept in the video library of Witness in New York and are available for review by arrangement with MDRI. Eugene Richards, a professional photographer, donated his time to this project and provided all of his own equipment.
The Summary and Recommendations of this report have been translated into Albanian. A Serbian translation is pending. MDRI appreciates any corrections to the language of the translated editions or comments on the quality of the translation. If there are any disparities in the contents of the different language versions, the English language text should be recognized as the original language used by the authorities.

C. A Note on Language and Terminology

This report refers to “Kosovo” using the internationally accepted designation for the area. We use Albanian place names for all other locations in Kosovo. This is not a political statement and is purely motivated by ease of use. The main text of this report has been translated into Albanian, and we are planning a Serbian translation. We will use Serbian place names in that version of the report.

This report uses the term “mental disability.” We use the term in its broadest possible sense: it includes individuals with a psychiatric disability or an intellectual disability, individuals with no disability who may be subject to discrimination based upon an improper perception that they have a mental disability or other mental disorder, and individuals who may be subject to discrimination based upon a record or past history of mental disability. The term “psychiatric disability” includes individuals who are given a psychiatric diagnosis, whether or not that diagnosis is proper. The term “intellectual disability” includes individuals diagnosed properly or improperly with a developmental disability, such as mental retardation, or any cognitive disability. While this report is not primarily focused on the rights of individuals with physical disabilities, there are a number of people detained in Kosovo’s institutions purely because of physical disabilities. This report includes their concerns as well.

In the English language, the term “mental disability” is somewhat awkward, and we recognize that it is not widely used outside the United States. Different terminology is used to describe people with disabilities in different countries and different languages, and this report is not intended to favor one national approach over another.
I. Introduction

A. Recent political chronology

In 1989, under former President Slobodan Milosevic’s rule, Kosovo’s status as an autonomous province within the former Yugoslavia was revoked. The political, economic, and civil rights of the majority Albanian population were dramatically restricted as the government in Belgrade sought to enhance Serbian power in the region. The majority of Kosovar Albanian professionals were fired from their positions. They created a “shadow government” and developed a “parallel structure” of social, political, cultural, educational, and health care systems. These services operated informally and - at times - illegally under Yugoslavian law. This parallel structure remained in place until the war in the late 1990s. Many of the programs established during this period have become the most active and well-established non-governmental organizations (NGOs) operating in Kosovo today.

The conflict between the pro-Serbian Yugoslav government and majority Albanian population of Kosovo became increasingly violent in 1998, and thousands of Kosovar Albanians were displaced from their homes during Serbian-driven ethnic cleansing efforts. The North Atlantic Treat Organization (NATO) initiated air strikes against the former Yugoslavia in March 1999. The United Nations established the UN Interim Administration in Kosovo, known as UNMIK, in June 1999 with the passage of UN Security Council Resolution 1244.

B. Legal structure of Kosovo

UN Security Council Resolution 1244 establishes that one of the primary tasks of the international civil presence in Kosovo is to “promote and protect human rights” (paragraph 11(j)). The UN Secretary General’s report of July 12, 1999 assigns the lead role in human rights to the Organization for Security and Cooperation in Europe (OSCE), the institution-building pillar within UNMIK.

In May 2001, a new constitutional framework was established to provisionally expand Kosovar self-government, though the issue of Kosovo’s future status in relation to Yugoslavia remains unresolved. The first Kosovo-wide elections took place in November 2001 and a new government is now in place. However, UNMIK retains ultimate administrative authority for the operation of services in Kosovo, and OSCE is responsible for the protection of human rights.

Despite Kosovo’s indeterminate geo-political status, international human rights conventions are fully binding in the province. The interim legal structure in Kosovo has been determined by UNMIK. Applicable law includes regulations promulgated under the UNMIK administration, in addition to those laws, which had been in force in Kosovo on 22 March 1989, before Kosovo’s autonomy was revoked. In the case of conflict between the two sources of law, the UN regulations take precedence. Non-discriminatory laws in force after 22 March 1989 may be applicable regarding a subject matter or situation not otherwise

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2 Applicable law is governed by UNMIK Regulation No. 1999/24, passed on 12 December 1999, retroactively entered into force as of the establishment of the UNMIK administration on 10 June 1999.
addressed by the UNMIK regulations or the original Kosovar laws. Additionally, internationally recognized human rights standards are to be observed by all those who undertake public duties or hold private office.³

C. Development of a strong independent sector in Kosovo

The decade between the loss of Kosovo’s autonomy to Serbian rule in 1989 and the establishment of the international administration in 1999 was one of great struggle and survival for the Kosovar people. Local human rights activists emerged, and a multitude of local non-governmental organizations were established.¹⁰ Many of these organizations were formed to address general public interest and human rights concerns, while many others focused on groups with special needs, such as women and children. Some of these NGOs filled roles within the parallel service system established by the Kosovar Albanians. For example, the Mother Teresa Society, provided much of the health care available to Albanians within this informal system. Other local NGOs have offered services for people with disabilities (though not specifically for people with mental disabilities) and some services for women and children that included psychosocial components.

At present, there are no organizations run by people with psychiatric or intellectual disabilities. We met a number of parents of people with mental disabilities who are in the process of establishing organizations. There is an umbrella disability rights organization that includes people of all disabilities, known as Handikos. Established in 1994, Handikos currently has a Kosovo-wide network of 25 offices and 10 community rehabilitation centers. The Director of Handikos, Halit Ferizi, reported to MDRI that Handikos does not currently have specialized programs for people with intellectual or psychiatric disabilities and it lacks expertise in this area. However, individuals with such disabilities and their families often seek community services and support at the Handikos community centers. Handikos leaders have expressed interest in integrating services for people with mental disabilities into their work and including them in ongoing disability advocacy efforts.

Other organizations and human rights leaders have also expressed an interest in expanding their work to include people with mental disabilities. Dr. Gani Demolli, Coordinator of Health Services for the Mother Teresa Society, currently heads the Board of Directors of Deshira, a clubhouse for people with mental disabilities. Igballe Rogova, of Motrat Qiriazi (a rural women’s group initially established in 1989 to combat illiteracy) and the Kosovar Women’s Network (an alliance of local and international women’s rights NGOs

³ Regulation 1999/24 includes a particularized list of international human rights documents, which is not intended to be exhaustive:
The Universal Declaration of Human Rights of 10 December 1948;
The European Convention for the Protection of Human Rights and Fundamental Freedoms of 4 November 1950 (and its Protocols);
The International Covenant on Civil and Political Rights of 16 December 1966 (and its Protocols);
The International Covenant on Economic, Social and Cultural Rights of 16 December 1966;
The Convention on the Elimination of All Forms of Racial Discrimination of 21 December 1965;
The Convention on Elimination of All Forms of Discrimination Against Women of 17 December 1979;
The Convention Against Torture and Other Cruel, Inhumane or Degrading Treatment or Punishment of 17 December 1984; and

¹⁰ According to staff of OSCE, there were 600 local NGOs operating in Kosovo before the war.
working in Kosovo), has expressed significant interest in expanding her work to include women with mental disabilities, and she stated that her organizations would be receptive to training, which would prepare them to do so. The work of such local allies and activists, with long-standing grassroots experience in the province, forms the foundation for the advocacy movement that will drive human rights reform in Kosovo.

D. Structure of mental health and disability services

1. Administrative structure

Kosovo is divided into 30 municipalities, with Prishtina / Priština as the provincial capital. The existing system of mental health services is centralized, with service delivery occurring almost exclusively in the neuropsychiatric clinic in Prishtina University Hospital and the neuropsychiatric wards throughout Kosovo (in the municipalities of Mitrovica / Kosovska Mitrovica, Peja / Peć, Gjakova / Djakovica, and Prizren / Prizren), for a total of 276 neuro-psychiatric beds. There are also two institutional settings: the “Special Centre” at Shtime / Štimlje (with 285 beds), and the “Elderly Home” in Prishtina (with 165 beds). While the former was established for individuals with developmental disabilities and the latter for elders, both have also become long-term custodial facilities for people with psychiatric disabilities. Administratively, hospitals have been the responsibility of UNMIK’s Health sector, while institutions such as Shtime and the Elderly Home have been a Social Welfare concern. While this division was initially a technical one, in November 2001, after the elections and administrative restructuring, the Department of Health and Social Welfare was divided between the ministries of Health, Environment & Spatial Planning and Labor & Social Welfare. This report refers to documents or interview material provided to MDRI by the former UNMIK Department of Health and Social Welfare (DHSW) where that material is relevant.

There has been a significant shortage of qualified mental health professionals to administer the existing system, due in part to the decade of professional marginalization under Serb rule. Psychiatry and neurology had historically been joint disciplines in the former republic of Yugoslavia, with most of the training in neuro-psychiatry taking place in Belgrade or Zagreb. Approximately 40 neuro-psychiatrists in the Kosovo region specialize in psychiatric disabilities.12 Approximately 120 medical nurses work in neuro-psychiatry.13 There are only five psychologists in the entire Kosovo region. This shortage is largely accounted for by the fact that there has never been a clinical psychology faculty in the region. There are also very few social workers, and most are not trained to work with mental disabilities.

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11Geographical divisions in Kosovo have both Albanian and Serbian names. While Albanian names are used throughout the report, Serbian names are noted here for clarification.

12According to the World Health Organization (WHO), there is one neuropsychiatrist per 57,270 inhabitants of Kosovo. With these neuro-psychiatrists dividing their time between the practices of neurology and psychiatry, this translates to one psychiatrist per 114,540 inhabitants, far short of the WHO standard of one psychiatrist per 10,000 inhabitants.

13With these nurses dividing their time between neurology and psychiatry services, WHO estimates that there is one psychiatric nurse per 37,500 inhabitants of Kosovo, significantly short of the WHO standard of one psychiatric nurse per 2,500 inhabitants.
Apart from Shtime (which is technically a “special institution” not part of the mental health system), psychiatric wards of general hospitals provide services to 276 people in Kosovo’s mental health system. In theory, psychiatric wards are supposed to provide assistance to individuals in need of acute psychiatric care. In practice, the majority of people on these wards are referred to as “chronic patients” who need long-term social support.

The role of the psychiatric wards has changed considerably from the pre-war years. The breakup of Yugoslavia had contributed to the breakdown and fragmentation of a mental health system that had parts of its infrastructure outside of Kosovo including professional training centers. The system was also burdened by the fact that, after the break-up of Yugoslavia, many long-term patients who had been placed in custodial facilities in Macedonia were bused back to Kosovo without any form of planning to assist them in reintegrating into their home communities. Many of these individuals found their way to beds at the psychiatric wards of general hospitals where some people languish to this day. Others were either taken in by family members or left to die. MDRI interviewed mental health professionals in both Macedonia and Kosovo who say that there has been no public accounting for what may be hundreds of people with mental disabilities bused back to Kosovo in the years before the war.

2. System of financing services

During the initial stage of UN governance in Kosovo, all health and social services were funded by foreign donor money. According to Dr. Vuori, UNMIK is moving towards creating a “self-sustaining” economic system, as international attention and interest in Kosovo is slowly disappearing and funding is becoming more limited. In 2000, international donor funds represented about 60% of the operating budget. This level dropped to 30-40% in 2001 and has continued to decrease to less than 10% in 2002. The ultimate goal of the central fiscal authorities, according to Dr. Vuori, is to eliminate reliance on international donor funds in the operational budget. According to the chief of mental health for the Ministry of Health, a study by WHO found that funding for mental health services in real terms (accounting for inflation and other changes in relative costs) is lower under the UNMIK administration than it was in the Yugoslav era.

While funding depends on outside donors, UNMIK makes important policy decisions through the process of seeking foreign assistance. In May 2002, for example, the UNMIK Director of institutions described to MDRI that he had requested funds from the Dutch Government to refurbish Shtime. He also created a budget for the creation of 40 housing units in the community for current residents of Shtime. In his judgment, funding from the Dutch government would not possibly cover both costs. Therefore, he requested Dutch funds to fix up the institution rather than to establish community programs for Shtime residents.

E. International intervention in service reform

In August 1999, the United Nations Mission in Kosovo (UNMIK) asked the Norwegian Red Cross (Norcross) to take on the responsibility for fixing up and administering Shtime. MDRI investigators interviewed one staff member who described the horrendous conditions that had existed during the war. After months without salary or funding for food and medications, staff at Shtime abandoned the facility in 1999. Many people left behind in the facility died during the war, but a small core of staff members stayed and kept the
majority alive by seeking voluntary donations of food from neighbors. At the worst stage of
the war, according to Norcross staff, there were only four staff at the facility. One US
foreign assistance worker who visited the facility in early 2000 stated that, in his opinion, a
large proportion of people remaining in the facility at the end of the war would have died
without the active intervention of UNMIK and Norcross.

The Norcross mandate was guided by WHO and included patient care, structural
repair, and staff training. In May 2000, administration was shifted back to the Kosovar
director of the facility, though technical experts remained through December 2001. Norcross
made significant improvements at Shtime after the war. According to Norcross professionals,
when they first arrived at Shtime the facility was run down, conditions were dangerous, and it
was nearly impossible to impose any order on patients or staff. In December 2001, Norcross
terminated its assistance program at Shtime.

MDRI investigative teams observed significant improvements in the physical plant at
Shtime between September 2000 and December 2001. During our May 2002 visit to Shtime,
however, we observed a rapid decline in conditions at Shtime as many of the cosmetic
improvements in physical conditions made by Norcross began to wear off (windows were
broken, new floors were coming up, clothing was old and soiled, etc). Since Norcross
mental health professionals left, such essential practices as the medical record keeping and
psychiatric review of medication levels has declined. The overall degeneration of conditions
at Shtime is described further below.
II. Findings

A. Abuses in institutions

1. Inhuman and degrading conditions

While conditions at all inpatient facilities we observed are poor – and raise serious human rights concerns – conditions at Shtime are the worst. In part, this is because detention in Shtime usually means segregation from society and detention in the institution for life. Living in Shtime is an enormous form of deprivation for a person who must suffer through these experiences for many years. People spend their days in inactivity, without any semblance of privacy, living in filth. There are up to eight beds in a room. Rooms are barren, apart from beds and locked cabinets. While these cabinets are a recent improvement, patients complain that they still cannot keep personal possessions safe without having them stolen. There is no decoration or access to reading material, radio, or television in most living areas. There are no clocks to orient people as to time of day. Many people spend their days sitting on benches, wandering the grounds, or sleeping on bare concrete floors.

The lack of professional and non-professional staff at Shtime makes it impossible to ensure hygienic conditions and creates an atmosphere of chaos that leaves people subject to neglect. Parts of the building that have recently been rebuilt quickly degenerate. Outside the men’s ward at Shtime, which had recently been fitted with clean new toilet facilities, MDRI investigators in September 2001 found piles of excrement on the ground. In September 2001 and May 2002, we observed a number of adults at Shtime sleeping in soiled or urine-covered sheets. Much of the institution is engulfed in the stench of urine and feces and is infested with flies. The smell of urine is masked in places by the equally noxious fumes of cleaning solvents.

Clothing at Shtime is communal. In September 2001, patients were given new clothes, but they were spray-painted with large red or black letters to facilitate the return of clothing to the proper unit. Staff also reported that the spray-painted symbols on the clothing served to prevent patients from selling them. Much of the clothing fits poorly, and the identical patterned dresses or spray-painted clothing would make any person from Shtime stand out in a crowd if they were ever to have an opportunity to take an excursion outside the facility. Many people were issued bright white “Norwegian Red Cross” sweatshirts in September 2001. When we returned in May 2002, some wore the same clothes, now old, faded, and dirty. Others were wearing their old clothing again. Many women were not wearing underwear of any kind and intimate parts of their bodies could be seen through the ill-fitting clothing.

At Shtime, the only form of treatment for most people with mental illness is psychotropic medication – which is administered with a dangerous lack of monitoring by psychiatric professionals. There is no psychiatrist on staff, and medical records indicate that some patients are administered psychotropic medications on orders that are more than two years old. These orders are often ignored by untrained staff who are, in turn, authorized to give powerful antipsychotic medications as chemical restraints – a violation of medical ethics and international human rights standards.
The former Norcross psychiatrist and the current physician at Shtime both reported to MDRI that two-thirds of people at the facility are on psychotropic medications (though the Director of the facility states that 40% are on psychotropic medications. In total, 70% of patients are on “some form” of regular medication). The limited staff cannot possibly monitor the potentially dangerous side effects, blood levels of toxic substances, or appropriateness of psychotropic medications. While UNMIK authorities state that they are unable to find a psychiatrist to fill the vacancy, the UNMIK Director of Programs for Shtime informed MDRI that UNMIK is not willing to make an exception to its own pay scale so that it is possible to hire a Kosovar or foreign psychiatrist.

Although one-third of Shtime is made up of people with psychiatric diagnoses, the institution is officially designated for individuals with intellectual disabilities. Despite this, there are no professionals at Shtime with expertise in the assistance of people with such disabilities. For the two-thirds of the population who are diagnosed with intellectual disabilities, there are no specialized treatment, habilitation or other programs. Conditions for people with intellectual disabilities are among the worst at Shtime. There is one room on the men’s ward where a group of 10 to 15 men with the greatest intellectual disabilities literally spend all day sitting on benches doing nothing, with staff constantly watching them to keep them in seated. When MDRI visited in September 2000, these men were mostly naked. When we visited a year later, the same men sat in the same room on the same benches, but the walls had been painted and the Norwegian Red Cross had outfitted them with bright white “Norwegian Red Cross” sweatshirts. Despite this improvement, staff did no more than watch the men. We observed piles of feces on the ground outside the window, and the room was filled with flies. One man had an open scalp wound, covered with flies, that had gone untreated by staff (we have this documented on videotape). When we visited in May 2002, the same men remained in the room. Their clothes were again dirty. They sat in total inactivity on benches or on the concrete floor.

There is a “rehabilitation ward,” where five patients at any time can live in comfort with adequate furniture, decoration, and activities. A few select people who have family members in the community that agree to take in an individual can stay in the rehabilitation ward in advance of leaving the institution. For others with no family in the community, the luxury of the rehabilitation ward is temporary. These individuals are rotated back into the more bleak living areas of Shtime over time.

Dental care is inadequate and staff report that they do not have the resources to help most patients with daily oral hygiene. Individuals who cannot brush their teeth themselves generally receive no assistance. As a result, many people are missing teeth. These individuals are forced to eat a mush of bread soaked in soup. According to ward staff, no special diet is available for these people to ensure that they get adequate nutrients.

There are no legal regulations on the use of seclusion and restraint. In September 2001, we observed an outdoor caged seclusion room that had recently been used to detain an unruly man transferred from Prishtina University Hospital. At 3pm when staff on the day shift went home, we observed that the staff removed all door handles on a residential ward and locked many people in their rooms -- apparently for the convenience of the limited staff who could not supervise all the patients wandering around the grounds. In response to MDRI complaints, authorities at Shtime have reported that such practices have been terminated. Without any enforceable laws or regulations, however, such practices remain at the discretion of institution authorities. Without increased staff on the afternoon and evening shift, the
pressure to lock up patients for the convenience of staff is almost inevitable.

Over an eighteen-month period in 2000-2001 for which UNMIK has made statistics available, there were 18 deaths at Shtime. Almost half of these people were under age 50 (and 78% of the deaths were under age 60). According to UNMIK records, a number of people who died in their thirties and forties were ruled “natural deaths” by the facility. There is no independent system for determining whether deaths are “natural” or “suspicious.” Under current regulations, an autopsy or investigation takes place only when a death is ruled suspicious by the Director of Shtime.

Many of the problems we observed at Shtime we also found at other psychiatric facilities in Kosovo. Physical conditions are cleaner in most other facilities, but the same pervasive inactivity is common in other facilities. A leading psychiatrist in Kosovo reported that there are even fewer resources for treatment and rehabilitation in the psychiatric wards of general hospitals. This psychiatrist said that staffing is so low at the Prishtina University Hospital psychiatric ward that he “could not guarantee the safety” of patients at the facility. Indeed, MDRI investigators who spent two days observing conditions on the ward in September 2001 observed almost no staff on the ward. We observed broken glass and blood on the floor during our visit one day. These conditions remained the next day when we returned.

2. Physical violence and sexual abuse

MDRI has received credible allegations of physical violence, sexual abuse or sexual exploitation at Shtime, the Elderly Home, and the psychiatric ward of Prishtina University Hospital. Corroborating all of these allegations is extremely difficult, and MDRI is not able to come to firm conclusions about every case. However, we received such a consistent pattern of reports from both patients and staff that there is probable cause to conclude that physical violence and sexual abuse are significant problems within these institutions. In the absence of any system for independent monitoring, oversight, or human rights advocacy, such abuse is almost inevitable. The specific allegations of abuse we report here warrant official investigation. The observations we report here underscore the immediate need to create a system of independent investigation, monitoring, supervision, and accountability.

The official denial of any problem of physical or sexual abuses makes any individual report of abuse a challenge to official authority. The broad denial of the problem makes it difficult for authorities to prevent abuse in the future. MDRI brought evidence of physical and sexual abuse to the attention of UNMIK authorities in June 2001. Our letter was met with a flat denial in 2001 from Dr. Hannu Vuori, then director of UNMIK’s Department of Health and Social Welfare, and we have not received any indication that our report was investigated. According to Vuori, “There may be cases of sexual contacts between the inmates. Yet, not a single case of rape has been reported to the Director [of Shtime].” Vuori’s response appears to assume that, if a patient does not officially report a case of rape, authorities can assume coercion or abuse does not exist. The Director of Shtime was even more categorical, denying that there has ever been any form of physical or sexual abuse at his institution.

When MDRI investigators asked the Director of Shtime how he would protect against abuse at his institution, he stated “I would know if any abuse takes place.” The Director of Institutions for UNMIK similarly stated that he would personally look into any allegations of
abuse brought to his attention. Such personal involvement is not a substitute for an independent investigation. Directors of institutions are not independent; they have an inherent conflict of interest in investigating the possibility of improprieties in their own programs. Even if they approach this with the best of intentions, patients may be afraid of reprisals if they complain of abuse to staff. In one case at Shtime where a patient told MDRI investigators that a man had attacked her with a knife, the director of Shtime asked our interpreter not to translate the allegation.

The problem of identifying abuse is compounded by a climate of fear that inhibits patients or staff from coming forward with allegations of abuse. Current and former staff at Shtime and Prishtina University Hospital have reported to MDRI that they are afraid to come forward with allegations of abuse. International humanitarian aid workers are not immune from these fears. One mental health professional who worked at Shtime provided MDRI with extensive information on abuses and then asked us not to use this information because it would “jeopardize my working relationships” with staff at the facility. This individual also said that it would make it more difficult to obtain another job in the “Balkan Circuit” of international relief organizations.

a. Abuse at Prishtina University Hospital

Violence on the ward at Prishtina University Hospital is a serious problem. Staffing is so low, particularly during the night shift, that direct care staff reported to us that they fear for their own safety on the ward. Staff report that all employees have been attacked at one time or another. Officials at Prishtina University Hospital have acknowledged that, in Spring 2001, a patient was beaten to death with an iron bar by another patient on the ward. While the perpetrator of this killing was removed from the ward, staffing levels have not been improved and a climate of safety has not been created. Staff reported to MDRI that a woman patient was raped at the facility by another patient in May 2002. The same month, staff reported that a patient was injured when he was hit with a marble tile by another patient on the ward. Even though there are two security guards on the ward, staff report that they cannot see all living areas and cannot prevent violence.

In 2001, MDRI informed UNMIK that MDRI had information about an immediate problem of sexual abuse from one patient who was afraid to come forward to authorities until a system of investigation was established that could protect her privacy. MDRI never received any offer from UNMIK authorities to protect the woman in question. MDRI requested assistance from UNMIK, the World Health Organization (WHO), and the Organization for Security and Cooperation in Europe (OSCE) to create some form of protection for women seeking to make an official report about abuse within the mental health system, and all our requests were denied.

In May 2002, another former patient reported to MDRI that she had observed physical

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14 The murder of a patient at Prishtina University Hospital does indicate that an extreme case will trigger an investigation by criminal justice authorities. Unfortunately, not even this case resulted in the creation of protection or oversight systems that might protect against future abuses of this kind.

15 The security guards may be a threat in and of themselves. A member of the staff on the ward said that he had to separate a woman patient from the security guards on three occasions. He believed that the security guards were using the woman as a prostitute.
and sexual abuse, as well as sexual exploitation of women at Prishtina General Hospital. She is not able to come forward with this information unless she can obtain a safe, independent living arrangement in the community. She reported that she has been threatened by institution staff if she speaks out. This woman reports to MDRI that she is subject to domestic abuse at home and is in danger of being left homeless. Because her unstable living situation could lead her to being returned to the psychiatric institution, she feels she cannot risk upsetting staff at the institution.

We received independent reports from two women who are former patients at Prishtina University Hospital that a staff member has had sexual relationships with patients in the institution. A physician working for another organization reported to MDRI that he heard the same allegations from these two women. Both former patients have been threatened by this staff member if they come forward with this information. The physician was also threatened by this staff member with regard to other allegations against this individual.

In May 2001, an MDRI investigator observed a threat against a patient first hand. As a patient spoke to an MDRI investigator about abuses in the facility, she related that a nurse said to her in Albanian: “if you say anything bad about the staff God will kill you.” MDRI found that this woman was discharged from the institution the next day with no money and no place to go. When a member of the MDRI team interceded on her behalf, authorities readmitted her and said that her discharge had been a “mistake.”

b. Abuse at Shtime

MDRI investigators observed and received extensive reports of abuses at Shtime from international staff and patients. Violence is ever present on the wards. We observed patients being physically attacked by other patients on three occasions – two of them in May 2002. We observed two patients who had possession of knives and two others with large sticks. A woman who carried a broom handle with her at all times in May 2002 said she needed it for self-protection – and we observed her use it when attacked.

Two members of the Norwegian Red Cross staff reported serious abuses, and elements of their stories were corroborated by other UNMIK and Kosovar staff. A Norwegian Red Cross worker said that in November 1999 he observed a woman being raped by another patient in a hallway in front of staff. When he asked why employees did not intervene, he was told by staff that “she must have asked for it” and that such practices were normal in the institution. UNMIK authorities have responded to MDRI that this allegation of rape was a “very old” event and the director of the institution has since been changed. Despite the change in director at the facility (for other, unrelated reasons), there has never been an independent investigation of the case, no staff were ever disciplined for failing to protect the patient, and no independent system of oversight has been created to prevent further abuse of this kind. The woman is almost certainly at the facility without protection from her former abuser.

When we asked the Norcross worker in May 2001 whether he knew of any specific case in which staff sexually abused patients, he denied awareness of such incidences, but he provided an example of staff facilitating rape by another patient. He said that there was a woman in the facility with mental retardation who often became “wild,” broke windows, and tore up bed sheets. He stated that when staff locked her up in a room with a man this would “calm her down.” In May 2002, a Kosovar staff member confirmed this practice, but he
rationalized this behavior, stating that she was the man’s “girlfriend.” The Norcross worker earlier had informed MDRI that men in the institutions have what he referred to as “voluntary or involuntary girlfriends.”

There have been other independent reports of abuses at Shtime. In January 2002, the Kosovar Council for Advancing Human Rights of People with Disabilities visited Shtime and interviewed six women selected by the Director of the institution. Four of these six women reported that they had been subject to sexual abuse in the institution from male residents. One woman said that, “during a violent outrage” by one of the male residents she was raped and had an arm broken. In another case, the investigators found that “as a consequence of sexual abuse [the woman] needed to have an abortion.” The UNMIK Director of Institutions said he knew of one of the cases documented in this report, but that since the event took place “so long ago” (“more than a year and a half”) there was nothing he could do about it now. He said that there is “no place else to put the perpetrator” of this abuse so there is nothing he can do.

A Norwegian Red Cross worker reported in May 2001 that there is no locked door on the ward to prevent men from coming into the women’s ward at night and “having their way” with women. To this day, there is still no locked door separating men’s and women’s wards. UNMIK authorities claim that women can lock their own rooms from the inside, but they admit that this provides little actual safety given the fact that six to eight women may share a room, that they have to go out in the hall at night to get to the bathroom, and that some women may not even know how to use a lock because of their disability. The UNMIK Director of Institutions reported to MDRI in May 2002 that he was aware of a man who has a record of breaking down these doors and attacking women at the institution. The Director of Institutions informed MDRI that he lacked the funds in his budget to put up doors that this man could not break down.

In December 2001, MDRI investigators observed a door that had been broken down in a woman’s room. The woman identified the male resident who had broken the door and stated that this same man had recently attacked her with a knife. At the time this woman was speaking to MDRI through an interpreter, and the Director of Shtime instructed the interpreter not to translate her statement to MDRI staff.

When we returned in May 2002, the same man was following this woman around the facility and groping at her hair. The Director Institutions at UNMIK also said he was aware of this case and about the dangerousness of this patient. He said that when the male patient receives depot anti-psychotics, he is no longer violent but still pulls down his pants or touches women in a manner that is “merely annoying.” He said that he could do nothing to stop this behavior or protect the woman in question. He expressed concern that, after three weeks on depot medications, before the man is ready for another injection, he can still be violent.

\[\text{16}\] This statement reveals a stark lack of awareness on the part of the chief UNMIK staff person in authority of Shtime about the dangerous psychological impact of contact with a former abuser. For a brief discussion of the issue of “retraumatization” see detailed recommendation on the need to create trauma-informed services (p.26).

\[\text{17}\] In September 2001, MDRI had observed the same man touching the hair of a female staff member who did became increasingly “annoyed”, eventually striking him to make him stop.
c. **Vulnerability of children from Shtime**

A successful program established by UNICEF and operated by Doctors of the World (DOW) has removed children from Shtime, resulting in great improvements in health and quality of life for these children. Professionals who have worked with these children report that most of the children formerly institutionalized at Shtime show signs of having been sexually abused. One girl who was brought back to Shtime for a picnic with residents, for example, refused to get out of the van. Another girl speaks explicitly of sexual encounters she had with her “boyfriend” at the facility. These children continue to suffer from the psychological impact of this abuse.

Half of the children in the program are located in a group home just outside the perimeter of the fence at Shtime and they go to a school on the grounds of the facility. UNMIK regulations require that the children receive their medical care through Shtime, and the children remain under the legal authority of the institution. Even if the children are physically protected from further attack by residents of Shtime, continued association with the institution in which they were formerly abused could be detrimental to their mental health.

Despite the limitation of its continued linkages with Shtime, the DOW children’s program is the most successful program we observed in Kosovo. The UN and DOW deserve credit for its speedy implementation. UNICEF funding for this program has now terminated, however. Unless DOW is able to obtain new funding by the end of 2002, DOW reports that these children are at risk of being returned to Shtime. One financing arrangement proposed by UNMIK would shift responsibility for the administration of the program back from DOW to Shtime. Until authorities at Shtime recognize the risks of sexual and physical abuse and create programs to monitor and protect the rights of people with mental disabilities, it would be a mistake to place children back under the direct operational responsibility of Shtime. Sexual and physical abuse is a risk in the community as well as in institutions. Whether the children in the program are under DOW or Shtime authority, the creation of an independent oversight system to monitor rights protection in the community must also be established.

If DOW does obtain funds to continue its program, children in the program face an additional danger in the years to come. A number of the children in the program are approaching age 18, and they will no longer qualify for placement in the program when they become adults. Unfortunately, there are no community-based support programs for adults with intellectual disabilities in Kosovo. Thus, children who reach adulthood may be returned to Shtime as adults. Given their previous experiences of violence and trauma at the institution, a return to Shtime for these individuals would be devastating. The experience with this program demonstrates the risks of creating isolated pockets of community-based care rather than an integrated system that provides support to all people with mental disabilities.

d. **Abuses at the Elderly Home**

On our visit in May 2001, administration and staff at the Elderly Home in Prishtina reported ongoing problems in protecting their patients from sexual abuse. In one particular case, a male resident of the home with no mental disability was known to be “forcing himself upon” those women who feared him and “fooling” those women who did not resist him. While the administration of the Elderly Home reported that they could generally protect
women during the day, there was inadequate staff to ensure their safety at night. At one point, when the situation became unmanageable, this patient was sent to the Shtime institution for one week as “punishment.” Staff reported that his behavior subsequently improved upon his return to the home, but the sexual harassment and abuse has since resumed.

In December 2001, MDRI spoke with a former staff member of the Elderly Home, who believed that her termination was at least partially motivated by her observations and reports of sexual and physical abuse in the facility. She described several incidents of sexual abuse. In one incident in May 2001, a resident of the facility was reported by staff to be forcing oral sex upon a physically disabled young man. The Director was called, and the administrative council subsequently made a decision to discharge this resident, who purportedly had severe psychiatric difficulties which made him inappropriate for the facility. We also learned that he had previously attempted to force himself on other residents and nursing staff. Despite the decision to discharge him, the offending resident remained at the facility, at least while the reporting staff member was still employed at the facility. He is believed to reside still at the Elderly Home.

The former Elderly Home staff member reported another incident, in April 2001, in which a male resident of the facility solicited money from someone outside the institution for the involuntary prostitution of a female resident. This woman herself reportedly complained to the Director, as this had happened before, but nothing was done to address this abuse. The former staff member stated that there were several witnesses to these and other incidents of sexual abuse, but that staff and residents had been warned by the Director never to speak of these circumstances to outside authorities. This person also stated that incidents of physical violence were routinely ignored by the administration.

3. Vulnerability of women and trauma survivors

Kosovo’s social care facilities and psychiatric wards are not safe places. In addition to violating the rights of patients, the lack of protections against violence or sexual exploitation undermines the function of psychiatric wards as a safe places to assist people in need of acute mental health care. Given the widespread experience of trauma in the population of Kosovo – due to the history of human rights abuse, the experience of war, and the forced exile of much of the population18 – the lack of a safe place for people with mental disabilities can be particularly damaging. Individuals who have suffered from trauma can be easily “retraumatized” by the experience of violence or exposure to the risk of violence. Retraumatization can lead to great suffering and to the exacerbation of symptoms of post-traumatic stress. Staff at two psychiatric wards in Kosovo reported to MDRI that they are not equipped to provide specialized protection, counseling, or other services for people who have been subject to trauma.

The lack of protections in the mental health system is particularly serious for women. Women are especially susceptible to physical and sexual abuse within institutions in any country. In Kosovo, the experience of violence and trauma among women is particularly high since women were singled out for abuse and rape during the war. Women’s groups in

18 One study in 2000 estimated that over 17% of the Kosovar Albanian population exhibited sequellae of trauma serious enough to be diagnosed as a mental disorder. B. Cardozo, et al., Mental Health, Social Functioning, and Attitudes of Kosovar Albanians Following the War in Kosovo, 284 (5) Journal Of the American Medical Association (2 August 2000).
Kosovo also report high rates of domestic violence. Caught between abuse in the family and the risk of violence in psychiatric facilities, women with mental disabilities who experienced trauma may have nowhere to turn.

Following the war, there was a large influx of foreign aid to provide protection for women, trauma assistance, and mental health counseling in the community. While these programs may provide valuable services for the population as a whole, MDRI was not able to identify any community-based trauma programs that are especially designed to reach out to women with mental disabilities. Indeed, UNMIK informational material provided to MDRI states that some major internationally funded trauma programs were intended specifically to exclude women with “mental disorders.” A US psychiatrist who studied trauma programs in Kosovo observed that when the programs were planned, it was almost universally assumed that people diagnosed with major mental disorders would be referred to the public mental health system. Despite this, groups such as the Center for Protection of Women and Children report that they are open to serving women with mental disabilities but they have limited resources to do so.

Unfortunately, the public mental health system has not established linkages to women’s shelters or trauma services in the community and does not assist people in obtaining such services upon discharge. MDRI investigators learned of one particularly troubling case during MDRI’s September 2000 visit to the Prishtina University Hospital psychiatric ward that exemplifies the lack of awareness or attention to trauma issues we observed. MDRI investigators interviewed a sixteen-year-old girl whose entire family (five brothers and sisters and both parents) had been killed during the war. As an orphan, she was put up with friends in her village and moved from home to home. Two weeks before MDRI’s visit, this young woman had been gang raped. Shamed by the rape, she had no place to go and police brought her to the psychiatric facility. The chief technician on the ward informed MDRI investigators that she had received no trauma counseling or assistance. The only treatment she received was a sedative. There were no plans for her return to the community. When MDRI investigators asked whether this woman could be referred to one of the many internationally funded trauma programs in Prishtina, the chief technician on the ward said that he was unaware of any such programs.19

The case of the sixteen-year-old girl is not unique. Another woman we interviewed at Prishtina University Psychiatric Hospital in May 2001 was also left without a needed referral to trauma assistance and protection in the community. This woman reported to MDRI that she was on the ward, in part, to escape her abusive husband. While she did not want to remain at the hospital, she said she was afraid to leave the ward to return home. She complained that no one on the psychiatric ward would listen to her tell of her fears about returning to her husband. Each time she returned home she would be beaten again by her husband, her psychiatric symptoms would return, and she would be readmitted to the ward.

19 A year later, MDRI investigators inquired about the status of this woman. Staff on the ward described the woman as “one of our success stories” because she had married a man they said was “visiting another patient on the ward.” According to ward staff, she periodically had conflict with this man and his family and had to return to the ward under such circumstances. This case reveals the lack of understanding by ward staff of the complexities -- and possible dangers -- faced by women who leave the institution and return to an unstable family situation. In another case, a mental health worker informed MDRI that he had arranged the marriage of a former patient. This woman later had to be assisted out of her home by police after she was subject to domestic abuse.
psychiatric ward. She said that ward staff provided her with no assistance in finding an alternative place to stay or a way to receive help when she left the facility.

Planning is needed to ensure that all public mental health services are “trauma-informed.”\(^\text{21}\) Such programs recognize the widespread incidence of trauma in the population they serve. Even if public mental health services are not specifically tailored to provide trauma-specific services, they should be prepared to identify services for people in the community.\(^\text{22}\)

**B. Arbitrary detention and guardianship**

The majority of people detained at Shtime and on the neuro-psychiatric wards of hospitals in Kosovo are detained without regard to the existing laws of Kosovo or to international human rights standards. This practice violates the protection against arbitrary detention under Article 9 of the ICCPR. The failure to enforce Kosovo’s own laws for people with mental disabilities is a form of discrimination under Article 23 of the ICCPR.

OSCE deserves credit for taking the initiative to draft a new civil commitment law to protect against arbitrary detention,\(^\text{23}\) and it has pressed UNMIK to enforce existing law. UNMIK and the World Health Organization (WHO) also contributed to the development of this draft legislation, which was the product of extensive discussions by a subgroup of WHO’s Task Force on Mental Health. OSCE made efforts to ensure that the draft legislation conforms to international human rights standards. Unfortunately, by focusing narrowly on the process for civil commitment, the draft legislation leaves out a number of essential protections.\(^\text{25}\) MDRI raised the need, for example, for a general protection against discrimination that would greatly assist people with mental disabilities in avoiding institutionalization by protecting their right to live and work in society at large.\(^\text{26}\)


\(^{22}\)Id. at 5.

\(^{23}\)OSCE submitted the draft regulation to UNMIK for review in 2001. UNMIK’s Office of the Legal Advisor provided its comments and suggestions in May 2002, and the draft is currently undergoing further revisions.

\(^{25}\)MDRI suggested that the new mental health legislation add essential protections for rights within institutions, as recognized by international human rights law, such as the right to refuse treatment and the right to protection against improper seclusion and restraints. *See, e.g.*, MI Principle 11. These rights are now commonly violated in Kosovo’s mental health facilities and legislation is needed to prevent these abuses.

\(^{26}\)In 2002, OSCE began drafting a proposed Omnibus Anti-discrimination Law that would protect people with mental and physical disabilities. OSCE informs MDRI that this draft law will soon be sent to the Government of Kosovo for further consideration. MDRI suggests that this draft legislation be thoroughly reviewed by disability rights experts to ensure that provisions needed to protect against disability discrimination (such as the right to reasonable accommodation) are included.
informed by members of the working group that the new legislation had to focus narrowly on civil commitment.

One of the most important limitations of the draft mental health law is that it does not provide protections against improper guardianship or arbitrary limitations on the recognition of a person’s legal competence to make decisions about his or her own life. Despite MDRI’s efforts, neither UNMIK nor OSCE has challenged the *de facto* system of guardianship that strips people of their legal rights and leaves the directors of institutions in charge of most important life choices.

The draft law on civil commitment does not create protections in the guardianship process. Failure to protect against improper guardianship will create a loophole in any new civil commitment law. Once a person is placed under guardianship, the guardian can then consent to “voluntary” commitment on behalf of the person who is to be detained. Internationally mandated legal protections in the guardianship process are absent. The old Kosovar guardianship law, which is currently applicable by default, fails to provide the substantive and procedural protections required by international human rights standards. Guardianship decisions are currently made without the right to a hearing by an independent authority; without the right to counsel to represent the expressed interest of the client; with no requirement that a person’s judgments, opinions, or desires be legally respected and taken into account; and with no protection against the appointment of a guardian whose interests are in clear conflict with those of his or her ward.

In the absence of legal standards, detention decisions on psychiatric wards of general hospitals are left to psychiatrists or ward staff without independent clinical or judicial review. In Gjakove, hospital staff admitted that involuntary admissions “should be done through the courts, but the process is too slow.” According to OSCE, “no law is used to govern the use of detention/forced treatment in the hospital” psychiatric ward at Prishtina University Hospital. Despite the fact that this hospital has no secure areas and was not built to detain people involuntarily, OSCE reports that the majority of people at the facility are involuntarily detained. While wards are considered “open,” hospital staff reported to OSCE that the practice of “chemical restraints” is used to detain people. Patients also reported numerous other techniques for keeping people in the institution, such as keeping patients’ money, identification, or other important papers.

As described by the UN Master Plan for Shtime, *all individuals were detained illegally* as of September 2001. According to OSCE’s Review of the Criminal Justice System (September 2001 – February 2002), “The largest number of illegal detainees in Kosovo remains in the Shtime/Stimlje Institute for the Mentally Retarded.” Despite UNMIK’s own Administrative Instruction (2001) stating that no person can be detained in the institution without a court order, illegal detentions continued as of May 2002. Those Shtime residents whose detention had been reviewed and found to be unnecessary, and therefore illegal, were told that they were now legally free to leave, but were also advised that they had no practical alternatives to survival outside the facility. These individuals continue to reside at the facility on a “voluntary” basis. In the absence of community supports or less restrictive alternatives to long-term institutionalization, individuals are given no real choice about detention in such facilities.

*De facto* guardianship by the director of an institution creates dangerous conflicts of interest. Under the law of the former Yugoslavia, individuals were placed under the
guardianship of Centers for Social Work. With many of these Centers now located outside Kosovo or no longer functioning, people at Shtime lack the legal right to make choices. In the absence of any other guardian, UNMIK recognizes the de facto guardianship of the institution’s director for many basic life choices (e.g. determining who has the capacity to exercise his or her right to vote).

UNMIK has deferred to the Yugoslav-era guardianship law. Staff at Doctors of the World (DOW) told MDRI that when they designed a program to remove children from Shtime, they were told that children had to remain under the authority of the institution because the guardianship law would create a legal obstacle to their adoption or outplacement. As of May 2002, UNICEF no longer interprets the law to create such an obstacle, but they still recognize the law as binding legal authority. Thus, there are now discussions of shifting authority for the children under the law to the Centers for Social Work.

While getting children out from under the authority of Shtime is important, the rights of people with mental disabilities will not be effectively protected as long as UN authorities defer to the Yugoslav guardianship law. Under the legal framework of Kosovo, a discriminatory Yugoslav-era law need not be enforced. As a practical matter, the Yugoslav-era guardianship law is already ignored for many other purposes. UNMIK should no longer defer to this law as an obstacle to protecting the rights of children to outplacement from Shtime.

C. Reinforcing segregated services

International experience has demonstrated that large, custodial facilities for people with intellectual or psychiatric disabilities are not suitable environments for rehabilitation. Behind the closed doors of these facilities, in every part of the world, serious human rights abuses are common. As a result of these findings, there has been a shift from institution-based to community-based care for people with mental disabilities in many countries of the

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27 In Eastern Europe, where there is a long history of reliance on institutions, the transition to community services is particularly challenging. Despite this, successful models of reform exist. In addition to providing better care, the move to community integration makes sense from an economic as well as a human rights perspective. See The World Bank, MOVING FROM RESIDENTIAL INSTITUTION TO COMMUNITY-BASED SERVICES IN EASTERN EUROPE AND THE FORMER SOVIET UNION (April 1999).

world. With appropriate support in the community, the vast majority of people—even with the most serious mental disabilities—can experience great improvements in quality of life through the creation of community-based services. Safe and effective transition from institutions to the community requires the creation of community services and support systems. Effective community-based programs must be responsive to individual choice of the service user. In recent years, programs built on a “recovery model” that emphasize non-professional peer support have proven to be an effective and relatively low cost way to provide community-based services for many people.

In recent years, international human rights law has come to recognize that community integration is not just good policy—it is a recognized right. The UN’s Standard Rules on the Equalization of Opportunities for People with Disabilities recognizes the right of all people with disabilities to full participation in society. MI Principle 3 establishes that “[e]very person with mental illness shall have the right to live and work, as far as possible, in the community.” The United Nations Committee on Economic, Social, and Cultural Rights has adopted General Comment 5, which states that, to protect against discrimination, governments must adopt policies to “enable persons with disabilities to live an integrated, self-determined and independent life.”

A number of different UN programs in Kosovo have adopted the stated goals of promoting community integration for people with disabilities. The World Health Organization (WHO), together with a working group of Kosovar mental health professionals, has developed a sophisticated program for mental health system reform. This valuable program, now operated by the Kosovar Ministry of Health, is unfortunately limited in scope. Even if fully funded over the next eight years, the program is designed to serve only a maximum of 140 people in supported living arrangements. While a larger group of people will be served through in-home care, the program will meet the needs of only a small fraction of an estimated 40,000 individuals with mental disabilities in Kosovo.

The most significant limitation of the WHO/Ministry of Health plan is that it entirely leaves out the population of people with intellectual disabilities (at least 1% of the population of Kosovo). Apart from a few isolated programs, no other UNMIK or Kosovo government

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29 See e.g., World Health Organization, MENTAL HEALTH IN EUROPE: 10 YEARS ON (1985).


34 This number is a conservative estimate based on demographics from around the world—assuming that at least 1% of the population have intellectual disabilities and 1% of the population has psychiatric disabilities. Given the widespread violence and trauma experienced by the population of Kosovo, the actual number of people with psychiatric disabilities is probably much higher.

35 In September 2001, MDRI learned of a number of important special education programs being designed to assist children with intellectual disabilities to go to mainstream schools. Such programs, while valuable in themselves, can also form part of a community-based system of support for children and families of
Ministry is planning for the creation of community-based support systems for people with intellectual disabilities. Current programs assume that the small number of individuals now living in institutions will remain segregated from society. The greater number of such people will remain cloistered with families who will receive no assistance or support.

When international support for Kosovo was at its height, immediately after the war, the initial focus was on refurbishing Shtime rather than immediate support for community alternatives for its residents. Early support for advocacy by people with mental disabilities, family organizations, and other natural allies of reform would have greatly aided the reform process. International humanitarian assistance, development aid, and civil society support programs represented rare opportunities to promote community integration. Those opportunities may now be lost if an ambitious and sustainable program for reform is not developed while international support for Kosovo remains available.

Norcross programs at Shtime were originally intended to provide emergency assistance to end the horrendous physical conditions in the facility. That assistance probably saved many lives and some support to end life-threatening dangers at Shtime was clearly needed. Yet the assistance was also used to bolster a “Master Plan” developed by UNMIK that assumed the facility would remain the cornerstone of a system of institution-based services for people with intellectual disabilities. While children were immediately moved out of Shtime and placed into group homes, the international community unfortunately did not support a similar approach to assist adults from Shtime capable of living in the community.

What started as essential emergency assistance at Shtime became the first phase in the support of a segregated service system that would influence policy in the years to come.

In autumn 2001, a “Deinstitutionalization Team” made up of UN personnel and staff at Shtime found that the majority of people at Shtime have no medical need for

36 From early on, UNMIK and WHO partnered with an organization called Menkos. This organization was run by professionals and had a focus on the creation of income-generating projects. It did not see itself as an advocacy organization. While the Director of Menkos told MDRI that it was a “partnership” of professionals with users of mental health services, former Menkos staff and board members reported to MDRI that names of both staff and patients were used without their knowledge and permission in its membership registry and that there was never any real commitment to leadership by people with mental disabilities.

37 The group home program established by Doctors of the World in Kosovo is a model that demonstrates how people from Shtime can be rapidly integrated into the community. In this program, problems of stigma or ethnic division, often described as obstacles to integrating the population of Shtime in to the community, were overcome. Unfortunately, the creation of one “island” of community care rather than a complete system of services renders this an expensive model of services. A supported foster care or substitute family program would have been preferable for these children -- since all children need to grow up in a family-like environment. This model might also have been less expensive. Most adults at Shtime would benefit from group homes, family support programs, or supported independent living arrangements.

38 When MDRI investigators interviewed the UNMIK Director of Institutions in May 2002 and asked him why UNMIK was supporting new investments in Shtime rather than community alternatives for its residents, he explained that he was merely implementing a policy to support Shitme that had already been made before he arrived in Kosovo. Once the plan was established to rely on Shitme to support for people with intellectual disabilities, he explained, additional investments in building up the facility were essential.
institutionalization. According to UNMIK authorities, many of the people at Shtime are “social patients” who have only minor disabilities and reside at the facility because they have no place else to go. Despite the findings of the Deinstitutionalization team, UNMIK is now planning a new phase in the rehabilitation of Shtime. UNMIK has requested funds from the Dutch government and other funders to refurbish the facility.

The UN’s Master Plan for Shtime calls for the institution to be reduced in size but to remain permanently as an institution for people with intellectual disabilities. People with psychiatric disabilities are supposed to be removed from the facility by the “Deinstitutionalization Team.” In the absence of planning for community services, the only people who qualify for outplacement are the small number of individuals with family members who can support them without any public assistance.\(^{39}\) For most people at Shtime, there is no hope of returning to the community in the near future.

UNMIK has declared a “no new admission” policy at Shtime, but this policy may be untenable in the absence of adequate planning for community-based services. Both staff at Shtime and UNMIK authorities report of a constant pressure to place people in the facility who have no place else to go.\(^{40}\) In the absence of any community-based alternatives for people with intellectual disabilities, there are already great pressures for new placements in Shtime, and this problem will only get larger as the international community reduces funding in Kosovo. The UNMIK Head of Institutions reported to MDRI that, when the international community withdraws its participation in the mental health and social service system of Kosovo, he expects “the gates to open” and an increase in the population of the institution to its full capacity of almost 300 beds. The Director of WHO concurs in this analysis and goes further. According to her, there “will soon be a need for two institutions like Shtime” given the lack of community-based services for people with mental disabilities. To avoid this outcome, MDRI calls on UNMIK, the Dutch government, and other international funders to insist that current and future international assistance be used to support community integration for Shtime’s residents.\(^{41}\)

### D. Right to citizen participation

For a democratic system of government to operate effectively, citizens must be able to act publicly to demand enforcement of their rights and their share of limited resources. People with mental disabilities, subject to systematic discrimination, abuse, segregation from society, and economic marginalization, have not had the opportunity to demand enforcement of their rights in Kosovo. The UN’s Standard Rules recognize the right of people with disabilities to participate in policy-making and planning (Rule 14), legislation (Rule 15), economic policies (Rule 16), and program implantation (Rules 2 and 3). Rule 18 of the

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\(^{39}\) The exclusive reliance on family support in the official plans for community mental health leaves women in a particularly vulnerable position. Many women we interviewed at Shtime and the psychiatric wards of general hospitals reported that they were placed in the psychiatric institution by family members. In two cases, we interviewed women who had been abused at home and in the psychiatric facility and were forced to decide between two unsafe options.

\(^{40}\) Norcross staff reported to MDRI in September 2001 that, in the absence of resources to assist people with acute mental health care needs at psychiatric wards of general hospitals, Shtime is occasionally forced to admit people for acute care - a role for which it is not equipped.

\(^{41}\) MDRI does not oppose the use of international funds to end conditions that are imminently dangerous or life-threatening at any institution. UNMIK should avoid capital investments in institutions.
Standard Rules makes clear that token participation by a few individuals with disabilities is not sufficient. Organizations made up of people with disabilities that are representative of the stakeholder group also have a right to participate.

At the onset of post-war international involvement in the mental health reform process in Kosovo, there was no initial investment in training of people with mental disabilities and family members as activists, and there was no support for the creation of mental disability advocacy organizations. As a practical matter, such programs would have helped establish valuable partners in reform. To date, there is no organization in Kosovo led by persons with mental disabilities, nor have such stakeholders been integrated into policy development, human rights advocacy, service implementation, or legislative reform.

From early on, UNMIK and WHO partnered with an organization called Menkos, which UNMIK and WHO authorities often describe as a “consumer” or “user” group. In practice, this organization is run by professionals for the purpose of creating income-generating projects. As described by its own Director, the chief technician at Prishtina General Hospital's psychiatric ward, the organization does not see itself as an advocacy organization. While the Director of Menkos has told MDRI that it is a “partnership” of professionals with users of mental health services, former Menkos staff and board members reported to MDRI that names of both staff and patients have been used without their knowledge and permission in the organization’s membership registry and that there has never been any real commitment to leadership by people with mental disabilities.

While UNMIK has created a Disability Council to promote participation in policymaking by people with physical disabilities, people with psychiatric or intellectual disabilities have not been represented. According to the head of Handikos, the major physical disability rights group, he was told by a key UNMIK official that people with mental disabilities need not be represented on the Council. In place of stakeholders with a psychiatric disability, UNMIK and WHO have consulted with Menkos. When a coalition of disability activists, along with the Danish SIND organization, presented findings of a human rights investigation in Shtime to UNMIK’s Disability Council, they were again told that this matter had no relevance to a disability advisory body. UNMIK deferred judgment to the Director of Menkos, who said that “mental illness is an illness and not a disability.” Exclusion of the concerns of people with psychiatric disabilities not only violates the Standard Rules, it constitutes a form of discrimination under article 26 of the ICCPR.

In order to do more than superficially adhere to the Standard Rules, the United Nations should provide financial support and training to people with mental disabilities and their family members to create such civic organizations. While UNMIK has provided support for organizations run by mental health professionals, it has not provided support for organizations run by people with mental disabilities. Immediate support for advocacy by people with mental disabilities is needed.
III. Conclusions: Toward a Broader International Response

UNMIK deserves credit for responding quickly to an immediate crisis following the war in Kosovo at a time when hundreds of people in psychiatric facilities faced life-threatening conditions. While UNMIK organized an effective response to the medical emergency, it did not create a framework to protect the human rights of people detained in institutions. The high level of international interest and financial support for Kosovo in the immediate aftermath of the war provided an opportunity for fundamentally reshaping Kosovo’s mental health system, supporting advocacy by people with mental disabilities and their allies, and creating enforceable legal rights for this population.

UNMIK should now commit itself to raising the funds necessary to protect the rights of people with mental disabilities and promote their full participation in society. With or without international financial support, UNMIK must take immediate action to create a system of accountability to ensure the protection of people with mental disabilities from violence and sexual abuse within institutions.

The failure of UNMIK and other specialized UN agencies to comply with international human rights laws and standards is particularly disturbing, given the attention directed to this issue by the UN Human Rights Commission in recent years. In April 2000, the United Nations Human Rights Commission called for increased international attention to the human rights of people with disabilities—especially women, children, and people with developmental and psychiatric disabilities.42 The Commission called on governments to improve their reporting on compliance with their obligations to people with disabilities under United Nations human rights instruments.43 Most importantly, it called on the Secretary-General of the United Nations to maintain the integrity of programmes within the United Nations system relating to persons with disabilities...in order to promote the rights and the equalization of opportunities and full inclusion within societies of persons with disabilities.”

In April 2002, the Human Rights Commission specifically called on UN agencies and international development organizations to comply with international instruments, and it asked the UN Secretary General to report on their enforcement.

In November 2001, the UN General Assembly voted to create an ad hoc committee to begin work drafting a specialized new human rights convention for people with disabilities. Despite existing international human rights protections, the General Assembly observed that global efforts, to-date, had “not been sufficient to promote full and effective participation and opportunities for persons with disabilities in economic, social, cultural and political life...”44

This report strongly reinforces the findings of the UN General Assembly. A specialized new disability rights convention would provide the oversight of international agencies and governments necessary to help prevent these kinds of abuses in the future. It is our hope that we need not wait for the adoption of a new disability rights convention, however. The UN's own specialized agencies should take immediate action to bring about

42 Para. 13.

43 Para. 11.

the enforcement of human rights for people with mental disabilities in all their programs in Kosovo. We call on the UN Secretary General to report on the situation in Kosovo and to take immediate action to bring an end to the human rights abuses against people with mental disabilities.
IV. Recommendations

MDRI calls on the UN Secretary General to direct UNMIK to:

- Act immediately to protect people detained in institutions from further violence or sexual abuse, create safe living conditions, and separate abusers from patients;
- Create a system of human rights oversight and accountability to ensure rights enforcement in institutions and community-based programs; this should include the creation of a mechanism to investigate abuse that will protect the privacy and safety of witnesses and victims;
- Establish a comprehensive plan to create community-based services for people with mental disabilities that (1) does not exclude people with intellectual disabilities (2) provides services for people now detained in institutions who are capable of living in the community (3) builds on the support of Kosovar non-governmental organizations and families, and (4) creates independent community supports for individuals without families or with abusive family situations;
- Create a time-table for the closure of Shtime as soon as community-based alternatives can be created for its residents;
- Ensure participation by organizations of people with mental disabilities in policy-making, human rights advocacy, and program implementation through the creation of targeted outreach training, and civil society support programs for people with disabilities and their families;
- Report to the UN Human Rights Commission on steps taken to end abuses against people with mental disabilities in Kosovo, in accordance with the Human Rights Commission’s April 2002 resolution calling on the Secretary General to report on the enforcement of international human rights for people with disabilities by UN agencies.

MDRI would be pleased to provide technical assistance to the United Nations and Kosovo government authorities in developing programs to implement these recommendations.

Detailed Recommendations

A. To international relief and assistance agencies:

- Adopt voluntary reporting requirements to ensure that staff who observe human rights abuses against patients report it within their own organization and to appropriate public authorities. Protocols should be established to ensure that action is taken to investigate allegations and prevent further abuses when they are reported.

- Incorporate human rights oversight, monitoring, and enforcement programs into the design of both institutional and community-based programs. International organizations must take proactive steps to be prepared to operate within a context in which domestic laws do not provide adequate human rights protections for people with mental disabilities. Funds should be set aside to train both local and international staff in basic measures to protect and prevent human rights abuses. The
involvement of people with mental disabilities experienced with human rights advocacy would aid in the design and implementation of effective rights enforcement programs.

B. To the Dutch Government and other international funders:

- **Shift funds from refurbishing Shtime to community alternatives** – International funders should insist that UNMIK and the Kosovar Ministries of Health and Welfare shift existing assistance funding away from fixing up institutions. While some funding is needed to end conditions that are imminently dangerous in institutions, most international funds should be used to create community housing and supportive services to promote the community integration of people with mental disabilities. Funds should also be set aside to ensure the creation of human rights oversight and enforcement systems.

- **Support advocacy by Kosovar activists with mental disabilities and their allies** – All foreign assistance programs should comply with the UN Standard Rules on Equalization of Opportunities, which require stakeholder participation in program planning and implementation. In a society in which independent advocacy by people with mental disabilities does not yet exist, there should be a priority on the training of activists and the support of new advocacy organizations led by people with mental disabilities. Support for organizations made up of family members of people with disabilities is also necessary. Investment in these non-governmental organizations (NGO’s) will provide deeply committed and low-cost partners who will greatly aid in the development of effective, culturally appropriate, and sustainable programs.

C. To the United States Government:

- **Earmark USAID funds for the human rights of people with mental disabilities** – Section 504 of the Federal Rehabilitation Act requires that all US government programs be fully accessible to people with mental and physical disabilities. The US Agency for International Development (USAID) currently has a non-binding “Policy Guidance on Disability and Development” that says all international assistance programs should be open to people with disabilities. The existence of the abuses documented in this report demonstrates that current human rights and civil society programs have not reached people with mental disabilities. While the USAID has invested extensive funds in human rights, civil society, and rule of law, these programs are inaccessible to most people with mental disabilities. These programs will remain inaccessible until outreach programs are targeted to ensure the inclusion of this population and to accommodate their needs. Thus, the US Congress should require USAID to set aside funds for training and support of disability advocacy organizations.

- **US Department of State should report on abuses against people with disabilities in Kosovo** – The US Department of States should include an overview of the human rights abuses now taking place against people with mental disabilities in its Annual Reports on Country Practices that document human rights abuses in every country.

D. To UNMIK and the Government of Kosovo:

- **Protect the safety of people detained in institutions** - UNMIK and the new
Government of Kosovo should take immediate action to protect the safety of people detained at Shtime, the Elderly Home, and the psychiatric wards of general hospitals in Kosovo. A response to the problems of physical abuse and sexual violence in institutions cannot wait until new international funds are raised or until new community-based alternatives to institutions are created. Authorities at Shtime must identify abusers and keep patients with a record of abuse away from others who are vulnerable. Authorities should recognize that women are particularly vulnerable to abuse in institutions, but the existence of abuse should not be used as an excuse to lock up or isolate women. Institutions must guarantee safe living areas for all institutionalized persons consistent with the right to live in the least restrictive environment.

- **Establish independent investigation, oversight, and enforcement mechanisms to protect rights** - UNMIK should immediately establish mechanisms to investigate allegations of abuse in institutions and in community-based programs serving people with mental disabilities. These mechanisms must recognize that individuals reporting abuses by staff or other patients may be at risk of reprisals by these individuals. Therefore, policies and procedures must be established that protect individuals reporting abuse from being subject to further abuse during the investigation and afterwards. UNMIK should establish an oversight body that is independent of mental health and social welfare authorities. Criminal justice authorities should investigate allegations of abuse identified by this oversight body or from other sources.

The oversight body should be empowered to investigate abuses and conduct unannounced visits with full access to wards and patient records. Non-governmental advocacy groups – particularly with representation by women’s rights organizations – should be included in this oversight body. People with mental disabilities and other former patients, particularly women, should be trained as investigators; these individuals have unique abilities to understand and gain the trust of individuals subject to abuse.

- **Improve use of existing staff and hire staff as necessary** - At Shtime and in the psychiatric wards of general hospitals additional staff is needed to ensure adequate care and safety. At both institutions, we observed staff sitting in groups and not actively engaged in patient care. Training and oversight is needed to ensure that current staff is actively engaged in assisting patients. Staff not complying with job requirements should be removed. If necessary, UNMIK must be willing to raise salaries to hire qualified professionals. Specialists in the care and assistance of people with intellectual disabilities are essential.

- **Create “trauma-informed” services** - Given Kosovo’s history of violence, combined with a lack of protection against physical and sexual abuses within institutions, service providers should assume that a large percentage of people in institutions have been subject to trauma. The deprivation of control over basic decisions of living, lack of privacy, contact with former abusers, or even association with the location in which previous abuse has occurred, can cause psychologically damaging “retraumatization”. Retraumatization is the stimulation of traumatic feelings associated with prior violence or other extremely stressful events. This experience can cause great suffering and can compound pre-existing post-traumatic stress, dissociation, and other psychological or somatic conditions.
All inpatient and community services should be designed to protect against practices that may cause retraumatization. Both Kosovar and international staff should be sensitized to these dangers and trained to respect the choices of people in their care. Linkages should be established between public mental health services and trauma programs in the community so that people detained in institutions can receive care and assistance from community-based counseling and trauma programs. Community-based trauma programs should create necessary accommodations to assist people with psychiatric or intellectual disabilities in the community instead of referring them to institutions.

- **Create a comprehensive system of community services and support systems**—The Ministries of Health and Social Welfare should collaborate on the creation of plans to establish and finance a community-based service and support system for all people with disabilities. The community system must include support for people with intellectual disabilities as well as people with psychiatric disabilities. The system should plan for the community integration of people now detained in institutions, and it should meet the needs of people with mental disabilities now living on their own or in families.

Community service programs should include supported housing and supported employment. The community system should provide alternatives for women and men who have no family or who cannot live with their families because of a past experience of abuse or for other reasons. It is particularly important to create independent living situations or single-sex living situations for women who have been subject to sexual abuse. Community placements should also ensure that women can remain with their children.

Independent monitoring programs must be established to ensure quality of care and rights enforcement in community programs.

- **Set a timetable for the closure of Shtime**—Shtime is inappropriate, unhealthy, and dangerous for all its residents. The same funds now sought from the Dutch government to rehabilitate the institution should be used instead to create community-based housing for Shtime’s population. People now residing at Shtime should be guaranteed safe, supported community services before the facility is closed. A timetable should be established for the transfer of Shtime’s entire population to community-based services.

A number of individuals in Kosovo will need inpatient care. Once safety precautions have been established in psychiatric wards of general hospitals, these facilities should be used to provide short-term acute care. Long-term care for people with psychiatric or intellectual disabilities should take place in facilities that are as small and homelike as possible. Such care should be in the least restrictive setting suitable to the individuals’ health needs and the safety of others.

- **Build on existing “natural supports” in the community, including peer support and non-governmental organizations**—Given the shortage of trained professionals in Kosovo, and the lack of sustainable funds for important programs, the community system should rely heavily on existing support systems in Kosovar society. This
includes training and assistance for peer-support programs to involve consumers in the delivery of services. Families should also receive support to assist relatives with mental disabilities.

- **Create a system of family support and foster care for children with disabilities, and continue funding existing programs**— UNMIK and UNICEF should continue funding for two group homes administered by Doctors of the World to ensure that these children are not returned to Shtime. The current program should be made independent of Shtime as soon as possible. UNMIK and the Ministries of Health and Welfare should begin planning immediately for the creation of a family support program to prevent further abandonment of children with disabilities. UNMIK and the government of Kosovo should also begin planning for the creation of a supported foster care system that will include children with disabilities.

- **Support participation by people with mental disabilities and families** - The UN General Assembly’s resolution, “Standard Rules on the Equalization of People with Disabilities,” (Standard Rules) recognizes that people with mental disabilities have a right to participate in human rights advocacy, policy-making and program implementation regarding matters that affect their lives. In order for meaningful participation to be possible, authorities must invest in training and support for individuals with mental disabilities and organizations made up of people with mental disabilities. Groups made up of people with different disabilities (physical, mental and sensory disabilities), such as Handikos, can serve as valuable partners. Support for advocacy by people with mental disabilities is also essential. While not a substitute for the direct involvement of people with disabilities, authorities should also support advocacy by families of people with disabilities.

Internationally funded civil society, rule of law, and human rights programs should ensure the inclusion of people with disabilities. Full inclusion and access to such programs for people with mental disabilities will require the creation of targeted outreach programs designed to accommodate the special needs of individuals with mental disabilities.

- **Adopt comprehensive anti-discrimination legislation** that protects the rights of people with mental and physical disabilities. As the UN Committee on Economic, Social and Cultural Rights’ General Comment 5 states, “such legislation should not only provide persons with disabilities with judicial remedies as far as possible and appropriate but also provide for social-policy programmes which enable persons with disabilities to live an integrated self-determined and independent life.”

- **Do not let stigma based on disability or ethnicity stand in the way of community integration**— Various UN agencies have pointed to stigma against people with mental disabilities as an excuse for not including this population in community programs. UN Agencies have also stated that people who are ethnically Serbian cannot be integrated into Kosovar society. The Doctors of the World program that has integrated ethnically Serbian children from Shtime into community life in a Serbian enclave demonstrates that stigma based on disability and ethnicity can be overcome. The anti-discrimination law of Kosovo should prohibit the exclusion of people with disabilities.

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45 General Comment 5, para.16.
disabilities from community programs based on stigma, disability, or ethnic origin. Special accommodations will need to be created to overcome these barriers – as they are in any society in the world.

- **Establish legal protections against arbitrary detention and coercive treatment** – OSCE has drafted legislation that would protect against arbitrary civil commitment. It is essential that this legislation provide the procedural protections required under international human rights law, including a right to review by an independent judicial authority, a right to representation by counsel, and a right to appeal to a higher court. (See MI Principles 15-17.) Under international law, detention in a psychiatric facility does not entail the forfeiture of all other rights. Thus, the right to make choices about treatment should be recognized even for people who have been involuntarily detained. Legislation should provide an independent right to refuse treatment.

- **Protections against improper guardianship should be established** – Protections against the deprivation of liberty or coercive treatment can be circumvented unless there is also an effective law to protect against the improper use of guardianship. Under international law, people with mental disabilities have the same rights as other citizens. Thus, guardianship should be limited only to those activities for which an individual is found to be mentally incompetent. Given the lack of attorneys in Kosovo, civil commitment and guardianship legislation should permit representation by specially trained and licensed lay advocates. Funds should be set aside to provide training for such counsel. UNMIK authorities should not recognize Yugoslav-era legislation providing Centers for Social work with guardianship authority without the provision of full protections required by international human rights law.
Appendix: Relevant International Human Rights Law

As the effective government authority in Kosovo, the United Nations is under an obligation to people with mental disabilities to ensure that their basic rights are protected under such conventions as the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social, and Cultural Rights (ICESCR), and the European Convention on Human Rights (ECHR). The United Nations General Assembly has also adopted a number of guidelines on the minimum human rights protections due people with mental and physical disabilities. People detained or receiving treatment in mental health facilities are protected by the “Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care” (the “MI Principles”). The UN “Declaration on the Rights of Persons with Mental Retardation” especially protects people with intellectual disabilities. All people with disabilities are protected by the “Standard Rules on Equalization of Opportunities for Persons with Disabilities,” which protects the right to full participation in all forms of community life.

This report finds that UNMIK has failed to abide by its obligations under international conventions or by the UN General Assembly standards to which it holds other nations.

A. Obligation to protect rights in institutions

International human rights law creates a number of obligations to protect rights in institutions. The level of suffering caused by such treatment over the course of a long detention easily amounts to “inhuman and degrading treatment” in violation of Article 7 of the ICCPR and article 3 of the ECHR. Detention may also violate the “inherent right to life” as protected by Article 6 of the ICCPR and Article 2 of the ECHR. The lack of protections against physical and sexual abuse in other social care facilities and in the psychiatric wards of general hospitals also violates articles 6 and 7 of the ICCPR and articles 3 and 2 of the ECHR.

Protections against inhuman and degrading treatment under international human rights law are internationally recognized as the most fundamental rights. Under Article 4 of the ICCPR, the full enforcement of these rights cannot be limited or delayed under any circumstance – even in a “time of public emergency which threatens the life of the nation.” Thus, even in the political chaos that characterizes the post-conflict society of Kosovo,

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46 For an overview of the international human rights of people with mental disabilities under international human rights law, see Eric Rosenthal and Clarence Sundram, “The Role of International Human Rights in Domestic Mental Health Legislation,” a study commissioned by the World Health Organization, submitted April 2002. The World Health Organization has committed to publishing this article on their website. Until that time, the article is available from MDRI.

UNMIK is under an obligation to ensure that inhuman and degrading conditions are brought to an immediate end. The lack of finances is no excuse for inaction. As the entity responsible for rule of law in Kosovo, UNMIK must immediately provide the funds to protect basic rights of all people who are protected by the ICCPR, including people detained in psychiatric facilities.

International human rights law does not necessarily require UNMIK to spend resources fixing up a facility. International law recognizes the right to protection against arbitrary or improper detention. Article 9 of the ICCPR protects “the right to liberty and security of the person” including a protection against arbitrary detention. Article 5 of the ECHR provides similar rights. The European Court of Human Rights has determined that individuals can only be detained in an institution after review by an independent authority that demonstrates people meet required minimum standards for detention. These standards must be set down under law. The MI Principles set forth a number of detailed procedural protections against arbitrary detention (Principles 15-17). As the Organization on Security and Cooperation in Europe (OSCE) has determined, all detentions at Shtime have been made without procedural protections and without compliance with the operative law of Kosovo. As such, detention at Shtime constitutes arbitrary detention in violation of article 9 of the ICCPR and article 5 of the ECHR.

While psychiatric wards of general hospitals are theoretically open (and some patients do come and go freely from some facilities), the use of coercion to keep people on these wards also violates article 9 of the ICCPR and article 5 of the ECHR. The practice of “chemical restraints” – the use of psychiatric medications to sedate people into compliance with authority – is particularly troubling. The use of psychotropic medications as chemical restraints circumvents protections against arbitrary detention. Chemical restraints also violate MI Principle 10, which state that medications shall only be used “for therapeutic or diagnostic purposes” to “meet the best health needs of the patient.” The use of chemical restraints is a dangerous practice that may constitute a form of inhuman and degrading treatment.

Detention in Kosovo’s social care or psychiatric facilities may threaten the physical or mental health of people with mental disabilities. In the absence of protections for health and safety, and without any form of habilitation or rehabilitation to assist people to return to community life, psychiatric detention in Kosovo violates Article 12 of the ICESCR, which protects the right to the “highest attainable standard of physical and mental health.”

International human rights law also recognizes the obligation to create safeguards against abuses within institutions. MI Principle 22 states that governments “shall ensure that appropriate mechanisms are in force to promote compliance with these Principles, for the inspection of mental health facilities, for the submission, investigation and resolution of complaints, and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient.” The lack of any independent mechanism in Kosovo to investigate abuses while protecting the rights of patients against reprisals violates MI Principle 22.

**B. Right to community integration**

In addition to protecting rights within institutions, international law recognizes a right
Policies that promote community integration are not just good practice to promote mental health; they have also been recognized as a right under international human rights law. Under the MI Principle 3, “[e]very person with mental illness shall have the right to live and work, as far as possible, in the community.” For people in need of mental health treatment, Principle 7 recognizes that “[e]very patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives.” The right to community integration can only be limited where a person meets the formal standards for civil commitment, as set forth in Principles 15-17.

The right to community integration has recently been recognized as a legal obligation under the International Covenant on Economic, Social, and Cultural Rights (ICESCR). The United Nations Committee on Economic, Social, and Cultural Rights has adopted General Comment 5, which describes the obligations of governments to protect against discrimination under the covenant. To protect against discrimination, the General Comment 5 recommends that governments adopt legislation and policies that “enable persons with disabilities to live an integrated self-determined and independent life.” The General Comment goes on to make clear, by citing the UN’s World Programme of Action concerning Disabled Persons, that anti-discrimination laws should not only require social policies that promote community integration but that these are individual rights. Governments are required to allocate resources accordingly. Thus, the right to protection against discrimination:

implies that the needs of each and every individual are of equal importance, that these needs must be made the basis for the planning of societies, and that all resources must be employed in such a way as to ensure, for every individual, equal opportunity for participation. Disability policies should ensure the access of [persons with disabilities] to all community services.

General Comment 5 recognizes that, for people capable of living in the community, the provision of services only in an inpatient setting -- segregated from society -- constitutes a form of discrimination under article 26.

The MI Principles and General Comment 5 have major implications for the structure of mental health services. Enforcement of the right to community integration requires the dedication of resources, and the ICESCR recognizes that funding is always limited. While the right to community integration under international law cannot require the investment of limited resources, article 2(1) of the ICESCR does require governments to promote rights “to the maximum of its available resources.” The ICESCR also requires governments to

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48 For an overview of the right to community integration for people with mental disabilities, see Rosenthal and Sundram, supra note 40 at 44.


51 General Comment 5, para.16.
immediately begin planning for the full enforcement of rights recognized by the convention. To fulfill the right to community integration, UNMIK should shift available resources from the Dutch government way from Shtime (or other institutions) and towards community integration.

While it is easier and less costly to integrate people into the community who have the fewest disabilities – or no disability at all – this approach is discriminatory. The Director of Institutions explained to MDRI the “Master Plan” for Shtime prioritizes the community integration of people with few or no disabilities – and people with intellectual disabilities will be left behind because of the increased cost of integrating them into the community. As General Comment 5 states, “[t]he obligation…is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.”